

**JULIAN SMITH MP**

Skipton & Ripon



HOUSE OF COMMONS

LONDON SW1A 0AA

Cllr Lisa Mulherin  
Chair  
Joint Health Overview and Scrutiny Committee  
3rd Floor (East)  
Civic Hall  
Leeds LS1 1UR

Our ref: SR4596

12 September 2011

Dear Cllr Mulherin,

Please find attached Mr Smith's response to the consultation which sets out his view on the reconfiguration of Children's Congenital Cardiac Services. I hope this is helpful in advance of your meeting on Monday 19 September.

With best wishes.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'S Naylor', with a long horizontal flourish extending to the right.

**STEPHEN NAYLOR**  
Office of Julian Smith MP



Sir Neil McKay CBE  
Chair of the Joint Committee of Primary Care Trusts  
NHS  
2-4 Victoria House  
Capital Park, Fulbourn  
Cambridge CB21 5XB

Our ref: SR4397

1 June 2011

Dear Sir Neil,

As we are approaching the end of the Safe and Sustainable public consultation on the future of children's congenital heart services, I wanted to set out my views following meetings, discussions and research into the proposals being set out.

I believe strongly that the Children's Heart Surgery Unit at the Leeds General Infirmary should be retained.

There have been many compelling human stories told to me over recent months from constituents across the Skipton and Ripon constituency.

Lois Brown, from Cononley, has been one of the leaders of the campaign. Her three-year-old daughter Amelie was born with a heart defect and Lois and her husband spent months at her daughter's bedside in Leeds. They say Amelie would not have survived without the Leeds unit.

██████████ eldest daughter had major heart surgery at the Leeds General Infirmary about four years ago. He says that he practically lived there for about six weeks, travelling back and forth to work in Skipton every day. Without the surgery, he says his daughter would not have lived and without the ward being there he would have had to make some fairly tough choices between family commitments and continuous employment.

I have also spoken to parents in Ripon who credit the Leeds unit with saving their child's life, a mum from near Addingham wrote to me to tell me of their experiences and why they think the unit is so valuable and doctors from across North Yorkshire who believe having children's heart surgery in Yorkshire is essential to the care of very sick children.

However, I know that in a review like this those stories, no matter how emotional or compelling, are not enough. The review will be examining facts and figures, medical data and medical views. From all my research, discussions and enquiries I believe the case for keeping the Children's Heart Surgery unit in Leeds is equally compelling.

The Leeds General Infirmary is in the middle of one of the densest population areas of the country. 14 million people are within two hours travel time including the five and a half million people in the Yorkshire and the Humber region. It encompassed both the urban areas of West and South Yorkshire and the more rural parts of North Yorkshire, including my constituency. One of the concerns expressed to me is that getting to another unit – be it Newcastle or Leicester or Liverpool - from somewhere like

the Yorkshire Dales or Nidderdale would mean significantly increased travel times, especially for those parents who have to rely on public transport.

The Leeds unit has the capacity to expand and is also part of the Leeds General Infirmary Leeds General Infirmary. This means it is the only unit to have true co-location - all the specialist services required by the Children's Heart Surgery Unit in one place. This is a huge asset for healthcare, for doctors and nurses, for children and for parents. I believe this important element has been underplayed in the current review process.

Another key element is the multiracial mix of Yorkshire's population. No account has been made of the Asian community of Yorkshire and the fact that doctors have told me that children of Asian parents are more susceptible to heart conditions.

There have also been concerns raised with me about the consultation process itself. Parents and campaigners have not been happy with the public meetings that have been held and some have raised issues regarding the criteria being used to make the decisions.

I have no doubt that there are passionate views around the future of any children's heart surgery unit. However, the case for the facility in Leeds is compelling and overwhelming. It has an excellent record for providing safe, high quality children's heart surgery, a dense population with some parts of that population more predisposed to heart conditions and high quality transport links to the north, south, east and west by road and rail.

