

CONGENITAL CARDIAC NETWORK BOARD

June 2011

RESPONSE TO THE SAFE & SUSTAINABLE REVIEW OF CHILDRENS CONGENITAL CARDIAC SERVICES IN ENGLAND

- 1. The network has considered the whole process of the review, and as a group we feel that the following issue should have been given more weight in the appraisal of options:**

The definition of co-location

Standard B9 of the review documentation states that where a baby is likely to require immediate postnatal intervention or surgery the parents should be given the choice of delivery at or close to the specialist surgical centre. Many of these babies also require diverse services which at present are co-located in one hospital building.

As a network, our view is that the gold standard for care would be delivery in a maternity unit with tertiary neonatal care on the same site as the cardiac unit, to avoid any unnecessary delay in treatment. The parents in our region currently have this choice, so options A, B and C would be viewed by parents in our region as a retrograde step.

The statements above equally apply to children with congenital heart disease in our region.

Could further consideration be given to the standards for designation to encourage designated centres to include plans for true co-location of service such as paediatrics, maternity and adult congenital services?

We are led to believe that the definition of co-location used in this review is different to that used in the neurosurgery review. We are keen to understand more about the reasons for this, as it is unclear from the review documentation.

2. In the view of our network and its stakeholders around the region, the preferred option would be for Leeds Teaching Hospitals Trust to retain their service.

However, if option A, B or C were agreed, patients in our region (and the current catchment area of Leeds) would be spilt between several different surgical centres.

If Leeds were required to become a 'Children's Cardiology Centre' (CCC), the implication is that the team would need to be involved in as up to three different surgical MDTs, depending on the postcode of the individual patient. The involvement with these various MDTs would be for routine work as well as the highly specialised work, resulting in the staff at the CCC having to juggle multiple different protocols and ways of working, depending on the postcode of the child. There would be knock-on effects for clinical governance, and the mitigation of clinical risks. There would be issues to resolve in terms of 'inreach' and 'outreach'.

We would therefore welcome further clarity on how this model would work in practise.

An exploration of the implications of the various options for specific types of patient in our region are included as Appendix 1.

3. The network would like the following issues to be fully considered by the national review team before a decision is taken:

- i. We are keen to be assured that the implementation process is planned and carried out with careful attention to the transition period. We are committed to doing whatever we can, as a regional network, to ensure that the patients and families in Yorkshire and Humber continue to have a high standard of care in the short and medium term, as well as the longer term, regardless of which centres are eventually designated. We are keen to be assured that services such as these are maintained throughout the transition or expansion period, and that patients do not experience a disjointed service.
- ii. We would value further clarity regarding the specific role and the expected staffing profile of 'Children's Cardiology Centres' (CCCs). The review documentation indicates that these centres would act as a base for a team of paediatric cardiologists to work in. However, we are concerned that the differences between the role of the CCC and the next level of service – the 'District Children's Cardiology Units' (DCCs) may not be great enough to justify or sustain both of these

two tiers of service. We feel that further consideration of the following questions is essential:

- What level of clinical support and training would the paediatrician at the DCC receive?
 - Would the paediatrician at the DCC be supported by a cardiologist in the CCC or the surgical centre?
 - Would the paediatrician in the DCC also be expected to manage pregnant mothers with fetal heart disease and supervise their delivery in the DGH?
 - Where will the specialised diagnostic and counselling element of the fetal cardiac scanning service take place in the future, since at present it is only delivered within the surgical centre?
- iii. In our view, a key piece of outstanding work involves giving further consideration to the smaller specialties which are linked to children's heart surgery, such as diagnostic MRI, electrophysiology, ablation and pacing, where the loss of one person from a unit can seriously affect the ability of that unit to continue to offer a safe service. Diagnostic and interventional catheterisation services also need careful consideration, given that these are not usually delivered in centres lacking surgical backup. We are keen to understand the vision for how these services will be maintained and delivered during the transition period and beyond. There is a possibility that even if these services are initially set up to run in the CCC, they will retreat into the surgical centre over time, due to the dependency on 'cardiac' anaesthetics.
- iv. We feel strongly that services for adults with congenital heart disease (ACHD/GUCH) should be given consideration as part of this review. For some units around the country (Leeds included), the ability of the centre to continue to perform surgery on ACHD patients relies heavily on the future of their paediatric cardiac surgery – because the surgeons and interventional cardiologists do both. In planning the future of children's heart surgery, the knock-on effects for adult patients should not be underestimated. We are aware that there are plans for the designation of ACHD centres to run in parallel to the review process, and welcome this approach.
- v. We would welcome further consideration of the impact of options A, B and C on children with multiple needs. We are keen to be assured that staffing considerations take into account procedures on children with congenital heart disease that are not cardiac in nature, but require an anaesthetist with experience of congenital heart disease.

