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Leeds CITY COUNCIL

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

Meeting to be held in the Civic Hall, Leeds on Thursday, 22nd September, 2011 at 10.30 am (Pre-meet for all Members at 10.00 a.m.)

MEMBERSHIP

Councillors

S Ali	-	Rotherham MBC
J Bromby	-	North Lincolnshire CC
D Brown	-	Hull City Council
J Clark	-	North Yorkshire CC
M Gibbons	-	Bradford MDC
R Goldthorpe	-	Calderdale MDC
B Hall	-	East Riding of Yorkshire CC
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	-	NE Lincolnshire CC
J Worton	-	Barnsley MBC

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

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A G E N D A

Item No	Ward/Equal Opportunities	Item Not Open		Page No
1			**APPEALS AGAINST REFUSAL OF INSPECTION OF DOCUMENTS** To consider any appeals in accordance with Procedure Rule 25* of the Access to Information Procedure Rules (in the event of an Appeal the press and public will be excluded). (*In accordance with Procedure Rule 25, notice of an appeal must be received in writing by the Chief Democratic Services Officer at least 24 hours before the meeting.)	
2			**EXEMPT INFORMATION - POSSIBLE EXCLUSION OF THE PRESS AND PUBLIC** 1 To highlight reports or appendices which officers have identified as containing exempt information, and where officers consider that the public interest in maintaining the exemption outweighs the public interest in disclosing the information, for the reasons outlined in the report. 2 To consider whether or not to accept the officers recommendation in respect of the above information. 3 If so, to formally pass the following resolution:- **RESOLVED –** That the press and public be excluded from the meeting during consideration of the following parts of the agenda designated as containing exempt information on the grounds that it is likely, in view of the nature of the business to be transacted or the nature of the proceedings, that if members of the press and public were present there would be disclosure to them of exempt information, as follows:-	

3			**LATE ITEMS** To identify items which have been admitted to the agenda by the Chair for consideration. (The special circumstances shall be specified in the minutes.)	
4			**DECLARATIONS OF INTEREST** To declare any personal/prejudicial interests for the purpose of Section 81 (3) of the Local Government Act 2000	
5			**APOLOGIES FOR ABSENCE AND NOTIFICATION OF SUBSTITUTES** To receive any apologies for absence and notification of substitutes.	
6			**MINUTES OF MEETINGS HELD ON 2 AND 19 SEPTEMBER** To follow	
7			**PROPOSED RECONFIGURATION OF CHILDREN'S CONGENITAL HEART SERVICES IN ENGLAND: QUESTIONS TO THE JOINT COMMITTEE OF PRIMARY CARE TRUSTS** To receive and consider the attached report of the Head of Scrutiny and Member Development	1 - 16
8			**PROPOSED RECONFIGURATION OF CHILDREN'S CONGENITAL HEART SERVICES IN ENGLAND: ADDITIONAL INFORMATION FROM LEEDS TEACHING HOSPITALS NHS TRUST (LTHT)** To receive and consider the attached report of the Head of Scrutiny and Member Development	17 - 30

9			**PROPOSED RECONFIGURATION OF CHILDREN'S CONGENITAL HEART SERVICES IN ENGLAND: DETAILS OF COUNCIL MOTIONS FROM ACROSS YORKSHIRE AND THE HUMBER** To receive and consider the attached report of the Head of Scrutiny and Member Development	31 - 56
10			**PROPOSED RECONFIGURATION OF CHILDREN'S CONGENITAL HEART SERVICES IN ENGLAND: SUBMISSIONS FROM MEMBERS OF PARLIAMENT (YORKSHIRE AND THE HUMBER)** To receive and consider the attached report of the Head of Scrutiny and Member Development	57 - 68
11			**DATE, TIME AND VENUE OF NEXT MEETING** Thursday, 29 September 2011 at 10.00 a.m. (Pre-meet for all Members at 9.30 a.m.) – Rooms 6 and 7, Civic Hall, Leeds	

Leeds CITY COUNCIL

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Report of the Head of Scrutiny and Member Development

Report to the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

Date: 22 September 2011

Subject: Proposed Reconfiguration of Children's Congenital Heart Services in England: Questions to the Joint Committee of Primary Care Trusts (JCPCT)

Are specific electoral Wards affected? If relevant, name(s) of Ward(s):	☐ Yes	☒ No
Are there implications for equality and diversity and cohesion and integration?	☐ Yes	☒ No
Is the decision eligible for Call-In?	☐ Yes	☒ No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Not applicable Appendix number: Not applicable	☐ Yes	☒ No

Summary of main issues

1. The Joint Health Overview and Scrutiny Committee HOSC (Yorkshire and the Humber) forms the statutory overview and scrutiny body to consider and respond to the proposed reconfiguration of Children's Congenital Heart Services in England – taking into account the potential impact on children and families across the region.

2. In considering the proposals set out in the *Safe and Sustainable Consultation Document: A new vision for Children's Congenital Heart Services in England (March 2011),* Members of the Joint HOSC have sought to consider a wide range of evidence and engage with a range of key stakeholders.

3. As part of the public consultation on the future of Children's Congenital Heart Services in England, HOSCs have been given until 5 October 2011 to respond to the proposals.

4. In preparation for the previous meeting (2 Septmeber 2011), direct input was sought from the Joint Committee of Primary Care Trusts (JCPCT), as the appropriate decision-making body. However, the invitation to attend the meeting was declined.

5. At the meeting on 19 September 2011, the Joint HOSC considered a series of questions aimed at the JCPCT and the associated responses. However, representatives from the JCPCT were unable to attend that meeting.

6. The questions aimed at the JCPCT and the associated responses (referred to above) are presented at Appendix 1. This includes some supplementary questions/ responses to the original questions posed. Supplementary responses were received on 16 September 2011.

7. Furthermore, additional information on a number of points identified in the original response has been sought by a member of the Joint HOSC (Cllr. Smaje). Details of the request and the response provided are attached at Appendix 2.

8. A representative from the JCPCT will be in attendance at the meeting to discuss the responses and address any further questions identified by the Joint HOSC.

Recommendations

9. Members are asked to consider the details associated with this report and identify/ agree any specific matters for inclusion in the Committee's report to be presented to JCPCT later in the year

Background documents

- A new vision for Children's Congenital Heart Services in England (March 2011)

Questions posed to the Joint Committee of Primary Care Trusts (JCPCT)

1	**Why was the Leeds unit not included in all four options on the grounds of population density in the Yorkshire and the Humber region, on the same basis that the units at Birmingham, Bristol, Liverpool and the 2 London centres, which feature in all four options?**
	No centres have been included in options solely on the grounds of 'population' but rather on the grounds of high caseloads and the ability of other surgical centres to assume these caseloads were surgical centres with high caseloads to be removed from potential configuration options (population levels are of course a good indicator of a caseload in any individual centre but are not in themselves sufficiently informative to evaluate potential configuration options). For example, Birmingham Children's Hospital has been included in all options because the JCPCT concluded that its very high caseload (555 surgical procedures) could not reasonably be met by other surgical centres taking into account existing caseloads at other centres and reasonable travel times. Similarly, the JCPCT concluded that the combined caseload for the London centres (around 1,250 surgical procedures covering London, South East and Eastern England) could not be reasonably met by one surgical centre in London, or by other surgical centres outside of London were there to be no surgical centre in London. NHS Specialised Services supports the work of the National Specialised Commissioning Group (NSCG). The NSCG oversees and co-ordinates the work of regional Specialised Commissioning Groups, providing support and guidance. By contrast, Leeds Teaching Hospitals NHS Trust has a relatively low caseload (316 surgical procedures in 2009/10, and 336 in 2010/11). The JCPCT□s analysis did not suggest that other surgical centres in potential configuration options would struggle to assume the Leeds caseload were the Leeds centre removed from potential configuration options. In your letter you refer to Alder Hey Children□s Hospital. This centre was not included in all options on the grounds solely of its own caseload (400 surgical procedures) but because the retention of Alder Hey was a reasonable recommendation after applying the following two working principles: i. The population and caseload suggests a need for two surgical centres in the North of England, as there is insufficient forecast activity to reasonably suggest the retention of three centres ii. A potential option that comprised the Freeman Hospital and Leeds Teaching Hospital NHS Trust (at the exclusion of Alder Hey Children□s Hospital) would not be viable as for both centres to achieve a minimum of 400 surgical procedures (as required by the Safe and Sustainable standards) would require significantly unreasonable changes to patient flows and clinical networks. Because of this, only options which included Liverpool and Leeds or Liverpool and Newcastle were considered. You also refer in your letter to the surgical centre in Bristol, but this centre has not been included in configuration options on the grounds of population or caseload.

2	**Why isn't the genuine co-location of paediatric services provided at the Leeds Children's Hospital, alongside maternity services and other co-located services and specialisms on the same site at Leeds General Infirmary given greater weighting? Such service configurations have been described as the 'gold standard' for future service provision, yet it appears not to have been given sufficient weighting in the case for Leeds.**
	I am advised that Leeds Teaching Hospitals NHS Trust received the maximum score of 'excellent' for current co-location of services, and a very high score for how those services could continue to be delivered in the event of an increased caseload. These high scores reflect the provision of on-site services that you describe in your letter. However, the Trust was also assessed against its ability to meet other quality standards and when considered in the round, the Trust received the second lowest score of all eleven surgical centres.
3	**Why isn't the "exemplar" cardiac network which has operated in the Yorkshire and Humber region since 2005 given greater weighting in the drawing up of the four options? The future network model proposed in the consultation document is again described as the 'gold standard' for the future service delivery model, yet three of the four options put forward would see the fragmentation of this unique and exemplary cardiac network.**
	Professor Sir Ian Kennedy's panel advised that none of the current surgical units have developed networks that fully comply with the Safe and Sustainable standards, but the panel acknowledged the strength of the current network in Yorkshire and Humber by assessing it as 'strong'. However, the panel also identified a number of gaps in compliance and as such the network was not described as „exemplary□. As I describe above, the Trust was assessed NHS Specialised Services supports the work of the National Specialised Commissioning Group (NSCG). The NSCG oversees and co-ordinates the work of regional Specialised Commissioning Groups, providing support and guidance. against a number of different standards and the cumulative conclusions of the panel led to Leeds Teaching Hospital being awarded the second lowest score
4	**Why doesn't the Leeds unit feature in more of the four options put forward given that all surgical centres are theoretically capable of delivering the nationally commissioned Extra Corporeal Membrane Oxygenation (ECMO) service?**
	It is not correct that „all surgical centres are theoretically capable of delivering the nationally commissioned Extra Corporeal Membrane Oxygenation (ECMO) service□. During the assessment process, all centres were asked whether they would be able to provide nationally commissioned services, including ECMO for children with severe respiratory failure. Leeds Teaching Hospitals NHS Trust submitted an application to deliver ECMO services but the application was declined as the panel was not confident that the Trust had demonstrated that it had the appropriate skills and infrastructure to deliver respiratory ECMO for children.