The Leeds Children's Heart Surgery Unit is an excellent facility for the whole of Yorkshire and the whole of the North of England. I hope you will ensure it has a strong future.

Due to the huge public interest in this consultation, I am releasing this letter to the media.

Yours sincerely,

**JULIAN SMITH MP**

cc Rt Hon Andrew Lansley MP, Secretary of State for Health  
cc Kevin McAleese, North Yorkshire and York Primary Care Trust Chairman  
cc Jayne Brown, North Yorkshire and York Primary Care Trust Chief Executive  
cc Alisa Claire, Yorkshire and The Humber Specialised Commissioning Group



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LONDON SW1A 0AA

Jeremy Glyde  
Safe and Sustainable Programme Director  
NHS Specialised Services  
2<sup>nd</sup> Floor  
Southside  
105 Victoria Street  
London  
SW1E 6QT

28<sup>th</sup> June 2011

Dear Mr Glyde,

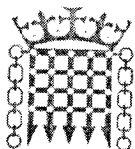
**Re: Listen to Barnsley – Save Leeds Children’s Heart Unit**

In response to the 'Safe' and Sustainable' Service Review into the future of children's heart services, on behalf of my constituents I would like to press the case for retaining the service at Leeds General Infirmary.

My constituents and I have been determined to fully participate in this consultation and there has been a lively debate across the local media in Barnsley, plus the issue has been discussed at a range of local meetings, including most recently at a formal round table I held in Hoyland in my constituency. Attending this meeting was Kevin Watterson, Heart Surgeon and Sara Matley, Consultant Clinical Psychologist, both Trustees of the Children's Heart Surgery Fund, as well as a number of former patients whose lives had been saved thanks to the brilliance of the clinicians and the care they received at the Leeds General Infirmary.

So my submission to your consultation is one that is rooted in real peoples' lives and real peoples' experiences. I believe that their evidence makes for a powerful and overwhelming case for retaining a Children's Heart Service in Leeds. Please listen to those Barnsley residents who have made their strong feelings known throughout this submission.

We all want better outcomes for children with congenital heart disease and the highest quality national children's heart service. I am fully aware that the aim of this Review is to drive up the quality of treatment and I understand the principles that lie behind favouring a reduction in the number of units to create hubs of excellence and pool surgical expertise. It is right that decisions are made that improve the service on a clinical basis. However, these decisions must also be made in consultation with patients, their families and staff and on the basis of other relevant facts such as population size, travel times and the need to ensure patients have proper family support during their care in hospital.



### A locally delivered service

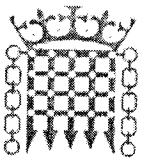
One of the five principles that guided the Review was the need for a locally delivered service where possible. The significance of this cannot be underestimated and the actual location of the services and the impact on travel times is one of the most important things to get right in this Review.

- Nearly 14 million people are within 2 hours' travel time of the Leeds General Infirmary and its location means it can accommodate patients from outside the current catchment area via some of the UK's major transport links, such as the M1, A1, M62, East Coast, TransPennine and Cross Country rail network.
- The Unit at Leeds covers a population of 5.5 million people in Yorkshire & Humber, Lincolnshire and North Derbyshire regions – covering one of the highest populations of all the Units in England. Newcastle by contrast has a population coverage of 2.6 million. Population density must be taken into consideration in health planning and if it is based on this principle, all of the problems due to reconfiguration, such as extra distance and extra cost for individual families, are minimised because you move the doctors to the patients, not the patients to the doctors.
- The birth rate is growing above the national average in Yorkshire and Humber – in other areas it is falling. Population growth predictions for 2028 put Yorkshire and Humber at 6.1 million and Newcastle at 2.8 million (half the national projection growth rate). With about 1 baby in every 133 births being born with congenital heart disease – it makes sense for services to be based where they will be more babies.
- Heart surgeons and intensive care doctors have said that increased travelling time is not good for children and their families, especially in the case of emergency surgery where it could prove fatal.

