

Children's Heart Surgery Fund report to the Joint Overview and Scrutiny Committee (Yorkshire and the Humber)

Background

The Children's Heart Surgery Fund (CHSF) is a registered charity based at the Yorkshire Heart Centre in Leeds General Infirmary and supports children with heart defects. The Centre covers Yorkshire, Humberside and the West Midlands. The CHSF funds revolutionary equipment, resources and research for the treatment of Children with heart defects.

The Yorkshire and the Humber Specialised Commissioning Group (SCG) commission the service, with funding from Primary Care Trusts (PCTs) across the region, and each year approx 250-380 children undergo open heart surgery at the unit – a figure that has remained quite static for over a decade.

In comparison, the Liverpool unit treats 250-380 patients a year but as it also serves North Wales and Ireland it is felt to be safe under the review. Newcastle treats around 200 patients and has a smaller catchment area with the North East having a lower population density.

The population within a 2 hour drive time of each centre in the North is Newcastle 2.8 million, Leeds 13.8 million and Liverpool 11.4million.

The Bristol scandal of the 1990's called into question the ability of children's heart surgeons, which led to the national review of safety and it was asserted that there is a "critical mass" in the ratio of patients and surgeons per unit. 400 patients and 4 surgeons in 2003, Hewlett and Munro recommended a reduction in the number of centres due in part to the static number of patients. In 2006 the panel of experts recommended the reform of the current system, and in 2007 the Royal College of Surgeons recommended fewer larger paediatric cardiac surgery services.

The review has been guided by four principal – namely, quality, high standards, a personal service and one that is delivered locally where possible. The review has also been informed by the overall opinion that a reduction in the number of centres is the best way forward to secure a 'safe and sustainable' future service. In addition to this, criteria considered has included population, access and travel times and a set of quality standards that centres must meet in future.

In January 2011, the CHSF Trustees voted unanimously to launch a campaign against the potential threat of closure of the Yorkshire Heart Centre – with Leeds only featuring in one of the four options presented by the Safe and Sustainable team. The CHSF felt it was essential to raise public awareness around the proposals and the potential impact of each option on children and families across Yorkshire and the Humber. To do this, and in order to reach out to potential campaigners, we proceeded to organise a series of Saturday morning events in a number of areas across the region where we know our families travel from.

CHSF events

Involvement and engagement events were held in the following areas:

- Rotherham
- Hull
- Sheffield
- Leeds
- Huddersfield
- Bradford
- Scunthorpe
- York
- Doncaster
- Halifax

The events were publicised through local media/social media, ie Facebook/Twitter, and through letters to our existing membership database. We also had leaflets printed and placed in the regional peripheral clinics.

The meetings were held in local hotels and were attended by parents, some local MP's and on occasions by the local media. We delivered a 1 hour presentation outlining the key features of the proposed re-configuration, followed by questions and answers. The presenters were

- Kevin Watterson-Cardio thoracic Heart Surgeon
- Mike Blackburn -Consultant Cardiologist
- Sara Matley- Psychologist
- Sharon Cheng -Director CHSF

Precise attendance details were not recorded, although attendance ranged between 50 and 80 people depending on the area.

At the meetings we also guided those present through the Ipsos Mori response document. General feedback was that the response document was very complex, so we created a guidance note to help the public understand and fill in the forms correctly. We also stressed to families that they could voice their opinions and any concerns by writing to their local MP and encouraged people to help us grow our petition; we explained we would like to have a petition in order for us to instigate a back bench debate in the House of Commons. As members of the Joint Health Overview and Scrutiny Committee may be aware, this was achieved and the petition grew to a staggering 580,000 signatures.

Feedback from the engagement activity

Access and travel times

- Many of the concerns from our parents were from the outer regions ie Doncaster and Hull around travel times. At the time of many events, the business case from Safe and Sustainable predicted people would travel from Hull to Newcastle; however many people stressed they would not choose to take that route and would rather go to Liverpool or London.
- Emergency cases also concerned families in terms of reaching the unit on time.

Co-location of services

- Some parents have children with more than one inherited condition and now the LGI has Children's hospital status they feel they should be able to access all they need with little disruption.

- Many families were concerned about the adult service and the impact this would have on them, as they now see the surgeon/cardiologist and would continue to see the same person if the surgery remained in Leeds, but if s/he moves, how would this situation affect them?

Financial Implications

- The cost of travelling was a major concern with many of our families. A number of people concerned were already struggling financially and some said they would simply not be able to visit another city.

Support

- Many of our families currently rely upon family members for support and felt they would lose this support, which would be an added strain during an already difficult situation.