5	**Why isn't travel and access to the Leeds unit given a higher weighting given the excellent transport links to the city by motorway and road network (including access to the M1, M62 and A1(M)), the rail network (including direct access to the high speed East Coast mainline and the Transpennine rail route) and access by air via the Leeds-Bradford airport? Almost 14 million people are within a two hour travelling distance of the Leeds unit.**
	Travel and access was considered as part of the options appraisal process, although the parents and clinicians with whom we consulted on the matter recommended that it receive the lowest of the criteria used for arriving at the final options for consultation. The model of care that we describe in the consultation document proposes to reduce travel times for the many families who currently travel long distances to receive treatment by bringing non-interventional assessment and follow-on care closer to the homes of children with congenital heart disease by establishing these services in local hospitals. All of the options for consultation also ensure that the children in Yorkshire and the Humber can be reached by a specialist retrieval time in compliance with the standards around emergency retrieval times set by the Paediatric Intensive Care Society (PICS).
6	**We are keen to understand in more detail the relative strengths and weaknesses of each surgical centre. We therefore request the detailed breakdown of the assessment scores determined by the Independent Assessment Panel, Chaired by Sir Ian Kennedy (referred to on page 82 of the consultation documents).**
	The detailed breakdown of scores will be made available once the JCPCT has concluded its deliberations. This is because the JCPCT members agreed last year that they did not wish to see the detailed breakdown of scores while they continued their work. Scrutiny committee members and other stakeholders have therefore received the same level of detail that has been shared with the JCPCT members themselves.
	Supplementary question: The original question asked for a detailed breakdown of the Kennedy scores. Please clarify: ***(a) What information about the scores has been made available to the Trusts.*** ***(b) What opportunity have Trusts had to challenge or correct inaccuracies in respect of the narrative feeding into the scores?*** ***(c) Is the intention to revisit the scores at any time to update or amend the values in the light of any challenges or concerns?*** *The Trusts were provided with the weightings for each element of the assessment when the self-assessment template was shared with them in March 2010. At the conclusion of the assessment an interim report on the panel's findings was shared with the centres in August 2010. The Trusts received Professor Kennedy's full report, with the cumulative weighted scores for each centre, in January 2011.* *In response to the interim report, Leeds Teaching Hospitals NHS Trust wrote to the secretariat to ask that alleged inaccuracies in the report be corrected. Professor Kennedy's panel met in December 2010 - before the panel's report was finalised - to consider the Trust's concerns. The panel concluded that it had not made any errors of fact and that its findings remained valid, though the panel agreed to change some wording in the final version of the report to clarify certain points in response to the Trust's concerns.* *The JCPCT has asked Professor Kennedy's panel to consider responses to consultation that allege that the panel's report includes factual inaccuracies and to advise the JCPCT as to whether, as a result of the panel's further deliberations, the panel wishes to advise the JCPCT of the need to re-visit the previous scores. The panel will present its report to the JCPCT in October 2011. The JCPCT will also consider the responses to consultation that have suggested that there is a need to reconsider the weightings attached the scoring process.*

7	**How has the potential impact of the proposed reconfiguration of surgical centres on families, including the additional stress, costs and travelling times, been taken into account within the review process to date?**
	Despite the potential impacts to families to which you refer, it is important to note that the outcome of the recent public consultation was overwhelming support for the need for reconfiguration of services. The issues that you have described have been explored during options-appraisal process, as well as during the consultation. Patients, their families and carers, clinicians and the public have told us about this during engagement events, undertaken while the options were developed, as well as at the consultation events, and responses to the consultation. Focus groups with young people and their families were run to explore these issues in depth. A Health Impact Assessment has been undertaken by an independent expert third party to explore, assess and analyse the positive and negative NHS Specialised Services supports the work of the National Specialised Commissioning Group (NSCG). The NSCG oversees and co-ordinates the work of regional Specialised Commissioning Groups, providing support and guidance. impacts resulting from the proposed changes , and the measures to enhance and mitigate these, on patients and the public with particular emphasis on the vulnerable groups. Locally, workshops were run by an independent third party in Leeds, Bradford and Kirklees to assess impacts of the proposed changes on vulnerable groups. The HIA Scoping Report, Key Emerging Findings from Phases 1&2, and the HIA Interim Report have been published and shared with HOSCs and LINKs. The JCPCT will consider the independent final HIA Report, as well as the independent qualitative report from Ipsos Mori. Additionally, the Safe and Sustainable standards provide for improved facilities for families in the designated surgical centres, including family accommodation.
	Supplementary question: The original question asked how the potential impact on families has been taken into account within the review process to date. The supplementary question is how has the potential impact on families (not the patient) fed into the short listing of the options for consultation. *The standards and model of care – the proposed standards and model of care were informed by the outcome of a comprehensive public engagement held between September and December 2009; comments received during the exercise have been published so that stakeholders can see how their comments have informed the final proposals.* *Family accommodation - parents have raised as a concern the provision of appropriate family accommodation at surgical centres in the future; the standards seek to address this issue and Sir Ian Kennedy's panel was asked to specifically assess the applicant centres against this standard; on the day of the assessment visits to each centre the panel met with a delegation of parents to hear their views.* *Journey times – parents and professionals have also raised as a concern the possibility of increased journey times, for both elective appointments and emergency retrievals; the criteria for the evaluation of potential options applied by the JCPCT has included a detailed analysis of travel times for elective appointments and an analysis of potential retrieval times against the current standards set out in the Paediatric Intensive Care Society standards.* *Financial costs – where the Safe and Sustainable review has not been able to respond to the concerns of parents because those concerns fall outside of the scope of the review – for example around the reimbursement of travel costs for families not entitled to financial assistance under the Healthcare Travel Cost Scheme - the Safe and Sustainable Team has brought those concerns to the attention of the relevant government department (in this case the Department of Health).*

	Supplementary question: Please can reassurance be given that patients and families in Yorkshire & the Humber are not being disproportionally disadvantaged in the options not including Leeds, compared to other areas of the country. *The Joint Committee of Primary Care Trusts has sought to deliver a number of options that provide the best "fit" of services taking into account the need for equitable access to high quality services. Indeed one of the key principles driving the review is that 'the same high quality of service must be available to each child regardless of where they live or which hospital provides their care'. The JCPCT has set out the potential 'risks and benefits' of each option on p115 – 166 of the consultation document and HOSC members are invited to advise the JCPCT on the extent to which, in their opinion, the options favour or disadvantage the population of Yorkshire and Humber.*
8	**Why have congenital cardiac services for adults been excluded from the review when, in some cases, the same surgeons undertake the surgical procedures?**
	The NHS is reviewing the provision of congenital cardiac services via two separate but related reviews. The view of experts, endorsed by the Steering Group in December 2008 and by the SCG Directors Group in 2009, was that the immediate concerns around safety and sustainability related to the paediatric element of the service. The process for the designation of adult congenital services will proceed in 2011 with reference to the separate standards that have been developed by a separate expert group and which were published in 2009.
	Supplementary question: The original questions relate to adult congenital heart services. Please can reassurance be provided that any decision taken relating to paediatric heart surgery will not, by default, impact detrimentally on the adult congenital heart services in Leeds. *The remit of the JCPCT is children's congenital heart services in England. A separate review of adult services is underway and the first stage of this review is to seek opinion from the public, NHS staff and scrutiny committees on draft quality standards. This exercise will be underway in the coming months. The final version of the standards will then be used to designate providers of adult congenital heart services in 2012. The aim of the NHS in both reviews is to improve congenital heart services, not impair them. If significant changes are recommended to adult services the NHS will hold a full and proper public consultation and it will be for stakeholders, including the scrutiny committee, to advise the NHS on the extent to which, in their opinion, the proposed changes impact positively or detrimentally.*

9	**We have heard that more children with congenital cardiac conditions are surviving into adulthood, which suggests an overall increase in surgical procedures (for children and adults), which is likely to be beyond the 3600 surgical procedures quoted in the consultation document:** **(a) As such, what would be the overall impact of combining the number of adult congenital heart surgery procedures with those performed on children, i.e. how many procedures are currently undertaken by the same surgeons and what are the future projections?** **(b) How would this impact on the overall number of designated surgical centres needed to ensure a safe and sustainable service for the future?** **(c) What would be the affect on the current and projected level of procedures for each of the existing designated centres?**
	Any adult congenital heart surgery is over and above the 3600 procedures for children (u16s). The current number of operations on adults is less than 870 p.a. (CCAD), so approximately 20% of the national caseload on congenital heart surgery is adult. This is likely to grow at a faster rate than children□s surgery given that more children are surviving into adulthood. Nevertheless the analysis that has been undertaken to date suggests that no centre will be overwhelmed by this additional activity. The HOSC should be aware that as a separate exercise a review of adult congenital heart surgery is being undertaken which will conclude where this surgery will take place and will have the benefit of the conclusions of the paediatric heart surgery review to support it.
	Supplementary question: Please can the 870 adult procedures quoted be provided broken down by region and parts (b) and (c) of original question 9 be answered. *The actual number of adult (>15 years old) surgical procedures was 859, excluding private patients, Scottish and NI centres. The breakdown is provided at Annex 2.* *In response to 9b and 9c, as I mentioned in my previous response the analysis to date (see p. 126 of the pre-consultation business case) implies that no centre will be overwhelmed by the adult congenital work (although until the GUCH review is completed it is not possible to know where the GUCH work will take place). It is reasonable to assume that the GUCH review would need to consider growth in this service in detail. The Safe and Sustainable assumed that every 5% increase in GUCH caseload is equivalent to a 1% increase in the paediatric caseload.*
	Supplementary question: Please can you explain why the number of adult congenital heart procedures can't be added into the number of procedures per centre? *The remit of this review is to reconfigure paediatric congenital heart surgery, and the adult procedures cannot be therefore added, as they are a subject of a separate review which has not yet reported.*
10	**How has the impact on other interdependent hospital services and their potential future sustainability been taken into account within the review process to date?**
	The review has assessed the impact of inter-dependent services and their sustainability. This is outlined in both the pre-consultation business case and the consultation document. The JCPCT will now consider evidence around inter-dependent services (including paediatric intensive care services) that has been submitted during consultation before making a final decision.

11	**The Government's Code of Practice on Consultation (published July 2008) sets out seven consultation criteria: Please outline how the recent public consultation process meets each criterion?**
	Please see Annex A.
12	**What specific arrangements have been put in place to consult with families in Northern Ireland?**
	The remit of the review is services in England and Wales. Responsibility for the NHS in Northern Ireland rests with the devolved administration in Northern Ireland. However, the NHS Specialised Services supports the work of the National Specialised Commissioning Group (NSCG). The NSCG oversees and co-ordinates the work of regional Specialised Commissioning Groups, providing support and guidance. Secretariat publicised the consultation and encouraged the population of Northern Ireland to take part in the consultation via advertisements in local newspapers in Northern Ireland.
13	**How have ambulance services (relevant to the affected patient populations) been engaged with in the review process – particularly in relation to drawing up the projected patient flows and associated travel times?**
	I understand that EMBRACE has presented to the JCPCT and to the OSC an analysis of potential retrieval times relevant to Yorkshire and the Humber. Furthermore, ambulance services were invited to sit on the Safe and Sustainable Steering Group and the separate group that developed the quality standards. They are also represented on the Health Impact Assessment Steering Group. The Health Impact Assessment has taken into account the impact of the proposed changes on the provision of ambulance services. Retrieval times have been considered and analysed. The proposed times for retrieval comply with the Paediatric Intensive Care Society (PICS) guidelines. The proposed Safe and Sustainable clinical standards include a mandatory requirement that there must be „an appropriate mechanism for arranging retrieval and timely repatriation of patients.
14	**How has the impact on training future surgeons, cardiologists and other medical/ nursing staff been factored into the review?**
	The JCPCT recognises that improved training processes will need to be put in place for clinical staff and the independent expert panel, chaired by Professor Sir Ian Kennedy, has also concluded that „the succession planning for surgeons must be a key consideration for the future delivery of paediatric cardiac service.□ The professional associations representing surgical, medical and nursing staff who sit on the steering group (which is chaired by the Director for Medical Education for England) and other experts with whom we have consulted (for example in the Deaneries) have advised that this is an issue for the implementation phase of the review rather than the assessment phase.
15	**What are the training records of each of the current surgical centres and how have these been taken into account in drawing up the proposals?**
	I am unsure as to what you mean by „training records and I would be grateful if you were to clarify your question so that I may provide an answer.

	Supplementary question: Please could you provide information on the number of new cardiologists and cardiothoracic surgeons who have been trained by each centre over the last 5-10 years. How has the "track record" for training new doctors fed into the assessment of each of the current surgical centres. The „track record for training new doctors' has not fed into the assessment of the current centres. We do not hold the data to which you refer.
16	**Why have services provided in Scotland been excluded from the scope of the review, when the availability and access to such services may have a specific impact for children and families across the North of England and potentially Northern Ireland?**
	As I have explained previously, the scope of the review is services in England and Wales. The small number of cases that flow from Scotland and Northern Ireland to English surgical centres have been taken into account by this review. However, the catchment area for Newcastle does not include Scotland as the children's heart surgical unit in Glasgow is part of the Scottish devolved administration's responsibility and therefore outside the scope of the Safe and Sustainable review.
	Supplementary question: Please can you clarify the position with regard to Scotland? Have Scotland been invited to take part in the consultation in the same way that Northern Ireland has? If they haven't, please can you explain why a different approach has been taken. *The approach was consistent. Responsibility for the NHS in Scotland rests with the devolved administration in Scotland but the secretariat publicised the consultation in Scotland via advertisements in local newspapers.*
17	**Please confirm whether or not a similar review around the provision of congenital heart services for children, is currently being undertaken in Scotland. Please also confirm any associated timescales and outline how the outcomes from each review will inform service delivery for the future.**
	A review of the surgical centre in Glasgow is not within the remit of the JCPCT and I believe that NHS Scotland is best placed to answer your question.