- vi. We believe further consideration should be given to the potential impact of patient choice on the projected numbers of procedures in each model. We believe that some of the options rely on counter-intuitive patient flows to attain the procedure numbers for the remaining centres. For instance, what would happen under options A, B or C if a number of patients currently modelled into the numbers of procedures for Newcastle decided to go to Glasgow for their procedures? Would this adversely affect the ability of Newcastle centre to achieve the necessary number of procedures? We accept that there is a different NHS system in operation in Scotland, and that Glasgow was consciously left out of the review options, but patients may choose not to 'respect' this organisational boundary. We feel that this issue could be given more detailed consideration before any decisions are made.

- vii. We are keen to be assured that full and careful consideration is given to the impact of each option on travel times for patients and families, and also on the patient transport services within and outside our region. We are aware that some of the postcode based modelling of patient flows is being revised, and we welcome this. However, we feel that however this modelling is carried out, it will be difficult to fully simulate the effect of patient choice and logic on the complex travel network we have in England. Our concern is that the journeys patients and families are willing to undertake will not be dependant on road travel times alone, but also on factors such as the feasibility and mechanism of travel, the public transport network, and the location of their family and extended family (siblings, grandparents, uncles and aunts). It is possible that once the service is rationalised into fewer, larger centres, the 'gravitational pull' of very large centres such as Birmingham and the London hospitals will result in entirely different patient flows than those shown currently under consideration.

During consultation events in our region patients from the Humberside area of our region have stated that it would be much easier (and probably quicker) for them to travel along the M62 to Liverpool, or down on the train to London, than to travel all the way up the A1 to Newcastle, particularly in the winter time. This issue is made even more acute by the recent harsh winters we have had, and the 'ease' of travel should be given further consideration.

4. Proposal of an Alternative Option

In the view of the Yorkshire and Humber Congenital Cardiac Network Board, many of the concerns outlined above can be solved by implementing a modified version of Option D. This version includes consideration of the services delivered in Glasgow, and would enable all centres to meet the required standards:

Seven surgical centres at:

- Leeds General Infirmary
- Alder Hey Children's Hospital, Liverpool
- Birmingham Children's Hospital
- Bristol Royal Hospital for Children
- 2 centres in London
- **Royal Hospital for Sick Children, Glasgow**

We believe this option is a good solution for the following reasons:

- The unit in Glasgow currently carries out less than the minimum number of procedures outlined in the review documentation. Although this is not the concern of the NHS in England, it is obviously not an ideal situation for patients and families in Scotland, and could be rectified by the option above.
- The patient group that currently flows into Newcastle would be split between Leeds and Glasgow, thus allowing them to easily achieve the ideal numbers of procedures.
- Access to truly co-located services would be maintained for patients who currently have this. Co-location for other centres could be something to work towards in cities where this doesn't currently exist, but, crucially, the implementation would not result in a 'backwards step' for any group of patients.
- The ECMO and transplantation services for Scottish residents would be strengthened by this option.

We therefore ask for further work to be undertaken to revise the scoring for option D, based on the inclusion of Glasgow.

Appendix 1: Patient Scenarios

Blue shading indicates scenario is the same for patients as the current service.

Please note the times below are calculated using Google directions. Distances are calculated from the centre of the city or town of origin, to the hospital named in the scenario. We are advised by colleagues working with Yorkshire Ambulance Service and EMBRACE, that emergency times are unlikely to be faster than this because driving speed will usually need to be moderated when dealing with very sick children and babies.

1) TGA (transposition of the great arteries) – approximately 19 cases per year.

