Safe and Sustainable
A New Vision for Children's Congenital Heart Services in England

Yorkshire and the Humber Regional Impact Assessment

1. Executive Summary

1.1. The 'Safe and Sustainable' report outlines four preferred options for the delivery of children's congenital cardiac services in England.

1.2. All of these options have specific implications for patients living in the region. This impact assessment considers these implications in a regional context.

1.3. The 'case for change' to congenital heart services in England is a strong one. Yorkshire and the Humber Specialised Commissioning Group (YHSCG) recognise this and has considered the impact upon patients if the specialist surgical centre is not retained within this region in this report.

1.4. The impacts outlined in this report need to be fully factored into the Joint Committee of Primary Care Trusts (JCPCT) discussion and further work being undertaken on health impact and patient flows at national level, to achieve the necessary balance between these impacts and the potential reduced clinical risk which will be achieved in a fewer number of higher volume, specialist surgical centres.

1.5. A summary of our conclusions, are presented below;

Future Projections of Congenital Heart Disease

The number of new cases of Congenital Heart Disease in Yorkshire and the Humber is stable, and is predicted to remain stable.

While it is predicted that the Yorkshire and the Humber population will grow slightly above the national average, any increases in cases associated with this growth will be manageable within planned capacity assumptions, wherever the specialist surgical centre may be located.

Some minority populations in Yorkshire and Humber are predicted to grow in the next twenty years, such as the Pakistani population in the region. The number of extra cases generated from this population growth in these communities will still be small.

Multiple Health Needs

911 out of 1200 patients (75%) with Congenital Heart Disease have been shown to have admissions for interdependent conditions or multiple health needs in Yorkshire and the Humber between 2007/08, 2008/09, and 2009/10.

Admissions for respiratory diseases are the most common. Areas with the greatest burden of these interdependencies in the region include Bradford and Kirklees.

Currently these patients access co-located services at Leeds prior to birth through to adulthood on one hospital site. This brings about benefits in terms of patient experience for these children and adults with interdependent conditions.

If the specialist surgical centre is not in Leeds, it is important that the network arrangements and the role of the specialist surgical centre and associated outreach functions are considered in line with the needs of this group of patients.

The role of the children's cardiology centre should also be considered in this light to ensure that whichever option is chosen, children with multiple health needs in all areas of the country have continued access to the services they require for these conditions and appropriate local support networks.

Further national analysis of this group of patients could be considered to assess the needs of children with interdependent conditions, use of local services, and how the new model of care will work to support them.

Patient Flows

Data on patient flows show that over the ten year period between 2000/01 and 2009/10, a small proportion (10%, n=126) of cases requiring surgical intervention were treated in centres outside of Yorkshire and the Humber region.

The largest numbers of these procedures were undertaken in Birmingham, Guys and St Thomas's, and Newcastle.

Because these numbers are relatively small, it is difficult to quantitatively assess the impact upon flows if Leeds were to cease to provide surgery. The reasons for patients flowing out of region are also complex and affected by;

- Availability and capacity of the service (e.g. patients from our region with hypoplastic left heart syndrome currently go to Birmingham for their surgery)
- Advice of the treating clinician
- Patient choice

The results of the 'testing the assumptions' workstream being undertaken by PriceWaterhouseCoopers (PWC) should be considered in detail alongside the quantitative admissions data presented in this report.

The conclusions of this work will help to ensure all specialist surgical centres are safe and sustainable, and can meet the minimum number of 400 procedures per year.

Network Configuration

It is essential to ensure that the network configuration reflects accurate patient flows, and that the factors of availability, capacity, clinical advice, and choice are fully taken into account.

If options A, B or C are chosen, the viability and sustainability of the proposed children's cardiology centre in Leeds would need careful consideration. Further detailed scoping of this model is being undertaken with the Leeds Teaching Hospitals NHS Trust.

If one of these options is chosen, it will be essential to ensure that all patients continue to experience the same level of outreach service which they receive under the current regional model of care. This will need careful planning because of the increase in distance from the surgical centre inevitably experienced by some patients.

If option D is chosen, the network will need to ensure that all communities outside the current regional network footprint have equitable access to the same level of outreach as the existing service offers.

Travel and Access

Under all options, some patients will experience an increase in travel time to the specialist surgical centre. This is an inevitability of moving to fewer centres.