Compliance of the *Safe and Sustainable* consultation with the *Code of Practice for Consultations*

Criterion 1: Formal consultation should take place at a stage when there is scope to influence the policy outcome.

The formal public consultation on the proposals to improve children"s congenital heart services was launched at the time when no decisions have been made on the number or location of the surgical centres, nor on the proposed standards and model of care, and the consultation has provided an opportunity to shape the proposals, bring forward relevant evidence and to submit alternative options for the JCPCT s consideration.

Additionally, informal consultation took place in the early stages of the Safe and Sustainable Review.

Patients and the public were invited to give their comments on the proposed clinical standards via an extensive public engagement exercise in the autumn of 2009, which included a national stakeholder event in October 2009.

Nine public engagement events were held in major cities across England between June and July 2010. The events were widely publicised in collaboration with local NHS commissioners, surgical centres and local interest groups. All events were well attended by parents, children, NHS staff, local scrutiny representatives and the media. At these events participants had the opportunity to put questions to a panel of experts. Written reports on the events were provided to the JCPCT so that the issues raised could be taken into account when developing criteria for the evaluation of options and in further development of the proposed clinical model of care.

From summer 2009 *Safe and Sustainable* has published a quarterly newsletter setting out background information, progress to date and future steps in the review process. A website provides background information and documents relating to the review, including detailed minutes of Steering Group meetings and Standards Working Group meetings and relevant reports. This enables the public to keep up to date with the process for the development of the draft standards and the review process. NHS Specialised Services supports the work of the National Specialised Commissioning Group (NSCG). The NSCG oversees and co-ordinates the work of regional Specialised Commissioning Groups, providing support and guidance.

In September 2010 the Office of Government Commerce undertook an independent review of the way in which the NSC Team had managed the *Safe and Sustainable* Review. The report was positive and the Review was particularly commended for “excellent clinician, patient and key stakeholder engagement”. Similarly in September 2010 the National Clinical Advisory Team undertook an independent review of the clinical case for change driving the Review and the review was commended for the level of engagement with NHS staff and the public.

A number of briefings tailored to specific interest groups were published before and during the formal consultation. For example, in August and October 2010 every Health and Overview Scrutiny Committee in England and every Local Involvement Network in England were briefed about the Review. A briefing for every Member of Parliament was published in September 2010 which encouraged them and their constituents to take part in consultation events. In November 2010, a briefing was published for the Chief Executive of every local authority in England and in March 2011, for every General Practitioner in England.

Criterion 2: Consultation should normally last at least 12 weeks with consideration given to longer timescales where feasible and sensible

The consultation was launched on 1 March 2011 and ended on 1 July 2011. It lasted four months, one more month than the 12 weeks as recommended above. The consultation has been extended to over 7 months for Health and Overview and Scrutiny Committees (up to 5 October 2011).

Criterion 3: Consultation documents should be clear about the consultation process, what is being proposed, the scope to influence and the expected costs and benefits of the proposals.

Consultation literature has clearly explained the background for the need for change, the process followed to deliver options for consultation, and the process of consultation itself. The outcome of the financial assessment is set out in the Pre-Consultation Business Case and Consultation Document. The benefits, as well as risks and proposed mitigation of risks associated with the proposed changes are outlined in the consultation documentation. NHS Specialised Services supports the work of the National Specialised Commissioning Group (NSCG). The NSCG oversees and co-ordinates the work of regional Specialised Commissioning Groups, providing support and guidance.

The outcome of the Health Impact Assessment was published in all key stages – in February 2011, the HIA Scoping Report was published, with Key emerging findings from Phases 1 and 2 published in June 2011 (during consultation, as set out in the guidance), and the Interim HIA Report was published in August 2011.

The response form included a mixture of open and closed questions, thus giving consultees an opportunity to express their views on issues not specifically addressed in the questions.

Criterion 4: Consultation exercises should be designed to be accessible to, and clearly targeted at, those people the exercise is intended to reach.

The consultation was targeted at different audiences. As many as 2,086 people attended 16 consultation events. These included three workshops specifically for young people, as well as a consultation document written for young people specifically. There were around 40 focus groups and workshops with parents, children, vulnerable groups, including BAME communities, supplemented by additional phone interviews and family interviews. The *Safe and Sustainable* review team has worked with clinicians, commissioners and voluntary sector to raise awareness of the consultation, in England, Wales, Scotland and Northern Ireland. During the consultation, the documentation was available in 12 languages: English, Welsh, Chinese, Polish, Hindi, Urdu, Gujarati, Punjabi, Bengali, Somali, Farsi and Arabic. This resulted in more than 75,000 responses, making it one of the biggest consultations in the NHS. Around 20% of responses came from Black and Ethnic Minority (BAME) groups, and 10% from young people, a reflection of the high degree of awareness raised among these groups.

Criterion 5: Keeping the burden of consultation to a minimum is essential if consultations are to be effective and if consultees' buy-in to the process is to be obtained.

Safe and Sustainable has kept the burden of the consultation to a minimum by consulting at the formative stage. The consultation response form was available online and was user-friendly (for example, username or password was not required to respond to the questions).

Criterion 6: Consultation responses should be analysed carefully and clear feedback should be provided to participants following the consultation.

NHS Specialised Services supports the work of the National Specialised Commissioning Group (NSCG). The NSCG oversees and co-ordinates the work of regional Specialised Commissioning Groups, providing support and guidance.

The consultation responses were analysed by Ipsos MORI, the independent expert third party, to ensure the analysis is independent and objective. The feedback was provided by publicising the outcome of the consultation in the national and local media, and on the *Safe and Sustainable* website. The responses that were received from organisations via letters or emails were published in full on the *Safe and Sustainable* website. The consultation documentation includes a high-level implementation plan. The response form includes the name of the Consultation Coordinator, to whom the consultees could submit comments about the consultation process.

Criterion 7: Officials running consultations should seek guidance in how to run an effective consultation exercise and share what they have learned from the experience.

A Consultation Coordinator was appointed and named in the consultation documentation as the person to contact with any queries or complaints regarding consultation process. Lessons learned are being shared within the organisation with those who are planning to consult.

Actual number of adult (>15 years old) surgical procedures (excluding private patients, Scottish and NI centres)

HOSPITAL	NUMBER
Alder Hey Hospital	7
Basildon Hospital	0
Birmingham Children's Hospital	19
Bristol Children's Hospital	65
Evelina Children's Hospital.	42
Freeman Hospital	88
Glenfield Hospital	41
Great Ormond Street Hospital	13
Hammersmith Hospital	1
Harley Street Clinic	*9*
Hull Royal Infirmary	0
John Radcliffe Hospital	16
King's College Hospital	10
Leeds General Infirmary	56
Liverpool Heart And Chest Hospital	27
Manchester Royal Infirmary	35
Northern General Hospital	0
Nottingham City Hospital	5
Queen Elizabeth Hospital	63
Royal Brompton Hospital	168
Royal Hospital For Sick C....	*2*
Royal Sussex County Hospital	9
Royal Victoria Hospital	*11*
Southampton General Hospital	66
St George's Hospital	20
St Marys Hospital, Paddington	8
St Thomas Hospital	0
University College Hospital	82
University Hospital Of No....	0
University Hospital Of Wales	18
Victoria Hospital	0
Sub-total	**881**
less private and non England and Wales hospitals	***22***
Total	**859**

Additional points of clarification

(1) Response to original question 2: '…*However, the Trust was also assessed against its ability to meet other quality standards and when considered in the round, the Trust received the second lowest score of all eleven surgical centres.'*

Point of clarification*: What is mean by other quality standards, can we have a list of quality standards from the trust that it has to comply to together with information on their compliance?*

Response: The quality (service) standards referred to are available using the following link:
http://www.specialisedservices.nhs.uk/library/30/Paediatric_Cardiac_Surgery_Standards_1.pdf

The report of the independent expert panel (Chaired by Sir Ian Kennedy) presented to the JCPCT is available using the following link:
http://www.specialisedservices.nhs.uk/library/30/Appendix_K1___Reports_of_the_Independent_Expert_Panel_Chaired_by_Professor_Sir_Ian_Kennedy_1.pdf

There has been an ongoing debate/ discussion around the availability of the breakdown in scores for each centre, and any assurance/ validation process with individual centres before these were published. The Joint HOSC has had varying opinions on the process, with LTHT stating that the Trust had not received a detailed breakdown of the scores, despite several requests. The breakdown in scores has been requested on behalf of the Joint HOSC. However, these have not been provided. It has been stated that the JCPCT has not considered the breakdown in the assessment scores.

(2) Response to original question 3: *'Professor Sir Ian Kennedy's panel advised that none of the current surgical units have developed networks that fully comply with the Safe and Sustainable standards, but the panel acknowledged the strength of the current network in Yorkshire and Humber by assessing it as 'strong'. However, the panel also identified a number of gaps in compliance and as such the network was not described as 'exemplary'.*

Point of clarification: *Can we find out from Safe and Sustainable what the safe and sustainable standards are for networks? Can we get a copy of Sir Ian Kennedy's report to see what it said in relation to this? Can Leeds tell us where the gaps are in relation to the standards referred to?*

Response: The network standards and the associated assessments are detailed in the above links. However, at this point the associated scores have not been made available.

(3) Response to original question 4: '…*Leeds Teaching Hospitals NHS Trust submitted an application to deliver ECMO services but the application was declined as the panel was not confident that the Trust had demonstrated that it had the appropriate skills and infrastructure to deliver respiratory ECMO for children.'*

Point of clarification: *Can Leeds Trust answer why this may be the case?*

Response: Leeds Teaching Hospitals NHS Trust have been invited to comment on the response received, including this specific point.

(4) Response to original question 5: '…t*hat the children in Yorkshire and the Humber can be reached by a specialist retrieval time in compliance with the standards around emergency retrieval times set by the Paediatric Intensive Care Society (PICS).'*

Point of clarification: Can we find out from the PICS what the standards are?

Response: The retrieval standard referred to is 3hrs from the decision to retrieve a child (or 4hrs in the case remote area, where the Retrieval Service has considerable distance to travel).

This standard is set out in Standard 123 (page 39) of the overall Standards for the Care of Critically Ill Children which is available here: http://www.rcoa.ac.uk/docs/sccic_2010.pdf Section D refers to retrieval and transfer times and is covered by standards 98-131.

Leeds CITY COUNCIL

Report author: Steven Courtney
Tel: 24 74707

Report of the Head of Scrutiny and Member Development

Report to the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

Date: 22 September 2011

Subject: Proposed Reconfiguration of Children's Congenital Heart Services in England: Additional information from Leeds Teaching Hospitals NHS Trust (LTHT)

Are specific electoral Wards affected? If relevant, name(s) of Ward(s):	☐ Yes	☒ No
Are there implications for equality and diversity and cohesion and integration?	☐ Yes	☒ No
Is the decision eligible for Call-In?	☐ Yes	☒ No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Not applicable Appendix number: Not applicable	☐ Yes	☒ No

Summary of main issues

1. The Joint Health Overview and Scrutiny Committee HOSC (Yorkshire and the Humber) forms the statutory overview and scrutiny body to consider and respond to the proposed reconfiguration of Children's Congenital Heart Services in England – taking into account the potential impact on children and families across the region.

2. In considering the proposals set out in the *Safe and Sustainable Consultation Document: A new vision for Children's Congenital Heart Services in England (March 2011),* Members of the Joint HOSC have sought to consider a wide range of evidence and engage with a range of key stakeholders.

3. As part of the public consultation on the future of Children's Congenital Heart Services in England, HOSCs have been given until 5 October 2011 to respond to the proposals.

4. The Joint HOSC has previously considered information provided by Leeds Teaching Hospitals NHS Trust (LTHT). The purpose of this report is to provide additional information provided by the Trust, in response to the information provided by the JCPCT. This information is provided at Appendix 1.

