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SUPPLEMENTARY INFORMATION

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

Meeting to be held in Rooms 6 and 7, Civic Hall, Leeds on Friday, 2nd September, 2011 at 10.00 am n.b. Pre-meeting at 9.30 a.m.

MEMBERSHIP

Councillors

S Ali - Rotherham MBC

J Bromby - North Liuncolnshire CC

D Brown - Hull City Council

J Clark - North Yorkshire CC

R Goldthorpe - Calderdale MDC

B Hall - East Riding of Yorkshire CC

J Hancock -Barnsley MBC

L Mulherin (Chair) - Leeds City Council

T Revill - Doncaster MBC

B Rhodes - Wakefield MDC

I Saunders -Sheffield City Council

L Smaje - Kirklees MDC

K Wilson - NE Lincolnshire CC

S Wiseman - York City Council

Please note: Certain or all items on this agenda may be recorded.

Agenda compiled by: **Andrew Booth Governance Services** Civic Hall **LEEDS LS1 1UR**

Tel: 24 74325

Principal Scrutiny Advisor: Steven Courtney

Tel: 24 74707

AGENDA

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			Additional Information attached.	
14			REVIEW OF CHILDREN'S CONGENITAL HEART SERVICES IN ENGLAND: SUBMISSION FROM LEEDS TEACHING HOSPITALS NHS FOUNDATION TRUST	11 - 16
			Additional information attached.	

Sheffield Children's NHS Foundation Trust



Impact Assessment of the Safe and Sustainable Children's Cardiac Surgical Review on the Embrace Transport Service.

Purpose of this Document

 This paper summarises the key issues surrounding the Impact of the Safe and Sustainable Children's review on the Embrace Transport Service

Sumi	mary of Recommendations
1.	That further work is under taken to explore the impact on transport networks nationally of the options described within the Safe and Sustainable review.
2.	That further work is undertaken as to the financial implications of the developments required by Embrace to meet the increased workload of the service under each of the four options of the Safe and Sustainable review.

Author and Contact	Date	Version	Issue	Review
Person		Number	Date	Date
Jeff Perring Alison Hollett Liz Murch	9 th June 2011	1	13 th June 2011	

Impact Assessment of the Safe and Sustainable Children's Cardiac Surgical Review on the Embrace Transport Service.

Executive Summary

It is unclear within this region as to the impact upon the Embrace transport service with regards to the Safe and Sustainable cardiac review. Current transport services have been set up to meet specific models of care and their patient flows.

It is unlikely that any transport service will be able to meet a significant increase in demand for its service without further financial investment.

Embrace have had limited contact with transport services from other regions regarding paediatric cardiac activity. Therefore the assumption is that overall activity and impact on paediatric and neonatal transport services is presently unknown.

Embrace would recommend that further work is under taken to explore the impact on transport networks nationally of the options described within the Safe and Sustainable review.

In addition Embrace would recommend that work is undertaken as to the financial implications of the developments required by the service to meet the increased workload under each of the 4 options of the Safe and Sustainable review.

1. Background

Embrace is the United Kingdom's first combined infant and children's transport service. It undertakes neonatal transfers alongside paediatric retrievals for the 23 hospitals in the Yorkshire and Humber region, serving four tertiary neonatal units and two paediatric intensive care units. Established in a phased approach from December 2009, Embrace undertook just over 2000 transfers in its first full year of operation.

As the provider of infant and children's transport services within the region Embrace recognises that there will be transport implications associated with any paediatric service reconfiguration such as those associated with children's cardiac surgery, neurosurgery and trauma services.

This paper models the service implications for Embrace of the proposals put forward as part of the Safe and Sustainable Review of Children's Congenital Cardiac Services.

2. Safe and Sustainable Review of Children's Congenital Cardiac Services in England

The review, published in February 2011, has proposed four options for the rationalisation of paediatric cardiac surgical units with the reconfiguration of some existing surgical units as cardiology centres.

The four options in relation to Yorkshire and Humber are described below:

	Specialist Surgical Centres to include:	Cardiology Centres to include:
Option A	 Freeman Hospital, Newcastle Alder Hey Children's Hospital, Liverpool Glenfield Hospital, Leicester 	Leeds General Infirmary
	Yorkshire and the Humber would be of Newcastle, Liverpool and Leicester N dependent upon which part of the reg children would travel to Newcastle, Livergery.	etworks. Therefore, ion in which they lived
Option B	 Freeman Hospital, Newcastle Alder Hey Children's Hospital, Liverpool 	Leeds General Infirmary

	 Glenfield Hospital, Leicester Birmingham Childrens Hospital 	
	East and South Yorkshire and Humber Newcastle Network and children from travel to Newcastle for surgical service Yorkshire (Bradford, Halifax and Hude the Liverpool Network and travel to Li	these areas would therefore es whilst those in West dersfield) would form part of
Option C	 Freeman Hospital, Newcastle Alder Hey Children's Hospital, Liverpool 	Leeds GeneralInfirmaryGlenfield Hospital,Leicester
	East and South Yorkshire and Humber Newcastle Network and children from travel to Newcastle for surgical service Yorkshire (Bradford, Halifax and Hudd the Liverpool Network and travel to Liv	these areas would therefore es whilst those in West lersfield) would form part of
Option D	 Leeds General Infirmary Alder Hey Children's Hospital, Liverpool 	 Glenfield Hospital, Leicester Freeman Hospital, Newcastle
	Yorkshire and the Humber would form Network and children from the region valueds for their surgical services.	part of an extended Leeds would continue to travel to