Frequently asked questions:

1. Why is the Health Impact assessment still being conducted when the options have already been delivered.
2. Why have the Ipsos Mori response sheets only been available in alternative languages for the last 4 weeks of consultation - shouldn't have been available sooner?
3. What happens if a baby in Yorkshire is delivered and it's a blue, it then goes to Newcastle, will it come back down to Leeds or will it be treated in Newcastle if it isn't a heart related problem? If it's not treated in Newcastle will that mean another journey back down to Leeds?
4. Why can't Leeds retain its service based on population density?
5. Why are patient flows still being assessed, when the options have been delivered?
6. Won't taking the service to Newcastle be like going back to a stand alone unit like Killingbeck used to be?
7. Yorkshire has a high population of BME and socially deprived groups that would be disproportionately affected by increased travel distance/cost and are additionally vulnerable because of English language issues, so how will these people be accommodated?
8. The A1 link road to Newcastle, is generally a notoriously bad road to travel on, I would rather choose to visit Liverpool than use this road – particularly in bad weather: Can I choose my hospital?
9. Will Newcastle reach the 400 operations suggested, as most people would more likely flow to Liverpool

Other recent work at the charity

Throughout the campaign we managed to generate:

- 500 news stories, including press releases. We had local press coverage in many areas across the region and the Yorkshire Evening Post (YEP) also took on our campaign and made it their own.
- We held a bill board campaign to highlight our concerns in the 17 areas where the peripheral clinics are held.

- We commissioned some Radio announcements (Sean Bean recorded these), to raise public awareness and draw people to the website and sign our petition.
- We also arranged for leaflet drops in most of the areas across Yorkshire and the Humber, which highlighted the need to respond to the consultation.
- Our parent campaigners gathered signatures from members of the public at many social events, fairs, football matches, areas with a high footfall. Our parents gathered in force and asked family and friends to help. One particular family gained 20,000 signatures in 2 weekends
- Our paper petitions superseded our online petition within a matter of weeks.
- We have also lobbied regional MPs, a number of whom have already been extremely supportive of keeping this service in Yorkshire. We managed to secure a back bench debate in the House of Commons and we also held meetings with MPs and peers to voice our concerns of the flaws in this whole process.
- Approx 3,500 response documents were received from the Yorkshire region and we believe there is a very strong case that Leeds should remain open and the service expanded.
- We are determined to take every opportunity of making the case for Leeds heard through our campaign, to as many different groups as possible. An example of the material we have produced is attached at Annex A.



CHILDREN'S HEART SURGERY FUND

Registered Charity: 700753

KEEP CHILDREN'S HEART SURGERY IN YORKSHIRE

The Children's Heart Surgery Unit at Leeds General Infirmary (LGI) serves Yorkshire, Lincolnshire and the North Midlands. Each year around 300 children undergo open-heart surgery at the unit.

The Children's Heart Surgery Fund (CHSF) is a registered charity based at the Yorkshire Heart Centre at Leeds General Infirmary and supports the Children's Heart Surgery Unit. We fund equipment, resources and research for the treatment of children with heart defects. The Charity also supports families - helping with travel and long term patient care costs.

There are 11 children's heart surgery units in the UK but the NHS is proposing under the 'Safe and Sustainable' Review to reduce this to 6 or 7 specialist hubs undertaking 400 operations per year.

The Review has published 4 re-configuration options for consultation with Leeds only featuring in one - Option D. If any of the other options are favoured then the Leeds Unit would close leaving a huge gap in provision from Leicester or Birmingham in the south, to Newcastle in the north and Liverpool to the west. This would mean children from Yorkshire, North Derbyshire and Northern Lincolnshire having to travel long distances for treatment and parents being put to significant expense to visit.

THE STRONG CASE FOR LEEDS

The choice facing the Review Team will be to retain Leeds or Newcastle to serve the north. The advantages Leeds has is that:

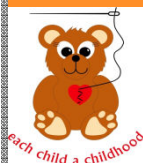
- ❑ It serves a population of 5.5 million people in Yorkshire & the Humber, Lincolnshire and North Derbyshire regions - one of the highest population coverages of all the units in England.
- ❑ Leeds has the capacity to expand and is centrally located within the North to accommodate patients from outside the current catchment area with 13.8 million people within two hours travel time.
- ❑ Leeds General Infirmary has centralised the whole of its children's services operation on one site – Newcastle's is split between the Freeman's Hospital and the Royal Victoria which are over 3 miles apart.