As with the rest of the country, journeys may be affected by adverse weather in winter months.

Linking back to patient flow analysis, the network configurations and patient flows need to reflect local patterns as widely as is practicable.

There will also be implications for the regional neonatal and paediatric critical care transport service, EMBRACE, where the amount of time spent out of region will increase whichever option is chosen. Assurances are required that the impact on neonatal and paediatric transport networks at national level has been carefully considered.

Patient Experience

Regional consultation workshops, as well as local patient and public involvement work, have highlighted the feeling amongst patients and families that their current experience of local services is high. Co-location of services, the level of outreach provided, and care pre-natally through to adulthood are key aspects of this.

If option D is not chosen, it is important to ensure that the new model of care continues to provide this high level of patient experience, alongside the clinical excellence generated by a move to fewer surgical centres.

Fetal cardiology

Whichever option is chosen, the management and delivery of mothers and babies with fetal heart disease must be given careful consideration to ensure appropriate and timely care regardless of where they live. The future network configuration and the future role of the Children's Cardiology Centre will be important in ensuring this.

Adults

There will be an impact on the sustainability of the current adult congenital surgical service in Leeds if option A, B or C is chosen.

Network arrangements for Grown Ups with Congenital Heart Disease (GUCH) / Adults with Congenital Heart Disease (ACHD) also need to be considered in detail to consider any differences from the current regional model of care for this group of patients.

Financial

Whichever option is chosen, it is possible that any family may experience financial impacts given the increase in cost associated with travel to a centre further away.

For all options, there will be financial implications for the regional neonatal and paediatric transport service, EMBRACE.

Staffing

There will be staffing implications whichever option is chosen. It is important that the national work underway to assess workforce issues captures the wider impact not just on surgeons, but surgical teams and support staff.

2. Background

2.1. The 'Safe and Sustainable' report outlines four preferred options for the delivery of children's congenital cardiac services in England.

2.2. All of these options have specific implications for patients living in the region. Some of these implications have been considered, and outlined, in 'Safe and Sustainable' in varying degrees of detail.

2.3. It was agreed at YHSCG Board in February that an impact assessment be undertaken to establish what these implications will be for patients and services in the context of the region as a whole, and within the sub-regional localities.

3. Methods

3.1. This impact assessment has been led by and compiled by YHSCG.

3.2. Quantitative data presented in this assessment has been obtained from a number of partners, including;

The Yorkshire and Humber Public Health Observatory (YHPHO)
EMBRACE
Yorkshire Ambulance Service (YAS)
Leeds Teaching Hospitals NHS Trust (LTHT)
East Midlands SCG
North East SCG
North West SCG
NATCANSAT

3.3. YHSCG thank all of the partners and individuals who have contributed to this Impact Assessment.

4. Regional Epidemiology

4.1. Numbers of cases

4.1.1. The Yorkshire and the Humber Congenital Cardiac Strategy[1] uses published estimates to approximate the number of new cases of congenital heart disease in the region as around 400 cases per year.

4.1.2. The Yorkshire and Humber Public Health Observatory (YHPHO) have produced figures which look at the number of hospital admissions for a cardiac procedure or relating to a congenital cardiac condition between 2007/08, 2008/09, and 2009/10. These results identify 1200 patients over this three year period. This approximates well with the assumptions made in the Congenital Cardiac Strategy. It also demonstrates that the incidence has been fairly stable over these years.

4.2. Surgical procedures by age group

[1] Yorkshire and the Humber Congenital Heart Network Strategy (2010)

4.2.1. There were 316 paediatric cardiac procedures performed at Leeds in 2009/10. Table 1 shows these procedures split by age group and Primary Care Trust (PCT).

4.2.2. Map 3 in Appendix 1 shows the current patient flows within Yorkshire and the Humber based on three years worth of data.

Table 1 Shows surgical procedures performed at LTHT by age-group and PCT 2009/10.