*"My family has had cause to appreciate first-hand the value of its predecessor, at Killinbeck after our daughter was born with a heart condition 28 years ago. The expertise of the unit and its closeness to our home did much to ensure she is alive today...Whatever the reasons made for closure, there is one fundamental reason why the unit must stay open: IT IS SIMPLY TOO FAR TO TRANSPORT A VERY SICK CHILD FROM OUR REGION TO EITHER NEWCASTLE OR LIVERPOOL"*

**[REDACTED]** Barnsley

*"With heart disease in children, one of the more noticeable signs seen is how rapidly and often that child can become very seriously ill. On 4 occasions in his life, Bradley collapsed and had stopped breathing. On one occasion Bradley had to be rushed to LGI from Barnsley (30 minutes by ambulance) after his heart went into SVT (Supra Ventricular Tachycardia). It is a medical fact that if SVT is not reversed within 1 hour of onset then full heart block and death quickly follows. It took a specialist unit like that at LGI to revert Bradley's deformed heart back to a normal rhythm. The new proposed alternative, Newcastle Upon Tyne, is hours further away, and will be way too late to save any child with specialist needs from any such emergency"* John and **[REDACTED]** Cudworth



- A local service means that families are able to rely on external practical and emotional support from family and friends who are close at hand. The length of time a child is in hospital can vary from a couple of days to many months. Therefore, the impact on organising childcare for siblings and continuing to work will be enormous if parents have to travel a significantly greater distance to visit their child. Some patients receive treatment from the time they are born right up until teenage years – the ability for friends to visit the patient on a regular basis has a morale boosting effect and should not be underestimated.

*“Having to travel, should the LGI, close will greatly affect siblings and other family members who will then be unable to visit heart children during their stay in hospital. Visits from siblings and family members is proven to help the recovery of the patient and boost moral during very upsetting and scary times”*

*[Redacted], Cudworth*

*“If children have to go to Newcastle for their treatment, an after work commute to see their children would be virtually impossible”*

*[Redacted] Darfield*

*“This is a vital service and serves a very wide area. Families will have long journeys and great inconvenience if this Centre closes. My own son had a heart echo scan when he was only a few days old and this could prove to be a great hardship for families in the future if they have to travel great distances”*

*[Redacted] Great Houghton*

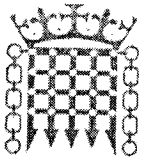
The service at Leeds General Infirmary also has a strong case in the other five principles that guided the review:

### **The need of the child comes first in all considerations**

The dedicated staff at the Leeds General Infirmary ensure that the necessity to fulfil the needs of all the children attending their Unit is paramount when making decisions about treatment and care. If this Unit closes, sick children will have to get used to a new environment, with new staff. For many children surgery is not a once in lifetime event but something many have to endure many times and the upheaval of travel and new environments is an added burden. Some families may have to think about moving house in order to be nearer a Unit and this would have a huge impact on family life.

*“It is a nice hospital where it’s a lot like being at home and everyone comes to see me which makes me feel much, much better”.* [Redacted] aged 9

Leeds offers a well established lifespan psychological support service with four members of staff. At other Units, the service is less established or not as well provided for. I have been told that Newcastle, for example, only has a part time psychologist limited to transplant patients.



## Quality

The Paediatric Cardiac Service at Leeds General Infirmary extends from pre-natal diagnosis to the treatment of congenital heart disease in adults. It has an excellent record of providing safe, high quality surgery. Staff at Leeds have fears that removing surgery will dismantle the rest of the high quality service and lead to a loss in expertise as it becomes harder to retain and attract high quality staff. Leeds General Infirmary is at the forefront of work on inherited cardiac conditions – this expertise should not be lost.