With each of the proposed options the Safe and Sustainable review has highlighted a number of factors that need to be considered. Two of these relate directly to transport but only the second of these directly affects retrievals and therefore the Embrace service. These were described below:

Factors	Option A	Option B	Option C	Ontion D
Access and journey times:	3.6%	6.2%	6.2%	Option D 3.6%
Proportion who would see an increase in travel time of more than 1.5 hours				
Retrieval Times	Compliant with Paediatric Intensive Care Society standards*			

^{*} The paediatric intensive care standard described is that of a 3-hour threshold

3. Modelling of data

Data was modelled for the 2010/11 year of Embrace activity. In addition data provided by Leeds has enabled us to model the potential increase in activity associated with patients born in or from the Leeds area who would have to move under any of the option. Journey times have been estimated utilising the RAC travel website journey planner tool.

There were a total of 224 transfers undertaken by Embrace with a cardiac diagnosis during 2010 / 11. In addition there were up to 188 children within the Leeds Paediatric Cardiac Centre at the Leeds General Infirmary (LGI) that may have to be transferred out under some of the options proposed.

4. Specific Factors for Safe and Sustainable Review

The Safe and Sustainable Review indicated that proposed changes to patient flows should not have a traveling time above 3 hours. Embrace took the transport activity and the LGI patient's for 2010/11 and modelled the effect of the options on transport times. The model below assumes that 100% of the activity will go out of region.

Factors	Option A	Option B	Option C	Option D
Proportion of			Option 0	Option D
transfers where	53.2% incl LGI*	73.3% incl LGI	73.3% incl LGI	N/A
increase in travel time of more than 1.5 hours	13.8% excl LGI	50.9% excl LGI	50.9% excl LGI	(From within region)
Retrieval Times (journey > 3 hours)	0.0% (Compliant)	0.0% (Compliant)	0.0% (Compliant)	N/A (From within region)

^{*} The transfer time from Leeds General Infirmary (LGI) to the Freeman Hospital, Newcastle is 1hr 59 mins and therefore in excess of the additional 1.5 hours.

5. Impact on Embrace

When comparing the options it can be seen that with the exception of Option D where LGI remains as a paediatric cardiac surgical centre, a significant proportion of transfers will take longer than at present. In addition there would be a significant number of transfers out of Leeds that are not undertaken at present as well as the repatriation of children following their surgery.

The proportion of children that will need to be transferred out of region in Options A, B and C depends upon the services that continue to be provided at the Leeds Cardiology Centre. Babies and children require transport for a number of cardiac related conditions not all of which require care in a cardiac surgical unit or are directly related to a surgical need/intervention. Those that are transferred to a cardiac surgical centre may not all be taken to a paediatric cardiac ICU. Some may be taken to the NICU, or paediatric cardiac HDU. In addition a proportion of transfers into Leeds would require onward transfer to a surgical centre after assessment.

Following completion of the surgical episode of care many patients would require repatriation to their local DGH or regional cardiology unit.

Appendix 1 shows a summary of the modelling undertaken on the impact of redesignation of cardiac centres on Embrace. This model, based upon 2010 data has taken a 'worse case' scenario in which all infants and children with a cardiac diagnosis are treated at the cardiac surgical centre rather than a cardiology centre. Of these 50% require a back transfer to their base hospital.

Option A

The impact on Embrace from the re-designation of cardiac centres in Option A will be significant. The modelling suggests that just less than 2,000 hours of additional Embrace time will be required annually to meet the increased demand. This is equivalent to 5.2 additional hours / day. However, only 13.8% of non-LGI patients would find that their transfer times would increase by 1.5 hours or more.

Option B / C

Options B and C will have the same impact on Embrace with just under 2,200 additional hours required annually to meet the increased demand. This is equivalent to 6.0 additional hours / day. There is a proportionally greater increase in journey times under these options with 50.9% of non-LGI patients having an increase in transfer times of 1.5 hours or more.

Option D

Option D may have little or no impact upon Embrace. Patients from the present Newcastle Network should be brought in by either the paediatric or neonatal retrieval teams from the Northern Region. However, there are hospitals at the Yorkshire border who may find it easier to use Embrace rather than the Newcastle transport services. It is not clear if the Newcastle retrieval services have modelled the increase workload related with the additional activity, associated with this option especially as the paediatric retrieval team is not a stand alone service such as Embrace.

There is potential that Embrace could undertake some of this activity although the level of such activity for Embrace is not known at present.

6. Discussion

At present Embrace undertakes transfers out of the Yorkshire and Humber Region for specialist care that is not available within the region, for capacity issues and for patient repatriation.