PCT	Total Paediatric	Rate/10,000 pop
Bradford and Airedale	51	4.73
Leeds	52	4.17
North East Lincolnshire	11	3.88
Wakefield District	21	3.77
Sheffield	31	3.55
Barnsley	13	3.28
East Riding of Yorkshire	17	3.22
Calderdale	11	2.92
Doncaster	15	2.90
Kirklees	22	2.81
Rotherham	11	2.41
Hull	10	2.28
North Lincolnshire	6	2.18
North Yorkshire and York	24	1.92
PCTs Outside Region	21	-
Total	**316**	**3.5**

Source: Leeds Teaching Hospitals NHS Trust

4.2.3. The numbers of surgical procedures per 10,000 paediatric population show that Bradford and Airedale has the highest rate per 10,000 population, followed by Leeds. The numbers tend to follow the largest population centres in the region with the exception of North East Lincolnshire, which has a very small paediatric population.

4.3. Ethnicity

4.3.1. Literature shows[2] that some groups have a disproportionately higher risk of congenital heart disease than others. These include some Asian groups of patients, of which the sub-group at highest risk of congenital heart disease is the Pakistani population.

4.3.2. This group has twice the risk of congenital heart disease than their 'non-Asian' counterparts[2].

4.3.3. The 'Pakistani' ethnic group is the most common Asian minority group in West Yorkshire, with the largest centres of population in Bradford, Kirklees and Leeds.

[2] Agadoorappa P[1], Oddie S, Pawson N, Sheridon E. Do Pakistani Babies Have More Congenital Heart Defects? Arch Dis Child 2011; 96:A35 doi:10.1136/adc.2011.212563.76

Table 2 shows the breakdown of the 316 surgical procedures performed at Leeds in 2009/10 by ethnic group.

Ethnic Group	Grand Total	Percentage
White British	221	70%
Asian or Asian British	56	18%
Unknown	14	4%
Other Ethnic Groups	8	3%
Other White	6	2%
Black or Black British	6	2%
Mixed	5	2%
Total	**316**	**100%**

Source: Leeds Teaching Hospitals NHS Trust

4.3.4. The most common group of patients were of 'White British' ethnicity.

4.3.5. 18% (56/316) of the surgical cases treated at Leeds in 2009/10 were from an 'Asian' or 'Asian British' ethnic group.

4.3.6. Of these 56 procedures, 64% (36) were of Pakistani ethnicity.

4.3.7. When looked at by PCT, over half of these procedures were performed on Bradford residents. 52% (27/56) were from an 'Asian' ethnic group. Kirklees, Sheffield, Leeds, and Calderdale accounted predominately for the remaining patients.

4.4. Future projections of Congenital Heart Disease in Yorkshire and the Humber

4.4.1. The most recent projections by the UK Office for National Statistics (not those published in Safe and Sustainable, which are based on 2006 population estimates) show an expected increase in the paediatric population of England and Wales by 11.4% from 2008 to 2025.

4.4.2. In Yorkshire and the Humber the paediatric population is expected to increase by 13.7%. In The North East, the paediatric population is expected to increase by 7%.

4.4.3. It is reasonable to assume that these increases could translate into an increase in the need for paediatric cardiac surgery. Based on these figures, we would expect an increase of 42 operations per year in Yorkshire and the Humber by 2025. In the North East, over the same period, they can expect 18 extra operations on top of the 255 procedures performed in Newcastle in 2009/10.

4.4.4. The current assumption is that any higher rates of incidence in specific areas can be managed within planned capacity assumptions.

4.5. Population projections by ethnic group

4.5.1. Due to the increased risk of congenital heart defects for the Pakistani population, YHSCG worked closely with the YHPHO to obtain detailed population projections by ethnic group and Local Authority area up to 2031.

4.5.2. These projections are based on a nationally recognised methodology developed by the University of Leeds[3] and endorsed by the Office for National Statistics.

4.5.3. Using these projections, combined with prevalence data obtained from the literature[2], our analysis shows we could reasonably expect an additional 102 to 124 cases of congenital heart disease in the Pakistani population by 2031.

4.5.4. These additional cases (on top of what we already get per year in the region), could equate to between 5 and 6 surgical cases a year in this ethnic group.

5. Interdependent conditions of congenital heart disease patients in Yorkshire and the Humber

5.1. Interdependent conditions in Yorkshire and the Humber

5.1.1. Patients who have a congenital heart condition often have associated or interdependent conditions. Interdependent conditions such as Down's syndrome and cystic fibrosis have been shown to most frequently occur in some high risk groups, such as the Pakistani population. For these conditions, patients currently access services at Leeds and/or at their local District General Hospital (DGH).