*“At the present time we have an excellent service from Leeds General Infirmary that is the hub of the best developed cardiac network in the UK. This network has been adopted as a blueprint of how cardiac services within the country should be run” Child Health Advisory Group for Yorkshire Region*

*“My Grandson was not expected to survive more than 5 minutes from birth. He spent his first 3 months from birth in LGI and had his first double heart bypass. His second bypass was just over a year ago and now he is aged 9 years, attends Carlton Primary School and is a good swimmer. Many thanks to LGI” [REDACTED] Cudworth*

## High Standards

Leeds General Infirmary is one of only two centres in the UK (the other is Southampton) which has co-location of children services on one site (cardiac surgery, cardiology and all paediatric services) and as such meets the requirements of the Department of Health's Critical Interdependencies report *Commissioning safe and sustainable specialised paediatric services - a framework* (2008). The British Congenital Cardiac Association (BCCA), a leading support organisation of the Safe and Sustainable Review, released a statement on 18 February that said: 'For these services at each centre to remain sustainable in the long term, co-location of key clinical services on one site is essential.' Other Units are stand-alone sites and as such do not offer the same level of service. This could mean children have to travel to various locations for treatment instead of one.

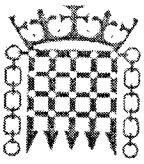
*“If a child is born in a District Hospital, they have a short transfer to Leeds for assessment and if it is felt the problem is not surgical they can continue to be looked after in the tertiary centre. If the future, it would mean a long transfer to either Newcastle, Liverpool or Birmingham for assessment...These hospitals are likely not to be sited at the same place as neonatal and paediatric services and therefore may require a further transfer. These transfers will provide a significant financial burden...and more importantly, pose a significant patient safety issue” Child Health Advisory Group for Yorkshire Region*

*“I was born with a rare form of heart disease. I was instantly transferred to Killingbeck Children's Heart Hospital – now Killingbeck Ward in the Cardiac Unit of Leeds General Infirmary - there parents felt their children were getting the right specialist treatment and it was closer to their homes to be able to visit their children after work” [REDACTED] Darfield*

## A personal service

Feedback from patients and families shows that they receive first class personal service throughout their treatment pathway with support from the Children's Heart Surgery Fund.





Patient Choice is important here too - if patients from Leeds, Yorkshire and the Humber choose to go to Liverpool because it is closer and more convenient to go to there from Yorkshire rather than travel to Newcastle, then it is likely that the Unit at Newcastle will not achieve the minimum 400 cases a year required by the Review.

In addition to all the points above, I have been told that there are significant factual inaccuracies contained in the report by the assessment panel that visited the Unit in Leeds and that there was no opportunity given to address these prior to the publication of the consultation. It appears for example, that Liverpool was given extra scoring due to its high population density, but Leeds was not, despite having a higher population density within a two hour drive.

I am extremely concerned about the impact on my constituents and other families in Yorkshire & the Humber region should the Leeds Unit be closed. It would leave a huge geographical gap in provision and as a result, the nearly 300 families which are currently supported each year would face huge logistical difficulties and increased costs to travel substantial distances at a time of great anxiety about their child's health.

Whichever Units are chosen, there must be steps taken to provide help with additional travel and accommodation costs that will be incurred as a result of this policy to reduce the overall number of Units. I would like to see measures put in place to support families who will have to make increased journey times and who will have no option but to stay overnight as a result. No matter which option is decided upon, families will need additional support, particularly those from areas like Barnsley, who for socio-economic reasons will find it harder to travel longer distances.

We all want better outcomes for children with congenital heart disease and I believe that the children's heart surgery unit at Leeds General Infirmary is ideally placed to act as one of the hubs of excellence. In terms of quality of service, ease of access and the size of population, it is clear that the Unit at Leeds should to be retained as the major centre serving the North Midlands, Yorkshire and the North East. As one person put to me - bring the doctors to the patients, not the other way round.

I am grateful for your consideration and look forward to your response.

Yours sincerely,

**Michael Dugher MP**  
**Member of Parliament for Barnsley East**