5. Representative from LTHT will be in attendance at the meeting to discuss the additional information provided and address any further questions identified by the Joint HOSC..

Recommendations

6. Members are asked to consider the details associated with this report and identify/ agree any specific matters for inclusion in the Committee's report to be presented to JCPCT later in the year

Background documents

- A new vision for Children's Congenital Heart Services in England (March 2011)

As outlined in Sir Neil Mckay's letter. Leeds Teaching Hospitasl NHS Trust (LTHT) (like all other surgical centres) were asked if we would be prepared to deliver any of the 3 nationally commissioned services :

- ECMO
- Transplant
- Tracheal Surgery

The process involved completing a proforma and returning it to the Safe and Sustainable team. The Safe and Sustainable team advised that an expert group then reviewed the information and provided comment /scored the submission. The Trust received high level feedback on its submission to deliver/ provide the 3 nationally commissioned services.

The Trust's completed proforma is attached at Annex A, in response to the very late invitation to provide a declaration of interest/option appraisal for delivery of the Nationally Commissioned Services (NCS), Transplant, ECMO and Complex Tracheal Surgery.

It should be noted that the template was received on 13th April 2010 for return by 7th May 2010, which equates to **16 working days**. The outcome of the expert panel review of our submission has influenced the decision about where these services could be delivered in the future. As such, it is our view that the NCS has now proven to be a fundamental factor in the consultation options and as such more time should have been afforded to this key part of the process.

We would also make the following additional points:

1) The timescale to complete the information was short , as this information was requested after the rest of the self assessment information.

2) The Trust has never been provided with the detail of the expert panel's view or given the scores / rationale as to why the team were not confident we could provide these services. The only reference to the outcome of the option appraisal is on page 103 -104 of the Safe and Sustainable new vision for children's congenital heart services in England Consultation document.

As for any centre who currently does not provide them , there would be a need to expand some of the skills / resource to deliver any of the 3 NCS. Therefore, without having any specific feedback regarding the Trust's submission , it is difficult to know why the expert panel took this view.

For ECMO specifically , of the 3 NCS this is the easiest to implement - we have perfusionists, surgeons , nurses in theatres and on ITU who have these skills and it would not be difficult to expand this if required.

The reality is (as previously identified to the Joint HOSC by Mr Watterson) any centre that has surgeons who are trained, perfusionists , PICU nurses who are trained and cardiac anaesthetists could provide and of these services if commissioned to do so. Clearly, there would be a period of training required (as there would for any centre new to set up), however there is at least a year between the planned decision and implementation of the new configurations which is more than sufficient time.

Leeds Teaching Hospitals NHS Trust

September 2011

Safe and Sustainable

Assessment of Nationally Commissioned Service (NCS) provision

Overview

1) Introduction

There are three services that are nationally commissioned by the National Specialised Commissioning Group (NSCT) and that are currently provided at some paediatric cardiac surgery centres in England. It is necessary for the *Safe and Sustainable* review to consider and address the future of these services as part of the process for delivering recommendations for reconfiguration of paediatric cardiac surgery services.

The nationally commissioned services are:

- Paediatric Cardiothoracic Transplantation and Mechanical Device as a Bridge to Heart Transplantation (currently provided at Freeman Hospital, Newcastle and Great Ormond Street Hospital)
- Extracorporeal Membrane Oxygenation (ECMO) for severe respiratory failure (currently provided at Great Ormond Street Hospital, Glenfield Hospital, Leicester and Freeman Hospital, Newcastle)
- Complex Tracheal Surgery (currently provided at Great Ormond Street Hospital)

These services all require cardiac surgery or surgical back up in order to operate safely.

The NSCT is not looking to increase the number of centres providing these services in the future. However it does need to be assured that whatever the future configuration of paediatric cardiac surgery provision, the nationally commissioned services can continue to be provided to a good standard of care with good geographical access across England.

It is important that you consider whether, if designated as a paediatric cardiac surgery provider in the future, you would also want to be in the position to provide one or more of the nationally commissioned services. Because final decisions on the designation of providers for Nationally Commissioned Services can only be made by the Secretary of State, he or she will need to be assured that all viable options for paediatric cardiac surgery services also enable high quality provision of these national services.

If you do not wish to provide one of the nationally commissioned services in the future, you should declare this now by emailing that as your response on the 7th May 2010.

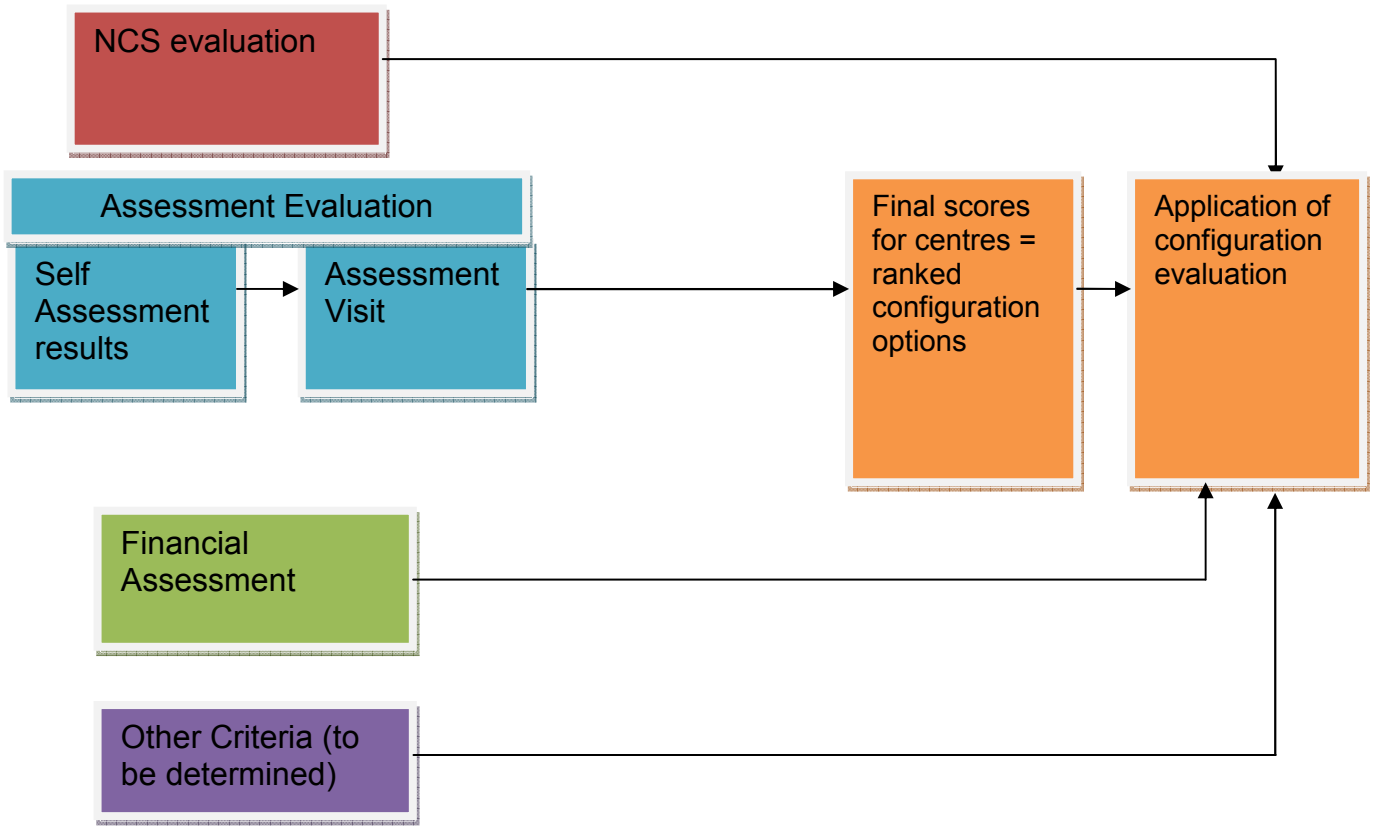
2) Process

The completion of this NCS template is separate from the self-assessment template that was sent you on the 22nd March 2010.

The self assessment template is attached again for your information (Appendix A). The scores derived from the completion of the self-assessment template will, with the assessment visits, enable us to arrive at a number of configuration options. Those configuration options will need to be tested against a number of criteria, in order to evidence the best configuration scenario for patients.

The information gained from this return will contribute to addressing one of those criteria – risk to other dependent services. Details of the other criteria to be used will be made available to you once known.

Although the NCS template is scored, these scores will not form part of the individual organisation assessment scoring – the scores will only be used when testing configuration options. This is illustrated below:



3) Service Guidelines

For each of the 3 Nationally Commissioned Services, we have attached some guidelines which indicate the level, type and complexity of the service.

This template asks you to consider these guidelines, and to judge the implications to your organisation in providing these services.

Paediatric Cardiothoracic Transplantation and Bridge to Transplant (Appendix B):

The guidelines have been taken from:

1. The existing NSCAG designation standards
2. The NHS Blood and Transplant National Standards for Organ Retrieval from Deceased Donors.

Respiratory ECMO (Appendix C): the criteria have been derived from the Extracorporeal Life Support Organization (ELSO) guidelines for Paediatric Extracorporeal Membrane Oxygenation, most recently updated in 2002.

Complex Tracheal Surgery (Appendix D): the criteria have been derived using the case definition applied by Great Ormond Street Hospital and agreed with existing clinical and commissioning experts.

4) Scoring

The information you supply in this exercise will be assessed as one of the criteria used in determining the configuration evaluation.

In order that we can apply the criteria fairly, we need to be able to quantitatively evaluate the potential of each centre that wishes to provide each of the Nationally Commissioned Services.

For each service that you do not currently provide, we require you to consider the guidelines for each service, and to assess your ability to provide the service in the future, if required.

The areas in which you will be scored against are your assessment of:

- Workforce requirements and risks
- Ability to meet the required capacity
- Team working and infrastructure
- Network arrangements
- Continuous professional development, training and education
- Governance structure and risk management.

Each area will be equally weighted, and will be scored as follows:

1	**Inadequate (the centre is unable to meet this requirement)**
2	**Poor (it is unlikely that the centre will be able to meet the requirement)**
3	**Unsatisfactory (there are significant risks or issues involved in the centre meeting this requirement)**
4	**Good (evidence supplied is good, and we are assured that the centre is in a good position be able to meet the requirement)**
5	**Excellent (evidence is exemplary and we are absolutely certain that the centre can meet the requirement)**

Each assessment will be scored by a panel of experts, once the submissions are returned on the 7th May. Further details of the membership of the panel will be sent to you in due course. There is a possibility that the evaluation panel will request clarifications/interaction with your centre in respect of this submission. This is likely to take place in late May 2010.

As discussed, the scores will be considered alongside other criteria, as part of the Configuration Evaluation stage. Full details of the configuration evaluation criteria will be sent to you once known.

Assessment

Please attach any additional information you feel necessary, such as strategies or project plans that demonstrate the answers to the questions.

1. Paediatric Cardiothoracic Transplantation and Bridge to Transplantation

Please refer to the guidelines in Appendix B

Area of Assessment
Are you confident that you will be able to recruit and sustain the required workforce for the service? What risks do you envisage, and how would you mitigate against these risks? Recruitment of an additional surgeon required to complete the additional paediatric cardiac procedures provides an opportunity for appointing a paediatric cardiac surgeon with a specific interest in transplantation although our current surgeons have had training in transplant surgery and would ensure the on call rota would cover transplant and bridge to transplant patients after appropriate re-training. The addition of paediatric cardiac transplantations adds additional requirements to the service and we would need to actively develop our staffing (both through training and recruitment) and infrastructure to meet this challenge. We believe that our service is capable of accommodating transplantations. A risk when considering development of such a service would be an inability to recruit appropriate clinical leads (e.g. a surgeon with a special interest), but given that this assessment document makes it clear that the NSCG is not considering increasing the number of providers in England the development of paediatric

cardiac transplants in Leeds would presumably mean the cessation of activity in another centre and the redistribution of existing skills should help mitigate against this risk.

We would invest in dedicated clinical nurse specialists and coordinators for transplantation who, if not already fully experienced, would be supported to gain the required knowledge and skills needed to care for this group of patients, through structured education and experience in transplant centres.