5.1.2. Under the options proposed in Safe and Sustainable, surgical and interventional cardiology may change centre. Patients would not routinely go to the specialist surgical centre for multiple health needs.

5.1.3. Hospital Episode Statistic (HES) data was obtained from the Yorkshire and Humber Public Health Observatory for the years 2007/08, 2008/09, and 2009/10. The data was extracted to include all patients who have had a surgical procedure or diagnosis of a congenital heart condition. For these patients, details of all further hospital admissions were extracted.

5.1.4. Of the 1200 patients admitted for a surgical procedure or diagnosis of congenital heart disease 911 (75%) had an admission for another condition. These 911 patients contributed 3276 admissions in total over the three year period.

5.1.5. Table 3 shows that for these 911 children in Yorkshire and the Humber, the most common conditions which result in other hospital admission are respiratory admissions, specifically comprising upper and lower respiratory infections (26% of all other admissions), abnormal clinical and laboratory findings (11%), factors influencing health status and contact with health services (11%), and certain conditions originating in the perinatal period (11%).

[3] Rees P, Wohland P, Norman P, Boden P. A local analysis of ethnic group population trends and projections for the UK. 2011. Journal of Population Research DOI 10.1007/s12546-011-9047-4, in press.

Table 3. Admissions by disease chapter for children with congenital heart disease in Yorkshire and the Humber 2007/08, 2008/09 and 2009/10 pooled. (n=911 patients)

Disease Chapter	No of admissions	Percent
Respiratory system	844	26%
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	546	17%
Factors influencing health status and contact with health services	376	11%
Certain conditions originating in the perinatal period	364	11%
Digestive system	204	6%
Congenital malformations, deformations and chromosomal abnormalities	195	6%
Infectious and parasitic diseases	256	8%
Circulatory system	126	4%
Injury, poisoning and certain other consequences of external causes	138	4%
Blood / immuno	54	2%
Eye and ear	54	2%
Genitourinary system	52	2%
Skin and subcutaneous tissue	17	1%
Nervous system	*	0%
Musculoskeletal system and connective tissue	*	0%
Endocrine, nutritional and metabolic diseases	*	0%
Neoplasms	*	0%
Mental and behavioural disorders	*	0%
Total Admissions	3276	100%

* Low numbers suppressed

Source: Hospital Episode Statistics (HES)

5.2. Where are patients treated for multiple health needs in Yorkshire and the Humber?

5.2.1. Map 3 (Appendix 1) is based on the number of patients admitted to hospital for a surgical procedure, cardiac diagnosis, or admission for an interdependent health issue. It shows that patients are treated locally, either in their local DGH such as Bradford Royal Infirmary or Sheffield Children's Hospital, or more commonly flow into Leeds for treatment. These patients access the co-located services in Leeds, such as respiratory services, which provide care prenatally through to adulthood.

5.2.2. Map 3 also shows the burden of admissions in the Yorkshire and the Humber Region for multiple health needs. Once again, patients from Bradford have the highest number of admissions for these multiple health needs.

5.2.3. Table 4 shows the postcode areas in Yorkshire and the Humber with the highest numbers of cardiac procedures, diagnoses, and admissions for interdependent conditions per head of population (>3.0 per 1000 population). Some of these postcodes (*) have been targeted by the national Health Impact Assessment work being undertaken by Mott Macdonald on behalf of Safe and Sustainable.

Table 4. Cardiac procedures or diagnoses by postcode area. Based on pooled admissions between 2007/08, 2008/09 and 2009/10.

Postcode	Cardiac Admissions	Rate/1000 pop
BD 3	181	6.4
BD 7	91	3.0
BD 8	99	3.3
BD 9	74	3.1
BD21	106	3.8
DN 8	73	4.4
HD 1	84	3.7
HX 1	88	3.8
HX 2	116	3.3
HX 7	49	3.5
LS18*	85	4.2
LS26*	94	3.0
S 4*	68	5.5
S 7*	66	4.0
WF 1*	106	3.1
WF 9*	134	3.4
WF12*	102	3.1
WF17*	135	3.3

Source: Hospital Episode Statistics (HES)
* Targeted Health Impact Assessment being undertaken by Mott Macdonald.

5.3. Interdependent conditions by ethnic group

5.3.1. 67% of all admissions were for patients in the White British ethnic group. 12% of admissions were of Pakistani ethnicity, 10% were 'Not Stated' and the remaining 11% were split equally across all other ethnic groups.