- ❑ Leeds General Infirmary is at the forefront of work on inherited cardiac conditions and has an excellent record for providing safe, high quality children's heart surgery
- ❑ Many of the population to the north or west of Newcastle would find the children's heart surgery Unit in Glasgow more convenient but this has not been taken into account by the Review team.
- ❑ The Yorkshire region has significantly higher birth rates than that of the North East meaning that demand for services at Leeds will rise more than at Newcastle.
- ❑ Part of Newcastle's case is that it has a transplant unit. This could be moved to Leeds where there is room in an integrated children's centre. After all, **Doctors should move where the patients are – not the other way round.**

WE NEED YOUR SUPPORT

Holly's Story

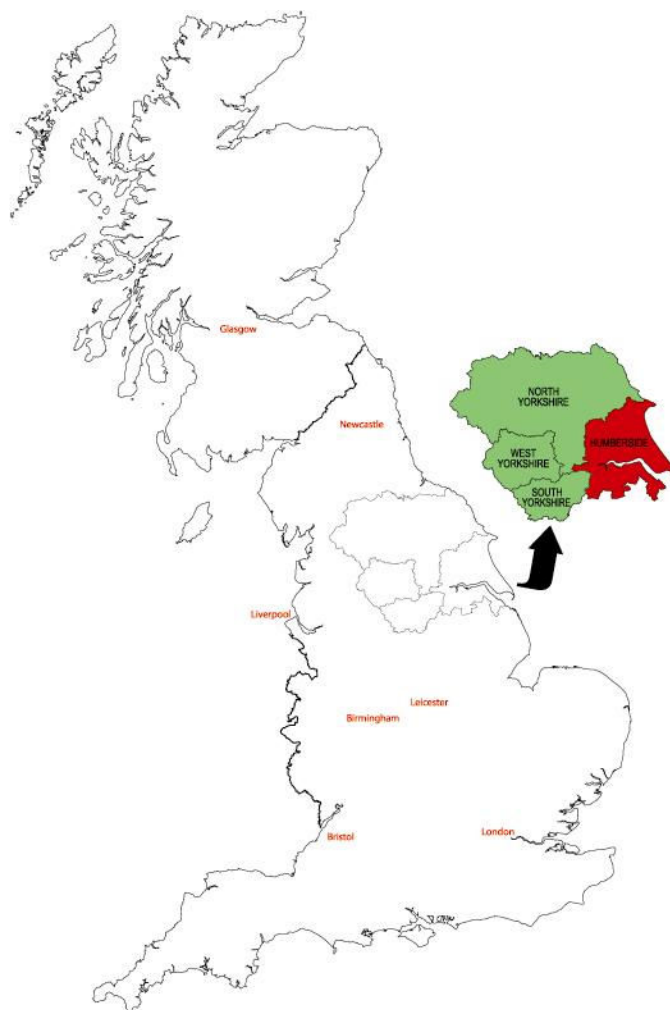
Holly was born with two holes in her heart and at just six-months old had to undergo life saving open heart surgery.



Now exactly a year on, she is a picture of health, something her parents Sharon and George could hardly dare to hope for.

"She was such a poorly little thing' says Sharon 'Her heart was working so hard she just couldn't put on any weight and it was heart-breaking to see her trying to breath"

To mark the anniversary of her life-saving operation, Sharon decided to do a Skydive and raised £2,000 for the Charity *"I wanted to give something back, we are so lucky to have units like this on our doorstep. If we'd had to travel further afield it would have made a very difficult time even worse."*



The Review is informed by the overall opinion that a reduction in the number of centres is the best way forward to secure a 'safe' and 'sustainable' future service. It is guided by four principles, in all of which we believe Leeds more than matches the requirements:

As you can see there is a huge gap in the North of England left isolated without a Unit in Leeds

- ❑ **Quality** - The Paediatric Cardiac Service at LGI extends right from pre-natal diagnosis to the treatment of congenital heart disease in adults **with excellent clinical outcomes**.
- ❑ **High Standards** - the children's hospital facility at the LGI exceeds the requirements of the 2008 DH Critical Independencies Report providing services on a single site
- ❑ **A personal service** - patients and families receive first class care throughout their stay in the hospital and afterwards with support from the Children's Heart Surgery Fund.
- ❑ **A locally delivered service where possible** - all Children's Services Units are accessible to 13.8 million people within 2 hours travel time of the Heart Surgery Unit in Leeds.

The Next Steps

The Committee has published its options which will be consulted on for the next four months. The final report and recommendation will be presented to Ministers in the autumn. Further information on the Review can be viewed on the 'Safe and Sustainable' website: www.specialisedservices.nhs.uk/safeandsustainable

How to help

- ❑ **Table a White Paper Motion at your next council meeting seeking cross-party support for the Unit and calling on the Department of Health to keep it open.**

- Write to your local MPs asking them to lobby Ministers to retain the Unit
- Make representations to the consultation on behalf of the Council in support of the Unit.

For more information or to lend your help and support please visit our website www.chsf.org.uk
or contact **Sharon Cheng**, Director of the Children's Heart Surgery Fund
by email: ch.sf@leedsth.nhs.uk or by phone **0113 3925742**
We look forward to hearing of your support