The activity for these services across England in 08/09 was:
Paediatric Cardiac Transplantation: 32 transplants
Paediatric Lung Transplantation 6 transplants
Bridge to Transplantation: 22 procedures

The length of stay in paediatric intensive care for transplantation varies considerably, but in 08/09 the range of was between:
For Assessment 0 to 0.6 OBDs
For Transplant – ITU 17 to 22 OBDs, ward 12 to 22 OBDs
For Follow up – ITU 0 to 0.4 OBDs, ward 1.5 to 2.5 OBDs
Outpatient attendances 704

For Bridge to Transplantation the average length of stay in paediatric intensive care was between 31-63 OBDs.

What is your assessment of the capacity required to run this service? What evidence do you have that your centre would be able to dedicate the required capacity?

Our current clinical footprint would require expansion to manage this increase in demand and would require a detailed project to allow for increased physical space and extra staffing. We would need to amend our existing designation capacity modelling plan to include the additional activity generated by providing transplant services. This includes required bed capacity for ICU, HDU and ward beds, as well as theatre sessions, and outpatient appointments. Using this information we would also be able to calculate the required staffing cohort that would need to be recruited.

The local reconfiguration required to accommodate this activity can be flexed quite substantially as there are several adult services that could be moved from the Leeds General Infirmary (LGI) site to the St James' University Hospital (SJUH) site in order to allow for further space at the LGI. This would allow Children's Services to remain centralised on one site and provide an opportunity to improve clinical adjacencies across the Trust, and have similar benefits for the Adult services. The Trust's Senior Management team are aware this plan would require significant capital investment for refurbishment of the LGI and providing new accommodation for adult services at SJUH and are committed to taking these plans forward as part of the emerging Clinical and Estates Strategy. Leeds Teaching Hospitals Trust has a proven track record of successfully completing highly complex service reconfigurations, the most recent of which has been to centralise Children's Services in the Leeds' Children's Hospital.

Referring to the guidelines at Appendix B, what is your assessment of the infrastructure and multidisciplinary team working required to effectively run this service? How can you evidence that this is, or will be, in place?

We already manage a significant amount of pre and post transplant care for our patients that receive transplant surgery elsewhere. The standards outlined in Appendix B reflect good clinical care, appropriate clinical assessment, data collection and communications with patients and families which are an important part of our existing philosophy of care. We would ensure appropriate clinical facilities and trained staff to deliver the services. We would adapt our electronic databases and systems (including additional data audit clerks) to ensure appropriate information recording.

We would develop appropriate structures to ensure communication and access for patients and families at all times and initiate appropriate communications and interactions between other transplant centres in the UK and further afield where appropriate. The current paediatric and congenital facility includes a full electrophysiology service, which is particularly important for children with end-stage cardiac failure, as

some may require implantable cardioverter-defibrillators and because cardiac resynchronisation therapy is emerging as an important alternative therapy for some transplant candidates. Transplant specific records would be created and would be available 24/7.

The co-location with other specialist children's and adult services clearly add to our ability to holistically manage these patients and we have existing experience in managing other transplant groups including renal, hepatic and bone marrow.

Please describe the network arrangements that you think need to be in place in order to ensure the effective operation of the service?

There has been a significant amount of time and energy invested into the development of a focussed paediatric cardiac services network, fit for purpose and aimed at achieving and maintaining high clinical standards. We feel that this provides the assurance that our wider service meets the current standard. Expansion of the service to cover a greater geographical area and transplantation and bridge to transplant would require us to work with a larger number of local commissioners and hospital Trusts. The current network model has proven successful and effective thus far and if managed appropriately and sensitively, including a two way dialogue with new network partners, we have no concerns that this expansion would have a detrimental effect. The network membership and remit is continually reassessed and has the mechanisms in place to be able to adapt to accommodate new stakeholders.

How will you ensure that training, education and continuous development is made available to all members of the team? How would you ensure that your service continued to improve so as to ensure sustainability?

LTHT is committed to support all staff through a process of ongoing appraisal and personal development plans to access role specific training and education.
We have strong links with Leeds University and would be able to utilise this relationship for future education and transplant research, particularly focussing on the immunology of rejection.

What service specific governance arrangements would you have in place?

We have a well defined clinical governance structure and clinical governance is an integral part of the Trust's performance management process. On a bimonthly basis the divisional medical manager produces a composite clinical governance report which is presented to the executive directors.

Within paediatric cardiac and cardiology services there is a monthly clinical governance meeting which comprises a morbidity and mortality meeting, audit meeting and a focus on general governance themes.

Within the Network there is a quarterly paediatric cardiology clinical network meeting which is attended by LTHT consultants, link consultants from peripheral hospitals and other professional staff. This meeting has a varied agenda which includes audit and governance issues.
There is recognition of the need to strengthen both clinical governance arrangements and research activity across the Network. In terms of governance, there are plans to create a Governance and Quality manager to ensure best practice is embedded in practice and lessons are learned across the Network. We recognise there are opportunities to learn from the experience of services such as Obstetrics and Oncology where these posts have been created and brought added focus and leadership to governance activities.

We acknowledge that there will need to be a focus on transplantation and bridge to transplant drawing on the experience of other centres but we feel our current governance arrangements are strong and are provide and excellent model for future service developments.

2. Extracorporeal Membrane Oxygenation (ECMO) for severe respiratory conditions

Please refer to the guidelines in Appendix C

Area of Assessment
Are you confident that you will be able to recruit and sustain the required workforce for the service? What risks do you envisage, and how would you mitigate against these risks? Many of the issues are analogous with those described in the transplant sections above. Recruitment of an additional surgeon required to complete the required additional procedures provides an opportunity for appointing a paediatric cardiac surgeon with a specific interest in ECMO although our current surgeons also have the skills to provide ECMO and ensure the on call rota would provide cover to the ECMO patients. Our current paediatric thoracic surgeon who is currently responsible for most of the non-cardiac thoracic and airway surgery in children is keen to join the ECMO team. Currently ECMO is already used in Leeds as a short term bridge after cardiac surgery by our existing team and we have a sufficient complement of trained perfusionists to provide this service 24/7. It can be assumed that if existing centres are no longer commissioned to deliver ECMO services there will be a number of staff with the appropriate skills who will relocate to the Leeds service. There are varying degrees of ECMO support, from short term post cardiac surgical support to long term ECMO support in non-cardiac patients with respiratory disease. Although we feel we have the potential infrastructure and critical interdependencies to support the development of any level of service, the implications and development issues vary enormously. Mitigating against risks would require a clear understanding of what level of service is required and development of the necessary infrastructure. We would invest in dedicated ECMO specialists, who, if not already fully experienced, would be supported to gain the required knowledge and skills needed to care for this group of patients, through structured education and experience in ECMO centres.
The activity for these services across England in 08/09 was 59 patients. **The length of stay in paediatric intensive care varies considerably, but in 08/09 the range was between:** **For Assessment 0 to 6 OBDs** **For ECMO procedure 7 to 17 OBDs** **What is your assessment of the capacity required to run this service? What evidence do you have that your centre would be able to dedicate the required capacity?** Our current clinical footprint would require expansion to manage this increase in demand and would require a detailed project to allow for increased physical space and extra staffing. We would need to amend our existing designation capacity modelling plan to include the additional PICU activity generated by providing ECMO services. This includes required bed capacity for ICU, HDU and ward beds and neonatal cots. Using this information we will also be able to calculate the required staffing cohort that would need to be recruited. The local reconfiguration required to accommodate this activity can be flexed quite substantially as there are several adult services that could be moved from the Leeds General Infirmary (LGI) site to the St James' University Hospital (SJUH) site in order to allow for further space at the LGI. This would allow Children's Services to remain centralised on one site and provide an opportunity to improve clinical adjacencies across the Trust, but also have mutual benefits for the Adult services to gain improved clinical adjacencies. The Trust's Senior Management team are aware this plan would require significant capital investment for refurbishment of the Clarendon Wing at the LGI and providing new accommodation for adult services at SJUH and are committed to taking these plans forward as part of the emerging Clinical and Estates Strategy. Leeds Teaching Hospitals Trust has a proven track record of successfully completing highly complex service reconfigurations, the most recent of which has been to centralise Children's Services in the Leeds' Children's Hospital.

Referring to the guidelines at Appendix C, what is your assessment of the infrastructure and multidisciplinary team working required to effectively run this service? How can you evidence that this is, or will be, in place?

Our current infrastructure is already supportive of many of the guidelines for providing ECMO. By 4th May 2010, all Children's services (including the specialised services mentioned in appendix B) will be provided on the same LGI site, co-located with paediatric and congenital cardiac services. Many of the paediatric services provided are well developed tertiary services such as respiratory medicine and neonates. We have dedicated paediatric and adult cardiac ICUs as well as general PICU/ICUs that provide tertiary level services.

Please describe the network arrangements that you think need to be in place in order to ensure the effective operation of the service?

We have provided significant detailed evidence with regard to the strength of our current network arrangements, which we believe are robust enough to accommodate ECMO pathways successfully. Detailed and focussed work on ECMO would be required, but we have strong systems and processes in place across the network to facilitate this service development.

How will you ensure that training, education and continuous development is made available to all members of the team? How would you ensure that your service continued to improve so as to ensure sustainability?

LTHT is committed to support all staff through a process of ongoing appraisal and personal development plans to access role specific training and education.
We have strong links with Leeds University and would be able to utilise this relationship for future education, development and research.

What service specific governance arrangements would you have in place?
We have a well defined clinical governance structure and clinical governance is an integral part of the Trust's performance management process. On a bimonthly basis the divisional medical manager produces a composite clinical governance report which is presented to the executive directors.

Within paediatric cardiac and cardiology services there is a monthly clinical governance meeting which comprises a morbidity and mortality meeting, audit meeting and a focus on general governance themes.

Within the Network there is a quarterly paediatric cardiology clinical network meeting which is attended by LTHT consultants, link consultants from peripheral hospitals and other professional staff. This meeting has a varied agenda which includes audit and governance issues.
There is recognition of the need to strengthen both clinical governance arrangements and research activity across the Network. In terms of governance, there are plans to create a Governance and Quality manager to ensure best practice is embedded in practice and lessons are learned across the Network. We recognise there are opportunities to learn from the experience of services such as Obstetrics and Oncology where these posts have been created and brought added focus and leadership to governance activities

We acknowledge that there will need to be a focus on ECMO drawing on the experience of other centres but we feel our current governance arrangements are strong and are provide and excellent model for future service developments.

3. Complex Tracheal Surgery

Please refer to the guidelines in Appendix D

Area of Assessment
Are you confident that you will be able to recruit and sustain the required workforce for the service? What risks do you envisage, and how would you mitigate against these risks? The LTHT currently undertakes complex tracheal surgery as defined in Appendix D. Children are admitted under the care of the complex regional respiratory service which is lead by a respiratory paediatrician and a paediatric thoracic surgeon. Treatment is provided by the paediatric thoracic surgeon, paediatric cardiac surgeons, paediatric ENT surgeons and paediatric radiologists, depending on the nature of the case. We maintain a regular practice with tracheal resection, aortopexy, endobronchial stenting. We are confident we can expand this service to cope with increased demand. This would involve investment in staff, who, if not already fully experienced, would be supported to gain the required knowledge and skills through structured education and experience in other centres.
The activity for these services across England in 08/09 was 28 patients. **The length of stay in paediatric intensive care varies considerably, but in 08/09 was:** **ICU stays: between 2 to 17 days** **Ward stays: between 1 to 4 days** **What is your assessment of the capacity required to run this service? What evidence do you have that your centre would be able to dedicate the required capacity?** Our current clinical footprint would require expansion to manage this increase in demand and would require a detailed project to allow for increased physical space and extra staffing. We would need to amend our existing designation capacity modelling plan to include the additional PICU activity generated by providing Complex Tracheal Surgical services. This includes required bed capacity for ICU, HDU and ward beds and neonatal cots and theatre sessions. Using this information we will also be able to calculate the required staffing cohort that would need to be recruited. The local reconfiguration required to accommodate this activity can be flexed quite substantially as there are several adult services that could be moved from the Leeds General Infirmary (LGI) site to the St James' University Hospital (SJUH) site in order to allow for further space at the LGI. This would allow Children's Services to remain centralised on one site and provide an opportunity to improve clinical adjacencies across the Trust, but also have mutual benefits for the Adult services to gain improved clinical adjacencies. The Trust's Senior Management team are aware this plan would require significant capital investment for refurbishment of the Clarendon Wing at the LGI and providing new accommodation for adult services at SJUH and are committed to taking these plans forward as part of the emerging Clinical and Estates Strategy. Leeds Teaching Hospitals Trust has a proven track record of successfully completing highly complex service reconfigurations, the most recent of which has been to centralise Children's Services in the Leeds' Children's Hospital.
Referring to the guidelines at Appendix D, what is your assessment of the infrastructure and multidisciplinary team working required to effectively run this service? How can you evidence that this is, or will be, in place? Our current infrastructure is already supportive of the guidelines for providing Complex Tracheal Surgery. By 4th May 2010, all Children's services will be provided on the same LGI site, co-located with paediatric thoracic surgery, paediatric cardiac surgery, paediatric ENT surgery and paediatric radiology. Many of the paediatric services provided are well developed tertiary services such as respiratory medicine and neonates. We have dedicated paediatric and adult cardiac ICUs as well as general PICU/ICUs that provide tertiary level services.