5.3.2. Of the admissions in the 'Pakistani' ethnic group, 48% of these were from Bradford and 19% from Kirklees.

5.3.3. Of the 751 admissions in the Bradford population, 42% of these were for patients with a Pakistani ethnicity. For Kirklees, 30% of the 127 admissions were for patients with a Pakistani ethnicity.

6. Patient flows in and out of Yorkshire and the Humber

6.1. Interpreting patient flow data

6.1.1. A detailed analysis of historical patient flows for patients with congenital heart disease in Yorkshire and the Humber is presented in section 6.2.

6.1.2. Because the numbers currently treated out of the region are relatively small, it is difficult to quantitatively assess the impact upon flows if Leeds were to cease to provide surgery. The reasons for patients flowing out of region are complex and affected by;

- Availability and capacity of the service (e.g. patients from our region with hypoplastic left heart syndrome currently go to Birmingham for their surgery)
- Advice of the treating clinician
- Patient choice

6.1.3. The results of the 'testing the assumptions' workstream being undertaken by PWC should be considered in detail alongside the quantitative admissions data presented in this report.

6.2. National analysis of patient flows (see Appendix 1, Map 1 and Chart 1)

6.2.1. Data on patient flows show that over the ten year period between 2000/01 and 2009/10, a small proportion (10%, n=126) of cases requiring surgical intervention were treated in centres outside of the Yorkshire and the Humber Region.

6.2.2. Map 1 (Appendix 1) shows where Yorkshire and the Humber patients have received their surgery for congenital heart defects over the 10 year period 2000/01 – 2009/10.

6.2.3. Map 1 shows that for this small proportion of patients who have been treated out of the region, the flows differ to those assumptions made in Safe and Sustainable. This may have been for a number of reasons, as outlined in 6.1.2.

6.2.4. Patients in Leeds and Bradford have historically travelled to Great Ormond Street in London for their surgery when the surgery is not performed at Leeds.

6.2.5. For East Yorkshire patients from Hull and East Riding, the map shows that they have historically travelled to Great Ormond Street or Alder Hey Hospital in Liverpool if they have not been treated in Leeds.

6.2.6. For North Yorkshire and York, if the surgery has not been performed at Leeds it has most commonly been undertaken in Newcastle; although it is noticeable that similar proportions of patients have also travelled to Liverpool and London Hospitals as well.

6.2.7. Map 1 also shows that patients from the North East have rarely had their surgery in Leeds when they have had to travel out of region over this ten year period.

6.2.8. Table A1 shows the numbers of procedures performed on Yorkshire and the Humber patients by centre if not performed in Leeds (n=126). Birmingham (n=41), Guys & Thomas's (n=27) and Newcastle (n=20) were the most common destinations over this ten year period.

6.3. Regional analysis of patient flows including interdependent conditions (see Appendix 1, Maps 2-3)

6.3.1. Map 2 shows where children with congenital heart disease in Yorkshire and the Humber have had surgical admissions but also admissions for other conditions. **The same caveats as outlined in 6.1.2 apply to this data.**

6.3.2. Each line represents a patient. It shows, like Map 1 and Table 1A, that the most common 'out of region' flows for children with congenital heart disease in Yorkshire, for their surgery or interdependent health needs, are to London hospitals or Birmingham, with some flow to Newcastle and Liverpool.

6.3.3. As with Map 1, there is evidence that the greatest flow to Newcastle occurs from Leeds or north of Leeds.

6.3.4 Again, it is difficult to accurately assess the quantitative impact on the numbers of surgical cases if Leeds were to cease to provide the surgical service, as this relies heavily on the factors outlined in 6.1.2. The 'testing the assumptions' workstream being led nationally by PWC will be critical into informing these assumptions at national level.

7. Network configuration

7.1. The configuration of the network(s) supporting the Yorkshire and the Humber population varies between the consultation options.

7.2. All options would result in a change to the current congenital cardiac network. The current network model is based on a collaborative regional approach, endorsed by commissioners and providers alike via the Yorkshire and the Humber Congenital Cardiac Network. It is not currently managed by the surgical centre. Over the past few years the network has put in place an outreach model which serves all DGHs in the region.

7.3. Under option A the population of Yorkshire and the Humber would be split across three different network footprints, relating to centres in Liverpool, Newcastle and Leicester, according to postcode.