From the overall recorded transport activity in 2010/11 there were 112 out of region transfers, The majority of these were planned neonatal and paediatric transports for specialist services (of which 18 where cardiac).

An increase to the number of out of region transfers both acute and planned will have a significant impact upon the Embrace service including the following areas:

Staffing of Embrace

Embrace is based upon a model of staffing (numbers and shift patterns) that has been developed to meet the present transport requirements within the Yorkshire and Humber Region. The modelling above suggests that in each of the three options where Leeds becomes a cardiac centre there will be an increase in the number of

longer (out of region) transfers. This will effect the staffing / shift model. It is clear that this could not be achieved with the present number of staff without significant overruns in shifts and periods where there was inadequate Embrace cover for the region.

This situation could be partially mitigated through the use of aeromedical transport but this also has limitations such as weather and night flying.

The most realistic model to develop is that of further investment in Embrace through an increase in the number of teams (driver, nurse and doctor) available to the service, long side an increase in the number of ambulances to meet demand and increased activity.

It is likely that the last option, where Leeds continues as a cardiac surgical centre will also have implications on the number of out of region transfers but the level of this activity is not known.

Weather Conditions

Weather conditions impact on patient transport. Currently during harsh weather conditions, each transport is risk assessed with regards to the safety of the team and the patient's acute condition. Adverse weather is likely to impact more with reconfiguration of services due to the longer distances required to be travelled.

Patient stability during long road journeys

Although Safe and Sustainable has used a timescale for retrievals of 3 hours there are patients in whom the length of transfers may have an impact on their outcome. This becomes more significant at a time of poor weather or significant traffic flow when even short road journeys can be extended indefinitely.

Communication with Clinical Teams

In the current service model, Embrace conference calls all relevant clinical staff into telephone discussions. In the options where Leeds is not the cardiac surgical centre there will be multiple centres that need to be included in discussions dependant upon which part of the region the patient comes from.

7. Summary

Within the Safe and Sustainable consultation paper, the impact of the transport of cardiac children for cardiac surgery to new designation centres has not been fully explored.

It is unclear within this region as to the impact upon the Embrace transport service. Transport services have been set up to meet specific models of care with their patient flows. It is unlikely that any transport service will be able to meet a significant increase in demand for its service without further financial investment.

Embrace have had limited contact with transport services from other regions regarding paediatric cardiac activity. Therefore the assumption is that overall activity and impact on paediatric and neonatal transport services is presently unknown.

The drive to reduce transportation time is leading to the exploration of air transportation which again would need financial investment.

Recommendations:

- Embrace would recommend that further work is under taken to explore the impact on transport networks nationally of the options described within the Safe and Sustainable review.
- 2. That further work is undertaken as to the financial implications of the developments required by Embrace to meet the increased workload of the service under each of the four options of the Safe and Sustainable review.

Appendix 1: Model to describe the effect of the Safe and Sustainable Children's Cardiac Surgery Review upon Embrace, the Yorkshire and Humber Infant and Children's Transport Service

	Initial Re	Referral to Cardiac Centre	iac Centre	Estima	Estimation of 50% requiring repatriation	equiring	Total] excludes l	Total Transport (NB this excludes handover, stabilisation time)	IB this abilisation
	No of cardiac referrals retrievals	Mileage Underfaken	Transport Time for Referral	No of back transfers	Mileage Undertaken	Transport time for Back Transfer	Total Transfers	Total Mileade	Total
	o Z	Miles	Hours - decimal	o Z	Miles	Hours - decimal	0 2	Miles	Hours -
Option D - current pathway no Leeds activity to transport	224.0	19,597.0	454.0	112.0	9 798 5	0 700	0000		
Option A includes Leeds activity	412.0	88,845.7	1,755.6	206.0	44,422.9	877.8	536.0 618 N	29,395.5 133.268.6	581.1
Option B or C includes Leeds Activity	412.0	92,847.3	1,910.7	206.0	46,423.7	955.3	618.0	139,271.0	2,866.0

Assumptions:

- 1. All cardiac activity presently undertaken by Embrace is transferred out to the designated cardiac surgical centre.
 2. LGI will transfer out its present cardiac activity.
 3. 50% of transfers out will require repatriation through back transfers by Embrace.
 4. There is no change in the length of stabilisation and handover times.

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Agenda Item 14

CHD Bonding & Attachment Psychologist, LTHT

Dr Sara Matley, Consultant Clinical

Bonding and attachment in CHD babies and young children

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

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

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

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

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

The sensitive period

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

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

Disruption to bonding

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

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

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

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

Leeds Early Intervention approach

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

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

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

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

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

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

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

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

Case Study

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

L was terrified that her child might die without any family around her; it was very important for her that either she or her husband be there when this happened. As the child was critically ill when she was born, there was a good chance that the child may die without her family around her, if the mother was separated from the child. The

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father was in a difficult position of wanting to support the mother after the birth, but also wanting to be around the baby when she was born.

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

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

<u>References</u>

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Dr Sara Matley, Consultant Clinical

CHD Bonding & Attachment Psychologist, LTHT

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