What service specific governance arrangements would you have in place?

We have a well defined clinical governance structure and clinical governance is an integral part of the Trust's performance management process. On a bimonthly basis the divisional medical manager produces a composite clinical governance report which is presented to the executive directors.

There are monthly clinical governance meeting which comprises morbidity and mortality meeting, audit meeting and a focus on general governance themes.

We acknowledge that there will need to be a focus on Complex Tracheal Surgery drawing on the experience of other centres but we feel our current governance arrangements are strong and are provide and excellent model for future service developments.

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Leeds CITY COUNCIL

Report author: Steven Courtney
Tel: 24 74707

Report of the Head of Scrutiny and Member Development

Report to the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

Date: 22 September 2011

Subject: Proposed Reconfiguration of Children's Congenital Heart Services in England: Details of Council motions from across Yorkshire and the Humber

Are specific electoral Wards affected? If relevant, name(s) of Ward(s):	☐ Yes	☒ No
Are there implications for equality and diversity and cohesion and integration?	☐ Yes	☒ No
Is the decision eligible for Call-In?	☐ Yes	☒ No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Not applicable Appendix number: Not applicable	☐ Yes	☒ No

Summary of main issues

1. The Joint Health Overview and Scrutiny Committee HOSC (Yorkshire and the Humber) forms the statutory overview and scrutiny body to consider and respond to the proposed reconfiguration of Children's Congenital Heart Services in England – taking into account the potential impact on children and families across the region. HOSCs have been given until 5 October 2011 to respond to the proposals.
2. In considering the proposals set out in the *Safe and Sustainable Consultation Document: A new vision for Children's Congenital Heart Services in England (March 2011),* Members of the Joint HOSC have sought to consider a wide range of evidence and engage with a range of key stakeholders.
3. A number of Council's from across Yorkshire and the Humber have debated the current proposals, which could see such services no longer provided from the current regional centre at Leeds Teaching Hospitals NHS Trust (LTHT). A number of Councils from across the region have passed motions calling for the retention of services at Leeds. Details of the motions passed and associated correspondence are presented at Appendix 1. Any further details received will be provided as soon as practicable.

Recommendations

4. Members are asked to consider the details associated with this report and identify/ agree any specific matters for inclusion in the Committee's report to be presented to JCPCT later in the year

Background documents

- A new vision for Children's Congenital Heart Services in England (March 2011)

APPENDIX 1

Details of Council motions across Yorkshire and the Humber

City of York Council – 7 April 2011

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

The choice facing the NHS review team will be to retain either the Children's Heart Surgery Unit at Leeds General Infirmary or the unit at Newcastle to serve the north; and,

Leeds serves a major population catchments area of 14 million people in Yorkshire and the Humber, Lincolnshire and North Derbyshire, has the capacity to expand and has centralised the whole of its children's services operations on one site; and,

Leeds General Infirmary is at the forefront of work on inherited cardiac conditions and is much valued for providing safe, high quality children's heart surgery;

Council asks Members to join with local MPs and community groups to express all-party support for keeping open the Children's Heart Unit at Leeds General Infirmary and asks the Chief Executive to write to the Department of Health to ask for the retention of the Leeds Children's Heart Unit as the centre best placed to serve as the specialist hub for the needs of young cardiac patients in Yorkshire and the north of England.'

East Riding of Yorkshire – 27 July 2011

'That this Council supports the retention of the Children's Cardiac Surgery Services at Leeds as the unit serves a region of population of almost 14 million people and Leeds General Infirmary is ideally placed to deliver services as it does now, to people living throughout Yorkshire and the Humber, Lincolnshire and the North Midlands.'

Harrogate Borough Council – 13 April 2011

'This Council supports the excellent work of the Yorkshire Heart Centre at Leeds General Infirmary and notes with concern the Unit's limited inclusion in the NHS proposals for the national reconfiguration of Children's cardiac Surgery.

The Services provided at present are an important and essential part of health services available to residents of Harrogate District.

The Council requests that the Chief Executive writes to the Secretary of State for Health in order to call for the retention of the vitally important surgical services in Leeds.'

Letter and response attached.

Kirklees Council – 23 March 2011

"This Council notes with concern the potential closure of the Children's Heart Surgery Unit at Leeds General Infirmary, as a result of the Department of Health's 'Safe and Sustainable' review of Children's Heart Surgery Units.

The closure of the Leeds Unit, which serves a large population centre, will have a severe impact on Yorkshire families, including those living in Kirklees, and would mean that parents with sick children would have to travel to Newcastle, Liverpool or Leicester, to receive the essential treatment currently provided in Leeds. This will cause extreme difficulty as a result of the distances families will have to travel, at a time of high anxiety about their child's health.

This Council recognises that a Joint Health Scrutiny Committee is currently meeting to fully consider the proposals for children's congenital cardiac surgery services. Whilst not wishing to predetermine the findings of that review, nevertheless this Council wishes to express serious concerns about the impacts of removing services from the Leeds area. These concerns to be forwarded in a letter to the Department of Health with copies to all MP's within the Kirklees area.

This Council also requests that representations be made on behalf of the Council as part of the Department of Health's consultation exercise in support of the retention of the Leeds Children's Heart Surgery Unit."

Report to Council (including letter and response) attached

Leeds City Council – 6 April 2011

'This Council supports the excellent work of the Yorkshire Heart Centre at Leeds General Infirmary, and notes with concern the unit's limited inclusion in NHS proposals for the national reconfiguration of children's cardiac surgery services.

This Council requests that the Chief Executive write to the Secretary of State for Health in order to call for the retention of these vitally important surgical services in Leeds. It also recognises the ongoing efforts of Leeds MPs to lobby the Secretary of State to the same effect.'

Letter and response attached.

Leeds City Council – 14 September 2011

'That this Council notes with concern the ongoing discussions regarding the proposed reconfiguration of children's cardiac surgery services and the devastating effect this could have on the Yorkshire Heart Centre at Leeds General Infirmary and the families of this region.

The Council supports the demands of the cross party Joint Health Overview and Scrutiny Committee for Yorkshire and Humber for the Government to re-examine the way in which the decision is being made and ensure that the democratic process is not being ignored.

Council therefore urges the government to confirm that all available information will be examined before a decision is made which could force parents from Yorkshire to travel hundreds of miles should their children need cardiac treatment.'

Rotherham Metropolitan Borough Council – 27 July 2011

'This Council recognises the expertise in Children's Cardiac Services which has been built up by the Leeds Teaching Hospitals NHS Trust (LTHT) based at Leeds General Infirmary (LGI). LTHT also supports outreach clinics at Rotherham Foundation Trust (RFT) which are used by approximately 300 children each year:

The Council wishes to register its opposition and serious concerns at the potential loss of the Children's Cardiac Unit in Leeds which would have a devastating impact on those children requiring the specialist services provided by the facility.

The Council resolves to work with all relevant stakeholders to campaign to retain specialist children's cardiac surgery in the region and to inform the Secretary of State for Health of our views.'

Sheffield City Council – 6 July 2011

That this Council

(a) *notes the NHS Safe and Sustainable Review into the way that children's congenital heart surgery services should be provided in the future*

(b) *is concerned by the likely closure of the surgical centre at Leeds General Infirmary (LGI) as the only such unit in the Yorkshire and Humber region*

(c) *is also concerned by the implications of this likely closure for critically ill children and their families in Sheffield who use this service*

(d) *resolves to continue to raise the profile of this issue locally to make the people of Sheffield aware of the knock-on effect of this closure*

(e) *fully supports maintaining the paediatric cardiac surgery unit at the LGI for the continued benefit of sick children and their families in Sheffield*

Wakefield Metropolitan District Council – 30 March 2011

Letter attached (dated 15 April 2011). Advised that no response received.

From the Rt Hon Andrew Lansley CBE MP
Secretary of State for Health

DH Department of Health

POC1_613235

Richmond House
79 Whitehall
London
SW1A 2NS

Tel: 020 7210 3000
Mb-sofs@dh.gsi.gov.uk

Kersten England
Chief Executive
City of York Council
The Guildhall
York
YO1 9QN

24 MAY 2011

Dear Kersten,

Thank you for your letter dated 21 April about retaining the Children's Heart Surgery Unit at Leeds General Infirmary.

I have taken note of your concerns. However, the *Safe and Sustainable* review of children's heart surgery units in England is being carried out within the NHS by the National Specialised Commissioning Team on behalf of the ten regional groups that commission specialised services, such as children's heart surgery, across England. I have, however, been following its progress.

The reasons they are carrying out the review are to improve services for patients in terms of safety, sustainability, outcomes and excellence of care for children. The review was instigated as a result of increasing concerns held by surgeons, other clinicians and NHS commissioners over a number of years about the risks posed by the unsustainable nature of having smaller surgical centres.

The aim of *Safe and Sustainable* is to ensure that children's heart surgery units in England deliver the very highest standard of care for children and their families well into the future. The development of the proposed model of care has been led by many clinicians directly involved in the care and treatment of children with congenital heart disease. From my knowledge of the process, it appears to me that it has been very much clinically driven.

I would like to reiterate that no decision has yet been made on the location of children's heart surgery units. The proposed options for

children's congenital heart services are currently being consulted on. Patients and the public have the opportunity to make their views known during the formal public consultation process which closes on 1 July. This is an open consultation and it is not pre- determined. The Joint Committee of Primary Care Trusts, overseeing the consultation, will consider an independent analysis of the consultation responses, reports from overview and scrutiny committees, and a health impact assessment. The Committee is expected to make a decision in Autumn 2011.

I would like to encourage you and other members of the City of York Council to respond to the consultation. I understand that there are public consultation events during the four-month consultation period. More information about the events and consultation can be found at: http://www.specialisedservices.nhs.uk/safe_sustainable/public-consultation-2011

ANDREW LANSLEY CBE

Harrogate
BOROUGH COUNCIL

Working for you

Mr T Riordan
Chief Executive
Leeds City Council
3rd Floor
Civic Hall
LEEDS LS1 1UR

Our Ref CE/LAN
Your Ref
Date 13 May 2011

Dear Tom

Children's Cardiac Services in Yorkshire And The Humber

Thank you for your letter of 5 May 2011 concerning the national review of Children's Cardiac Services and the options included within that review for consultation purposes.

This matter has already been considered by the Council in the form of the following Notice of Motion presented to its meeting held on 13 April 2011:-

"This Council supports the excellent work of the Yorkshire Heart Centre at Leeds General Infirmary and notes with concern the Unit's limited inclusion in NHS proposals for the national reconfiguration of Children's Cardiac Surgery Services.

The Services provided at present are an important and essential part of health services available to residents of Harrogate District.

The Council requests that the Chief Executive writes to the Secretary of State for Health in order to call for the retention of the vitally important surgical services in Leeds".

In debating the issue, the Council shared the City's concern over the potential loss of the Children's Cardiac Unit and the impact both locally and regionally of this. Members also discussed the transfer times and network issues to which you refer, were cardiac services to be sited in Newcastle and also the personal consequences of this in terms of children's care and the additional burden for families faced with commuting during a period of already intense pressure and stress.