7.4. Under options B and C the population of Yorkshire and the Humber would be split across two different network footprints, relating to centres in Liverpool and Newcastle, according to postcode.

7.5. Under option D the population of Yorkshire and the Humber would be served by one network. There is a well established network which currently covers Yorkshire and the Humber, plus the North Midlands, so for the population of Yorkshire and the Humber this would remain the same. However, the network would need to expand its boundaries to also include the North East and Cumbria.

7.6. In all cases, a change to the current network configuration is necessary. If options A, B or C are chosen, there would be implications for the remaining cardiology service in Leeds. The viability and sustainability of the proposed children's cardiology centre would need careful consideration. Clinicians would need to work with two or three networks, based upon the child's postcode. This would need to be managed carefully.

7.7. If option D is chosen, measures would be required to ensure that all communities within the future network footprint had equitable access to services, regardless of geographic location, level of deprivation and economic status. The outreach service currently in operation in the region would need to be expanded to cover the larger network footprint without diluting the service offered to the communities it currently serves. This would be possible with careful planning.

8. Travel and Retrieval times

8.1. Under all of the options there will be an increase in travel time to the Specialist Surgical Centre for some patients. This is an inevitability of moving to fewer centres.

8.2. Safe and Sustainable use a threshold set by the Paediatric Intensive Care Society of three hours. All of the options are compliant with this standard.

8.3. A detailed impact assessment has been conducted by the regional neonatal and paediatric critical care transport service, EMBRACE.

8.4. EMBRACE highlight that under option A, 53% of Yorkshire and the Humber patients would experience an increase in travel time of greater than 1.5 hours. Under options B and C this would be up to 73%. This increase is due to Leicester not appearing in these options thus increasing the time for patients in the South and East of the patch travelling to Newcastle.

8.5. Under option D, no patient in the region would experience an increase of greater than 1.5 hours. However, it is important to note that patients in Cumbria and the North East would experience increases under this option.

8.6. Appendix 2 presents a number of patient pathways which have been developed by the Congenital Cardiac Network Board. They highlight the differences in travel times under each option.

8.7. The most important factor relating to travel and access which was raised by families at the consultation events in Leeds was the ease of access to the proposed specialist surgical centre, particularly using current transport links.

8.8. It has been difficult to obtain or model specific journey times relating to concerns regarding seasonal variations in travel times. The ‘testing the assumptions’ workstream, being undertaken by PWC will further help to understand the impact of these issues.

9. Patient experience

9.1. Patient and parent involvement work carried out by the Yorkshire and the Humber Congenital Cardiac Network in 2010 showed that children, their parents and carers, are very happy with the children’s cardiac surgery and children’s cardiology services they receive.

9.2. If options A, B or C were chosen, the experience of Yorkshire and the Humber patients would almost certainly change. Issues raised at local consultation events have included: increased travel times, increased financial burden due to travel costs,

accommodation costs, potential loss of earnings while staying close to the surgical centre, childcare issues relating to siblings, and the value of extended family support.

9.3. If options A, B and C are chosen, it is imperative that the new model of care ensures families from our region continue to receive this high level of experience, alongside the surgical and clinical excellence generated by a move to fewer surgical centres.

10. Fetal cardiology

10.1. An important aspect of the paediatric cardiac service is the pre-natal detection of cardiac abnormalities. A good detection rate depends on strong links between the local hospitals providing pregnancy scans and the fetal cardiology service, and enables planned delivery and timely surgery for babies at risk.

10.2 Under options A, B and C it is unclear where the specialised diagnostic and counselling element of the fetal cardiac scanning service will take place, since at present it is delivered within the surgical centre. The future network configuration and the role of the children's cardiology centre will be important in determining these arrangements.

11. Adults with congenital heart disease (ACHD) / Grown Up Congenital Heart (GUCH)

11.1. Currently 19% (76 procedures in 2009/10) of the surgical workload for congenital heart conditions in our region is comprised of procedures on adults.

11.2. It is unclear where these adults will go for their surgery if options A, B or C are chosen. It is certain that if Leeds is not a paediatric surgical centre, the adult congenital surgical service would unsustainable, since it relies on exactly the same groups of theatre staff (anaesthetists, theatre nurses, surgeons) as the children's service.