Current Scenario 33.4 miles 46 mins	Scenario under option A 71.3 miles 1hr 22 mins	Scenario under options B & C 118 miles 2hrs 16 mins
TGA suspected in Doncaster at 20 week fetal scan.	TGA suspected in Doncaster at 20 week fetal scan.	TGA suspected in Doncaster at 20 week fetal scan.
Referred immediately to Leeds and has fetal echo within two days, plus contact with cardiac liaison nurse.	Fetal cardiac scan performed in Children’s Cardiac Centre (Leeds) or Specialist Surgical Centre (Leicester).	Fetal cardiac scan performed in Children’s Cardiac Centre (Leeds) or Specialist Surgical Centre (Newcastle).
Seen again in Leeds at later gestation. Includes meeting with surgeon, appointment in fetal medicine to plan delivery in Leeds, visit to delivery suite and paediatric cardiology ward.	Local obstetric care; may need to be seen in Leicester to plan delivery.	Local obstetric care; may need to be seen in Newcastle to plan delivery.
Delivers in Leeds. Mum (as an inpatient) and baby in same hospital, then mum has accommodation on ward when discharged. Immediate septostomy if required, without the need for a transfer of the baby. Mum is on site to consent (dad is not able to consent in all cases).	Delivers in a maternity hospital, either Leicester Royal Infirmary or Leicester General Hospital. Baby transferred to paediatric cardiology at the Glenfield, Leicester. Mum may not be fit to be discharged, and would be in a separate hospital. There are currently processes in place to ensure mother is fully informed and consent obtained.	Delivers in a maternity hospital, e.g. Royal Victoria Infirmary in Newcastle. Baby transferred to paediatric cardiology at the Freeman Hospital. If deemed unfit for transfer, mum would be in a separate hospital. There are currently processes in place to ensure mother is fully informed and consent obtained.
Baby has surgery and goes home. Cardiac liaison nurse is around on the ward, and the surgeon and cardiologists are on site. If problems arise, e.g. feeding issues, the baby may return to Doncaster, or to Leeds. Follow up would usually be in Doncaster, with the visiting cardiologist.	Baby has surgery at Leicester. There may be a whole new team involved. If problems arise the baby may be transferred to Leeds or Leicester or Doncaster. Follow up arrangements are as yet unclear.	Baby has surgery at Freeman Hospital. There may be a whole new team involved. If problems arise the baby may be transferred to Leeds or Newcastle or Doncaster. Follow up arrangements are as yet unclear.

2) **'Blue light baby'** – Currently 224 cases per year. This could increase to 412 including children born in Leeds that may require transfer under options A-C.

Current Scenario 10.4 miles 27 mins	Scenario under option A, B or C 64.8 miles 1 hr 44 mins
<p>'Blue light baby' born in Bradford.</p>	<p>'Blue light baby' born in Bradford.</p>
<p>Blue light visit to Leeds General Infirmary Neonatal service for cardiology assessment on site.</p> <p>EMBRACE undertake the transfer, either as cardiac or non cardiac.</p> <p>Cardiac transfer to the care of the Cardiac Services on the Leeds General Infirmary site.</p> <p>Non cardiac remains in the Neonatal Unit on the Leeds General Infirmary site.</p>	<p>Blue light visit to Liverpool Alder Hey for cardiology assessment.</p> <p>If blue light baby 'suspected' cardiac then in most cases the transfer will be straight to Alder Hey.</p> <p>EMBRACE undertake the transfer.</p> <p>Cardiac patient remains on the Alder Hey site for assessment and treatment.</p> <p>If non-cardiac, the baby is transferred to Neonatal Unit at Liverpool Women's Hospital. Another hospital site.</p>
<p>Mother transferred to the Leeds General Infirmary maternity services, or discharged to parental accommodation on the Leeds General Infirmary site.</p>	<p>Mother may be transferred to Liverpool Women's Hospital.</p> <p>Cardiac baby on a different site to mother.</p>
<p>Baby has surgery on Leeds General Infirmary site and has follow up by the Leeds team in Bradford by Leeds based Cardiologist.</p>	<p>Baby has surgery at Liverpool. Follow up in Leeds/Bradford by Leeds based Cardiologist</p> <p>There may be a whole new team involved.</p> <p>If problems arise the baby may be transferred to Leeds or Bradford. Follow up arrangements are as yet unclear.</p>