I am pleased to say that the Council supported the motion unanimously, and I have now written to the Secretary of State for Health calling for the retention of Children's Cardiac Services in Leeds in line with the requirements of the approved motion.

I will of course keep you informed of progress.

Yours sincerely

Wallace Sampson
Chief Executive
chiefexecutive@harrogate.gov.uk

Office of the Chief Executive
Council Offices, Crescent Gardens, HARROGATE HG1 2SG
T: 01423 500600 F: 01423 556160 TXT: 01423 556543
www.harrogate.gov.uk

Harrogate BOROUGH COUNCIL

Working for you

Mr A Lansley CBE MP
Secretary of State for Health
Richmond House
79 Whitehall
LONDON
SW1A 2NS

Our Ref CE/LAN
Your Ref
Date 13 May 2011

Dear Mr Lansley

Children's Cardiac Services in Yorkshire and the Humber

The extensive national review of Children's Cardiac Services across England has put forward four options for consultation aiming to consolidate Children's Cardiac Services into six or seven locations. As you are aware, Children's Cardiac Services are currently provided in Yorkshire and the Humber by the Leeds Teaching Hospitals NHS Trust. I understand that the National Review Team assessed all Children's Cardiac Services, including Leeds to be "safe". However, retaining the Leeds provision is only one of the four options being put forward in the public consultation. The preferred option places Children's Cardiac Services in Newcastle, Liverpool, Birmingham, Leicester, Bristol and two sites in London.

This region benefits from a comprehensive range of co-located services for adults and children, with Leeds being the only centre in the North of England to fulfil every child and adult inter-dependency. Leeds has pioneered clinical networks in this area and the majority of regional work has been adopted as national guidelines.

In response to the consultation exercise and concerns over the potential loss of Children's Cardiac Services, the Council, at its meeting held on 13 April 2011, considered the following Notice of Motion:-

"This Council supports the excellent work of the Yorkshire Heart Centre at Leeds General Infirmary and notes with concern the Unit's limited inclusion in NHS proposals for the national reconfiguration of children's cardiac surgery services.

The Services provided at present are an important and essential part of health services available to residents of Harrogate District.

The Council requests that the Chief Executive writes to the Secretary of State for Health in order to call for the retention of the vitally important surgical services in Leeds".

In debating the motion, Members of the Council were conscious of the great number of children and families within the Harrogate District, the region and from other parts of the country benefiting from the expertise held by the Leeds Teaching Hospitals NHS Trust.

Continued ...

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www.harrogate.gov.uk

Council also raised concern over the transfer times, were such services to be lost in favour of Newcastle and the additional anxiety and stress that would be faced by families and their children in commuting to Newcastle, a city itself not well served by a motorway network.

Following debate, the motion was unanimously approved by all Members of the Council and in accordance with its wishes I am, therefore, calling for the retention of these vitally important surgical services in Leeds.

Yours sincerely

Wallace Sampson
Chief Executive
chiefexecutive@harrogate.gov.uk

From the Rt Hon Simon Burns MP
Minister of State for Health

DH Department of Health

Richmond House
79 Whitehall
London
SW1A 2NS

Tel: 020 7210 4850

Your Ref: CE/LAN

PO00000616648

Mr Wallace Sampson
Chief Executive
Harrogate Borough Council
Council Offices
Crescent Gardens
Harrogate HG1 2SG

Dear Mr Sampson

06 JUN 2011

Thank you for your letter of 13 May to Andrew Lansley on behalf of Harrogate Borough Council about the children's cardiac surgery unit at Leeds General Infirmary. I am replying as the Minister responsible for this policy area.

The *Safe and Sustainable* review of paediatric cardiac surgery units in England is being carried out within the NHS by the National Specialised Commissioning Team on behalf of the ten regional groups that commission specialised services, such as paediatric cardiac surgery, across England. The Department of Health has been following its progress.

The *Safe and Sustainable* review was instigated as a result of increasing concerns held by surgeons, other clinicians and NHS commissioners over a number of years about the risks posed by the unsustainable nature of having smaller surgical units. The aim of *Safe and Sustainable* is to ensure that paediatric cardiac surgery services in England deliver the very highest standard of care for children and their families well into the future. The development of the proposed model of care has been led by many clinicians directly involved in the care and treatment of children with congenital heart disease, as have the proposed service standards.

I understand the Council's concern about the provision of continuity of care. Clinicians working in the service and their professional associations have identified the quality benefits of working in larger surgical centres, carrying out a larger numbers of procedures. This is not incompatible with maintaining continuity of care, such as a child continuing to see the same surgeon over their lifetime. A concentration of expertise facilitates research into the different

techniques and thus encourages sharing of best practice. More importantly, though, it ensures better cover in an emergency and less need for transfer of children between centres.

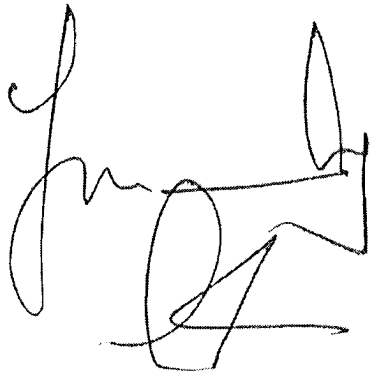
I am advised that travel times analysis has been used in the development of the options. There is a minimal impact on journey times for most families for the four options that are being consulted on. However, many children do not have access to the routine follow-up care service locally at present and have to travel longer distances unnecessarily to receive this care from a surgical unit. The proposed model of care will ensure that all children have access to a paediatrician with expertise in cardiology locally and that all follow-up routine care is provided closer to patients' homes.

I would like to highlight that there are no proposals to close any of the units. Surgery may cease at some units in the future but the aim is that these units will continue to provide specialist, non-interventional paediatric cardiac services for their local populations.

No decision has yet been made on the location of paediatric cardiac surgery units. Patients and the public have the opportunity to make their views known during the formal public consultation process, which closes on 1 July. The Joint Committee of Primary Care Trusts, which is overseeing the consultation, will consider an independent analysis of the consultation responses, reports from overview and scrutiny committees, and a health impact assessment. The Committee is expected to make a decision this autumn.

I would like to encourage you to respond to the consultation. More information about the consultation can be found at www.specialisedservices.nhs.uk by following the links.

I hope this reply is helpful.



SIMON BURNS

Kirklees COUNCIL

Name of meeting: Annual Council

Date: 25 May 2011

Title of report: Leeds Children's Heart Surgery Unit at Leeds General Infirmary and Adopted by Council

Is it likely to result in spending or saving £250k or more, or to have a significant effect on two or more electoral wards?	No
Is it in the Council's Forward Plan?	No
Is it eligible for "call in" by Scrutiny?	Not applicable - item for information only
Date signed off by Director & name Is it signed off by the Director of Resources? Is it signed off by the Acting Assistant Director - Legal & Governance?	16 May 2011, David Smith, Director of Resources No financial implications No legal implications
Cabinet member portfolio	Not applicable

Electoral wards affected and ward councillors consulted: Not applicable

Public or private: Public

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1. Purpose of report

For Council to note the response from the Department of Health to the Council's Motion on Leeds Children's Heart Surgery Unit.

2. Key points

Council, at its meeting on 23 March 2011, approved and adopted the following Motion:-

"This Council notes with concern the potential closure of the Children's Heart Surgery Unit at Leeds General Infirmary, as a result of the

Department of Health's 'Safe and Sustainable' review of Children's Heart Surgery Units.

The closure of the Leeds Unit, which serves a large population centre, will have a severe impact on Yorkshire families, including those living in Kirklees, and would mean that parents with sick children would have to travel to Newcastle, Liverpool or Leicester, to receive the essential treatment currently provided in Leeds. This will cause extreme difficulty as a result of the distances families will have to travel, at a time of high anxiety about their child's health.

This Council recognises that a Joint Health Scrutiny Committee is currently meeting to fully consider the proposals for children's congenital cardiac surgery services. Whilst not wishing to pre-determine the findings of that review, nevertheless this Council wishes to express serious concerns about the impacts of removing services from the Leeds area. These concerns to be forwarded in a letter to the Department of Health with copies to all MP's within the Kirklees area.

This Council also requests that representations be made on behalf of the Council as part of the Department of Health's consultation exercise in support of the retention of the Leeds Children's Heart Surgery Unit."

A response to the Motion has been received from the Department of Health, as set out below:-

Thank you for your letter of 25 March to Andrew Lansley about the Children's Heart Surgery unit at Leeds General Infirmary. I have been asked to reply.

The *Safe and Sustainable* review of children's heart surgery units in England is being carried out within the NHS by the National Specialised Commissioning Team on behalf of the ten regional groups which commission specialised services, such as children's heart surgery, across England.

The purpose of the review is to improve services for patients in terms of safety, sustainability, better outcomes and excellent care for children. The review was instigated as a result of increasing concerns held by surgeons, other clinicians and NHS commissioners over a number of years around the risks posed by the unsustainable nature of having smaller surgical centres. The aim of *Safe and Sustainable* is to ensure that children's heart surgery units in England deliver the very highest standard of care for children and their families well into the future. The development of the proposed model of care has been led by many clinicians directly involved in the care and treatment of children with congenital heart disease.

I am advised that travel times analysis has been used in the development of the options. There is a minimal impact on journey times for most families for the four options that are being consulted on. Many children, however, do not have access to the routine follow-up care service locally at present and have to travel longer distances unnecessarily to receive this care from a surgical unit. The

proposed model of care will ensure that all children have access to a paediatrician with expertise in cardiology locally and that all follow-up routine care is provided closer to patients' homes.

No decision has yet been taken on the location of children's heart surgery services. The proposed options for children's heart surgery units are currently being consulted on. Patients and the public have the opportunity to make their views known during the formal public consultation process which closes on 1 July. The Joint Committee of Primary Care Trusts, which is overseeing the consultation, will consider an independent analysis of the consultation responses, reports from Overview and Scrutiny Committees, and a health impact assessment. The Committee is expected to make a decision this autumn.

I would like to encourage you to respond to the consultation. I understand that there are public consultation events during the four-month consultation period, including two in Leeds on Tuesday 10 May at the Royal Armouries Museum. More information on these events and the consultation can be found at www.specialisedservices.nhs.uk by following the links.

I hope this reply is helpful.

3. Implications for the Council

None applicable to this report.

4. Consultees and their opinions

Not applicable.

5. Officer recommendations and reasons

That Council notes the response, which is for information only.

6. Cabinet portfolio holder recommendation

Not applicable.

7. Next steps

None applicable to this report.

8. Contact officer and relevant papers

Adrian Johnson: 01484 221712
Email: adrian.johnson@kirklees.gov.uk

Background Papers: Letter dated 14 April 2011 from the Department of Health.

9. Assistant director responsible

Vanessa Redfern, Legal, Governance and Monitoring

Kirklees COUNCIL

Legal and Governance
Second Floor, Civic Centre 3
Huddersfield HD1 2TG

Tel: 01484 221712
Fax: 01484 221707

adrian.johnson@kirklees.gov.uk

www.kirklees.gov.uk

Please ask for: Adrian Johnson

Our Ref: MAJ/PAW/DOC838A

25 March 2011

Andrew Lansey CBE MP
Secretary of State for Health
Department of Health
Richmond House
79 Whitehall
London SW1A 2NS

Dear Secretary of State

Resolution Passed by Kirklees Council in relation to Leeds Children's Heart Surgery Unit - Leeds General Infirmary (LGI)

At a meeting of the Kirklees Council held on 23 March 2011 the following resolution was passed:-

"This Council notes with concern the potential closure of the Children's Heart Surgery Unit at Leeds General Infirmary, as a result of the Department of Health's 'Safe and Sustainable' review of Children's Heart Surgery Units.

The closure of the Leeds Unit, which serves a large population centre, will have a severe impact on Yorkshire families, including those living in Kirklees, and would mean that parents with sick children would have to travel to Newcastle, Liverpool or Leicester, to receive the essential treatment currently provided in Leeds. This will cause extreme difficulty as a result of the distances families will have to travel, at a time of high anxiety about their child's health.