11.3. Of these adults with congenital heart disease, a subset of approximately 40 to 50 patients per year will become pregnant themselves and require maternity services linked to the GUCH/ACHD service.

11.4. Of the 738 patients admitted for a surgical procedure or diagnosis of congenital heart disease 585 (79%) had an admission for another condition. These 585 patients contributed 1995 admissions in total over the three year period.

11.5. Table 5 shows for adults in Yorkshire and the Humber, the most common conditions which result in other hospital admission are those relating to the circulatory system (31%), followed by abnormal clinical and laboratory findings (20%), and respiratory diseases (7%).

Table 5. Admissions by disease chapter for adults with congenital heart disease in Yorkshire and the Humber 2007-2010; pooled.

Disease Chapter	No of admissions	Percent
Circulatory system	610	31%
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	407	20%
Respiratory system	134	7%
Digestive system	130	7%
Neoplasms	94	5%
Factors influencing health status and contact with health services	85	4%
Musculoskeletal system and connective tissue	84	4%
Injury, poisoning and certain other consequences of external causes	101	5%
Genitourinary system	55	3%
Blood / immuno	53	3%
Endocrine, nutritional and metabolic diseases	51	3%
Pregnancy, childbirth and the puerperium	50	3%
Nervous system	36	2%
Eye and ear	34	2%
Skin and subcutaneous tissue	26	1%
Infectious and parasitic diseases	25	1%
Mental and behavioural disorders	*	0%
Congenital malformations, deformations and chromosomal abnormalities	*	0%
Total Admissions	1995	100%

Source: Hospital Episode Statistics (HES)

12. Finance

12.1. Whichever option is chosen, it is possible that any family may experience financial impacts given the increase in cost associated with travel to a centre further away. If option D is chosen, it is important to acknowledge that the same impact will be felt by patients and families in Cumbria and the North East.

12.2. There will be financial implications for the regional neonatal and paediatric transport service, EMBRACE, under all of the options.

12.3. There will be a financial impact on LTHT whichever option is chosen. If option D is chosen the financial infrastructure must be in place for the expansion of the service. If option D is not chosen the associated loss of workload will have an obvious financial impact.

12.4. Commissioners will need to carefully manage the transition period post designation and ensure that the impacts upon other interdependent services are accounted for.

13. Staffing

13.1. There will be staffing implications whichever option is chosen. It is important that the national work underway to assess workforce issues captures the wider impact not just on surgeons, but surgical teams and support staff.

14. Conclusions

Future Projections of Congenital Heart Disease

The number of new cases of Congenital Heart Disease in Yorkshire and the Humber is stable, and is predicted to remain stable.

While it is predicted that the Yorkshire and the Humber population will grow slightly above the national average, any increases in cases associated with this growth will be manageable within planned capacity assumptions, wherever the specialist surgical centre may be located.

Some minority populations in Yorkshire and Humber are predicted to grow in the next twenty years, such as the Pakistani population in the region. The number of extra cases generated from this population growth in these communities will still be small.

Multiple Health Needs

911 out of 1200 patients (75%) with Congenital Heart Disease have been shown to have admissions for interdependent conditions or multiple health needs in Yorkshire and the Humber between 2007/08, 2008/09, and 2009/10.

Admissions for respiratory diseases are the most common. Areas with the greatest burden of these interdependencies in the region include Bradford and Kirklees.

Currently these patients access co-located services at Leeds prior to birth through to adulthood on one hospital site. This brings about benefits in terms of patient experience for these children and adults with interdependent conditions.

If the specialist surgical centre is not in Leeds, it is important that the network arrangements and the role of the specialist surgical centre and associated outreach functions are considered in line with the needs of this group of patients.

The role of the children's cardiac centre should also be considered in this light to ensure that whichever option is chosen, children with multiple health needs in all areas of the country have continued access to the services they require for these conditions and appropriate local support networks.

Further national analysis of this group of patients chould be considered to assess the needs of children with interdependent conditions, use of local services, and how the new model of care will work to support them.

Patient Flows

Data on patient flows show that over the ten year period between 2000/01 and 2009/10, a small proportion (10%, n=126) of cases requiring surgical intervention were treated in centres outside of Yorkshire and the Humber region.

The largest numbers of these procedures were undertaken in Birmingham, Guys and St Thomas's, and Newcastle.