3) Transition age patient

Current Scenario 20.2 miles 30 mins	Scenario under option A B & C To Alder Hey: 55.1 miles 1 hr 5mins To Manchester: 33.2 miles 50 mins	
Patient from Huddersfield reaches the 14-16 years preparation made for transition to the ACHD service.	Patient from Huddersfield reaches the 14-16 years preparation made for transition to the ACHD service.	
Paediatric Cardiologist in Leeds refers to an Adult Congenital Cardiologist in the Leeds General Infirmary.	Paediatric Cardiologist in Leeds refers to an Adult Congenital Cardiologist in the Leeds General Infirmary.	
Children's Cardiac Nurse Specialist at LGI refers to Adult Congenital Cardiac Nurse Specialist at LGI.	Children's Cardiac Nurse Specialist at LGI refers to Adult Congenital Cardiac Nurse Specialist at LGI.	
Care continues to be provided in LGI.	Care continues to be provided in LGI.	
Patient requires further surgical intervention. Surgery carried out by the Congenital Surgeon who has undertaken previous surgeries.	Patient requires further surgical intervention. Original surgery carried out either in Leeds or Liverpool subsequent surgery carried out in Manchester by dedicated ACHD surgeon. Surgeons from Alder Hey may also go to Manchester to assist. Transferred back to the care of Leeds Adult Congenital Cardiologist.	

4) Child who requires second opinion from another specialty

Current Scenario 40 miles 52 mins	Scenario under option A 67.3 miles 1hr 19 mins	Scenario under options B & C 138miles 2hrs 35 mins
A Sheffield patient in intensive care in LGI following cardiac surgery requires an opinion from a Paediatric Neurologist.	Patient in intensive care in the Glenfield Hospital following cardiac surgery requires an opinion from a Paediatric Neurologist.	Patient in intensive care in the Freeman Hospital following cardiac surgery requires an opinion from a Paediatric Neurologist.
Consultant Paediatric Neurologist of the week on the LGI attends within the hour.	Paediatric Neurologist at the Leicester Royal Infirmary contacted and attends when work load permits.	Paediatric Neurologist at the Newcastle General Hospital contacted and attends when work load permits.

5) GP refers new murmur in under 1 year old

Current Scenario 60.5 miles 1 hr 12 mins	Scenario under A, B and D 145 miles 2hrs 42 mins
Refers to DGH (Hull Royal Infirmary). Seen by paediatrician with expertise in cardiology. Echo shows significant abnormality.	Refers to DGH (Hull Royal Infirmary). Seen by paediatrician with expertise in cardiology. Echo shows significant abnormality.
Seen in Hull Royal by local hospital by paediatric cardiologist from surgical centre (Leeds).	Seen in Hull Royal by local hospital by paediatric cardiologist from surgical centre (Newcastle).
Planned treatment at surgical centre In Leeds.	Planned treatment at surgical centre In Newcastle.
Return to follow up at local hospital.	Return to follow up at local hospital.

6) Adult patient with a coarctation and learning disability requiring surgery

Current Scenario 78 miles 1hr 27 mins	Scenario under option A 119 miles 2 hrs 6 mins	Scenario under options B & C 163 miles 2hr 58 mins
Coarctation diagnosed by DGH in a Grimsby patient referred by GP with hypertension.	Coarctation diagnosed by DGH in a Grimsby patient referred by GP with hypertension.	Coarctation diagnosed by DGH in a Grimsby patient referred by GP with hypertension.
Patient seen in Leeds by adult congenital cardiologist and specialist nurse.	Patient seen in Leeds by adult congenital cardiologist and specialist nurse or in Leicester.	Patient seen in Leeds by adult congenital cardiologist and specialist nurse or in Newcastle.
Initial and ongoing contact made with local learning disability team.	Initial and ongoing contact made with local learning disability team.	Initial and ongoing contact made with local learning disability team.
Independent Mental Capacity Advocate (IMCA) appointed.	Independent Mental Capacity Advocate (IMCA) appointed.	Independent Mental Capacity Advocate (IMCA) appointed.
Patient meets surgeon in familiar environment with IMCA present.	Patient travels to Leicester to meet surgeon with carers and IMCA.	Patient travels to Newcastle to meet surgeon with carers and IMCA.
Patient familiarises themselves with staff and ward environment in preparation for surgery.	Patient travels to Leicester to familiarise themselves with staff and ward environment in preparation for surgery.	Patient travels to Newcastle to familiarise themselves with staff and ward environment in preparation for surgery.
Planned surgery at Leeds.	Planned surgery in Leicester.	Planned surgery in Newcastle.
Follow up by familiar adult congenital team in Leeds.	Follow up in Leeds or local DGH.	Follow up in Leeds or local DGH.