This Council recognises that a Joint Health Scrutiny Committee is currently meeting to fully consider the proposals for children's congenital cardiac surgery services. Whilst not wishing to pre-determine the findings of that review, nevertheless this Council wishes to express serious concerns about the impacts of removing services from the Leeds area. These concerns to be forwarded in a letter to the Department of Health with copies to all MP's within the Kirklees area.

This Council also requests that representations be made on behalf of the Council as part of the Department of Health's consultation exercise in support of the retention of the Leeds Children's Heart Surgery Unit."

I would welcome your response in due course in order that I may report back to the Council accordingly.

As requested by the Council resolution I am copying this letter to Kirklees Members of Parliament.

Yours faithfully

Adrian Johnson
Governance Officer

c.c. Michael R Wood MP, House of Commons, London SW1A 0AA
Jason McCartney, House of Commons, London SW1A 0AA
Simon Reevell MP, House of Commons, London SW1A 0AA
Barry J Sheerman MP, House of Commons, London SW1A 0AA
Mary Creagh MP, House of Commons, London SW1A 0AA

Your ref: MAJ/PAW/DOC838A

Our ref: TO00000605259

Department of Health

Richmond House
79 Whitehall
London
SW1A 2NS

Tel: 020 7210 4850

Mr Adrian Johnson
Legal and Governance
Kirklees Council
Second Floor
Civic Centre 3
Huddersfield
HD1 2TG

14 April 2011

Dear Mr Johnson,

Thank you for your letter of 25 March to Andrew Lansley about the Children's Heart Surgery unit at Leeds General Infirmary. I have been asked to reply.

The *Safe and Sustainable* review of children's heart surgery units in England is being carried out within the NHS by the National Specialised Commissioning Team on behalf of the ten regional groups which commission specialised services, such as children's heart surgery, across England.

The purpose of the review is to improve services for patients in terms of safety, sustainability, better outcomes and excellent care for children. The review was instigated as a result of increasing concerns held by surgeons, other clinicians and NHS commissioners over a number of years around the risks posed by the unsustainable nature of having smaller surgical centres. The aim of *Safe and Sustainable* is to ensure that children's heart surgery units in England deliver the very highest standard of care for children and their families well into the future. The development of the proposed model of care has been led by many clinicians directly involved in the care and treatment of children with congenital heart disease.

I am advised that travel times analysis has been used in the development of the options. There is a minimal impact on journey times for most families for the four options that are being consulted on. Many children, however, do not have access to the routine follow-up care service locally at present and have to travel longer distances unnecessarily to receive this care from a surgical unit. The

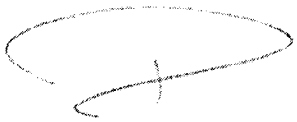
proposed model of care will ensure that all children have access to a paediatrician with expertise in cardiology locally and that all follow-up routine care is provided closer to patients' homes.

No decision has yet been taken on the location of children's heart surgery services. The proposed options for children's heart surgery units are currently being consulted on. Patients and the public have the opportunity to make their views known during the formal public consultation process which closes on 1 July. The Joint Committee of Primary Care Trusts, which is overseeing the consultation, will consider an independent analysis of the consultation responses, reports from Overview and Scrutiny Committees, and a health impact assessment. The Committee is expected to make a decision this autumn.

I would like to encourage you to respond to the consultation. I understand that there are public consultation events during the four-month consultation period, including two in Leeds on Tuesday 10 May at the Royal Armouries Museum. More information on these events and the consultation can be found at www.specialisedservices.nhs.uk by following the links.

I hope this reply is helpful.

Yours sincerely,



Daniel Nebel
Customer Service Centre

Andrew Lansley CBE MP
Secretary of State
Department of Health
Richmond House
79 Whitehall
London SW1A 2NS

Tom Riordan
Chief Executive
3rd Floor
Civic Hall
Leeds LS1 1UR

Tel: 0113 247 4554
Minicom: 0113 247 4000
Fax: 0113 247 4870
tom.riordan@leeds.gov.uk

Our reference: **let188/TR/MW**

13 April 2011

RESOLUTION OF LEEDS CITY COUNCIL

I write to inform you that Leeds City Council at a meeting of the Full Council on 6th April 2011 passed the following resolution:

"This Council supports the excellent work of the Yorkshire Heart Centre at Leeds General Infirmary, and notes with concern the unit's limited inclusion in NHS proposals for the national reconfiguration of children's cardiac surgery services.

This Council requests that the Chief Executive write to the Secretary of State for Health in order to call for the retention of these vitally important surgical services in Leeds. It also recognises the ongoing efforts of Leeds MPs to lobby the Secretary of State to the same effect."

I would be grateful if you could consider the views of Leeds City Council as expressed in the resolution.

Tom Riordan
Chief Executive

Nigel Richardson/S. Sinclair (TR)

From the Rt Hon Andrew Lansley CBE MP
Secretary of State for Health

DH Department of Health

POC1_611755

Your Ref: let188/TR/MW

MR. T. RIORDAN
25 MAY 2011
CHIEF EXECUTIVE

Richmond House
79 Whitehall
London
SW1A 2NS

Tel: 020 7210 3000
Mb-sofs@dh.gsi.gov.uk

Tom Riordan
Chief Executive
Leeds City Council
3rd Floor
Civic Hall
Leeds LS1 1UR

Also cc to Andy Koch → Group Leaders.

24 MAY 2011

Dear Tom,

Thank you for your letter dated 13 April about retaining the Children's Heart Surgery Unit at Leeds General Infirmary. Councillor Terry Grayshon also wrote to me on 28th April 2011 about this. I have also replied to his letter.

I have taken note of your concerns. However, the *Safe and Sustainable* review of children's heart surgery units in England is being carried out within the NHS by the National Specialised Commissioning Team on behalf of the ten regional groups that commission specialised services, such as children's heart surgery, across England. I have, however, been following its progress.

The reasons they are carrying out the review are to improve services for patients in terms of safety, sustainability, outcomes and excellence of care for children. The review was instigated as a result of increasing concerns held by surgeons, other clinicians and NHS commissioners over a number of years about the risks posed by the unsustainable nature of having smaller surgical centres.

The aim of *Safe and Sustainable* is to ensure that children's heart surgery units in England deliver the very highest standard of care for children and their families well into the future. The development of the proposed model of care has been led by many clinicians directly involved in the care and treatment of children with congenital heart disease. From my

knowledge of the process, it appears to me that it has been very much clinically driven.

I would like to reiterate that no decision has yet been made on the location of children's heart surgery units. The proposed options for children's congenital heart services are currently being consulted on. Patients and the public have the opportunity to make their views known during the formal public consultation process which closes on 1 July. This is an open consultation and it is not pre- determined. The Joint Committee of Primary Care Trusts, overseeing the consultation, will consider an independent analysis of the consultation responses, reports from overview and scrutiny committees, and a health impact assessment. The Committee is expected to make a decision in Autumn 2011.

I would like to encourage you and other members of Leeds City Council to respond to the consultation. I understand that there are public consultation events during the four-month consultation period. More information about the events and consultation can be found at: http://www.specialisedservices.nhs.uk/safe_sustainable/public-consultation-2011

Yours ever,

ANDREW LANSLEY CBE

Copy of letter from Wakefield Metropolitan District Council

Rt Hon Andrew Lansley, MP
Secretary of State for Health
Department of Health
Richmond House
79 Whitehall
London
SW12A 2NL

15 April 2011

Dear Mr Lansley

CHILDREN'S CONGENITAL HEART SERVICES – NHS CONSULTATION

I write in response to the NHS public consultation on the way children's congenital heart services should be provided in the future. The Council of the City of Wakefield at its meeting held on 30 March 2011, debated the issues arising from the consultation document with particular regard to the excellent services currently provided at Leeds General Infirmary.

Members of Council in debating the options for reconfiguring the services noted that the current service provided at Leeds General Infirmary only featured in one option, option D.

Members of Council were unanimously of the view that should any other option be pursued which would result in the closure of the Leeds Specialist Unit, there would be a huge gap in provision from Birmingham or Leicester in the south, Newcastle in the north and Liverpool to the west. The implications of such a decision would mean children from Yorkshire, North Derbyshire and Northern Lincolnshire having to travel long distances for treatment putting additional strain and costs on families. Council was also concerned that as specialism's were lost in the region, there would also be an adverse impact on adult cardiology services.

Members noted that Leeds General Infirmary was at the forefront of work on inherited cardiac conditions holding an excellent record for providing safe, high quality children's heart services. The centralised unit operating from a single site at the Leeds General Infirmary, currently serves a population of some 5.5 million people in the Yorkshire, North Derbyshire and Lincolnshire regions which is one of the highest population coverage's of all units in England.

The Council respectfully asks that there concerns and support to retain specialist children's congenital heart services at Leeds General Infirmary are taken into account as part of the consultation and decision making processes and that a favourable outcome will result.

Yours sincerely

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Leeds CITY COUNCIL

Report author: Steven Courtney
Tel: 24 74707

Report of the Head of Scrutiny and Member Development

Report to the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

Date: 22 September 2011

Subject: Proposed Reconfiguration of Children's Congenital Heart Services in England: Submissions from Members of Parliament (Yorkshire and the Humber)

Are specific electoral Wards affected? If relevant, name(s) of Ward(s):	☐ Yes	☒ No
Are there implications for equality and diversity and cohesion and integration?	☐ Yes	☒ No
Is the decision eligible for Call-In?	☐ Yes	☒ No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Not applicable Appendix number: Not applicable	☐ Yes	☒ No

Summary of main issues

1. The Joint Health Overview and Scrutiny Committee HOSC (Yorkshire and the Humber) forms the statutory overview and scrutiny body to consider and respond to the proposed reconfiguration of Children's Congenital Heart Services in England – taking into account the potential impact on children and families across the region. HOSCs have been given until 5 October 2011 to respond to the proposals.
2. In considering the proposals set out in the *Safe and Sustainable Consultation Document: A new vision for Children's Congenital Heart Services in England (March 2011),* Members of the Joint HOSC have sought to consider a wide range of evidence and engage with a range of key stakeholders.
3. On 8 September 2011, Members of Parliament from across Yorkshire and the Humber were invited to provide any comments to the Joint HOSC, with a view to these being included in the Joint HOSC's formal response to the review. The purpose of this report is to introduce any submissions received for consideration. Submissions received to date are attached at Appendix 1. Any other submissions will be made available as soon as practicable.

Recommendations

4. Members are asked to consider the details associated with this report and identify/ agree any specific matters for inclusion in the Committee's report to be presented to JCPCT later in the year

Background documents

- A new vision for Children's Congenital Heart Services in England (March 2011)

Comments from Members of Parliament representing constituencies across Yorkshire and the Humber

Philip Davies, MP for Shipley

"It is vital to keep the children's heart surgery unit at Leeds because it is accessible to people living throughout Yorkshire. I know from my constituents just how much this service is valued and used by local people - it is hard enough to have a child so poorly they need to use this service but then to have to travel miles away to be treated would put a tremendous strain on families struggling to support their children, work, possibly care for other children at home and any other commitments they may have.

Notice should be taken of Recommendation 178 of the Bristol Inquiry which states:

> ***Children's acute hospital services should ideally be located in a children's hospital, which should be physically as close as possible to an acute general hospital. This should be the preferred model for the future.***

Notice should also be taken of the petition supporting the children's heart surgery unit in Leeds - 600,000 signatures should be taken into account."

Julian Smith, MP for Skipton and Ripon

Letter attached.

Michael Dugher, MP for Barnsley East

“Thank you for the opportunity to submit to you my concerns about the 'Safe' and Sustainable' Service Review into the future of children's congenital cardiac services.

On the 28th June, I wrote to Jeremy Glyde, the Safe and Sustainable Programme Director with my response to their consultation. On behalf of my constituents I pressed the case for retaining the service at Leeds General Infirmary. I have enclosed a copy of that submission for you and hope that you will be able to included the comments and concerns of people from Barnsley in your regional response to the review.” (Letter attached)

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,

STEPHEN NAYLOR
Office of Julian Smith MP

Tel: 020 7219 7145 · Email: julian.smith.mp@parliament.uk · Website: www.juliansmithmp.com

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.

[redacted] 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

Michael Dugher MP
Member of Parliament for Barnsley East

HOUSE OF COMMONS
LONDON SW1A 0AA

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

28th 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.

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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

Michael Dugher MP
Member of Parliament for Barnsley East

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