Because these numbers are relatively small, it is difficult to quantitatively assess the impact upon flows if Leeds were to cease to provide surgery. The reasons for patients flowing out of region are also complex and affected by;

- Availability and capacity of the service (e.g. patients from our region with hypoplastic left heart syndrome currently go to Birmingham for their surgery)
- Advice of the treating clinician
- Patient choice

The results of the 'testing the assumptions' workstream being undertaken by PriceWaterhouseCoopers (PWC) should be considered in detail alongside the quantitative admissions data presented in this report.

The conclusions of this work will help to ensure all specialist surgical centres are safe and sustainable, and can meet the minimum number of 400 procedures per year.

Network Configuration

It is essential to ensure that the network configuration reflects accurate patient flows, and that the factors of availability, capacity, clinical advice, and choice are fully taken into account.

If options A, B or C are chosen, the viability and sustainability of the proposed children's cardiology centre (CCC) in Leeds would need careful consideration. Further detailed scoping of this model is being undertaken with the Leeds Teaching Hospitals NHS Trust.

If one of these options is chosen, it will be essential to ensure that all patients continue to experience the same level of outreach service which they receive under the current regional model of care. This will need careful planning because of the increase in distance from the surgical centre inevitably experienced by some patients.

If option D is chosen, the network will need to ensure that all communities outside the current regional network footprint have equitable access to the same level of outreach as the existing service offers.

Travel and Access

Under all options, some patients will experience an increase in travel time to the specialist surgical centre. This is an inevitability of moving to fewer centres.

As with the rest of the country, journeys may be affected by adverse weather in winter months.

Linking back to patient flow analysis, the network configurations and patient flows need to reflect local patterns as widely as is practicable.

There will also be implications for the regional neonatal and paediatric critical care transport service, EMBRACE, where the amount of time spent out of region will increase whichever option is chosen. Assurances are required that the impact on neonatal and paediatric transport networks at national level has been carefully considered.

Patient Experience

Regional consultation workshops, as well as local patient and public involvement work, have highlighted the feeling amongst patients and families that their current experience of local services is high. Co-location of services, the level of outreach provided, and care pre-natally through to adulthood are key aspects of this.

If option D is not chosen, it is important to ensure that the new model of care continues to provide this high level of patient experience, alongside the clinical excellence generated by a move to fewer surgical centres.

Fetal cardiology

Whichever option is chosen, the management and delivery of mothers and babies with fetal heart disease must be given careful consideration to ensure appropriate and timely care regardless of where they live. The future network configuration and the future role of the Children's Cardiology Centre will be important in ensuring this.

Adults

There will be an impact on the sustainability of the current adult congenital surgical service in Leeds if option A, B or C is chosen.

Network arrangements for Grown Ups with Congenital Heart Disease (GUCH) / Adults with Congenital Heart Disease (ACHD) also need to be considered in detail to consider any differences from the current regional model of care for this group of patients.

Financial

Whichever option is chosen, it is possible that any family may experience financial impacts given the increase in cost associated with travel to a centre further away.

For all options, there will be financial implications for the regional neonatal and paediatric transport service, EMBRACE.

Staffing

There will be staffing implications whichever option is chosen. It is important that the national work underway to assess workforce issues captures the wider impact not just on surgeons, but surgical teams and support staff.

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APPENDIX 1:

PATIENT FLOWS FOR CHILDREN WITH CONGENITAL HEART DISEASE IN YORKSHIRE AND THE HUMBER

1. Methods

1.1. Table A1 and Map 1 are both based on the NATCANSAT analysis commissioned by Safe and Sustainable. This analysis uses Hospital Episode Statistics (HES) data and looks at surgical procedures performed between 2000/01 to 2009/10 based on the patients PCT of residence.

1.2. Maps 2 and 3 have been produced by the Yorkshire and Humber Public Health Observatory (YHPHO). These maps are also based on HES data. These maps also include surgical procedures but are different to Table A1 and Map 1 in two ways;

- they also include data for children who have had a diagnosis of congenital heart disease but not necessarily a surgical procedure, and
- they include information on all the other types of admissions that these children who have congenital heart disease are admitted for (their multiple health needs or interdependencies).
- The map is based on 1200 identified patients between 2007/08, 2008/09, and 2009/10.

1.3. All maps are based on the paediatric population (0-16 years old).

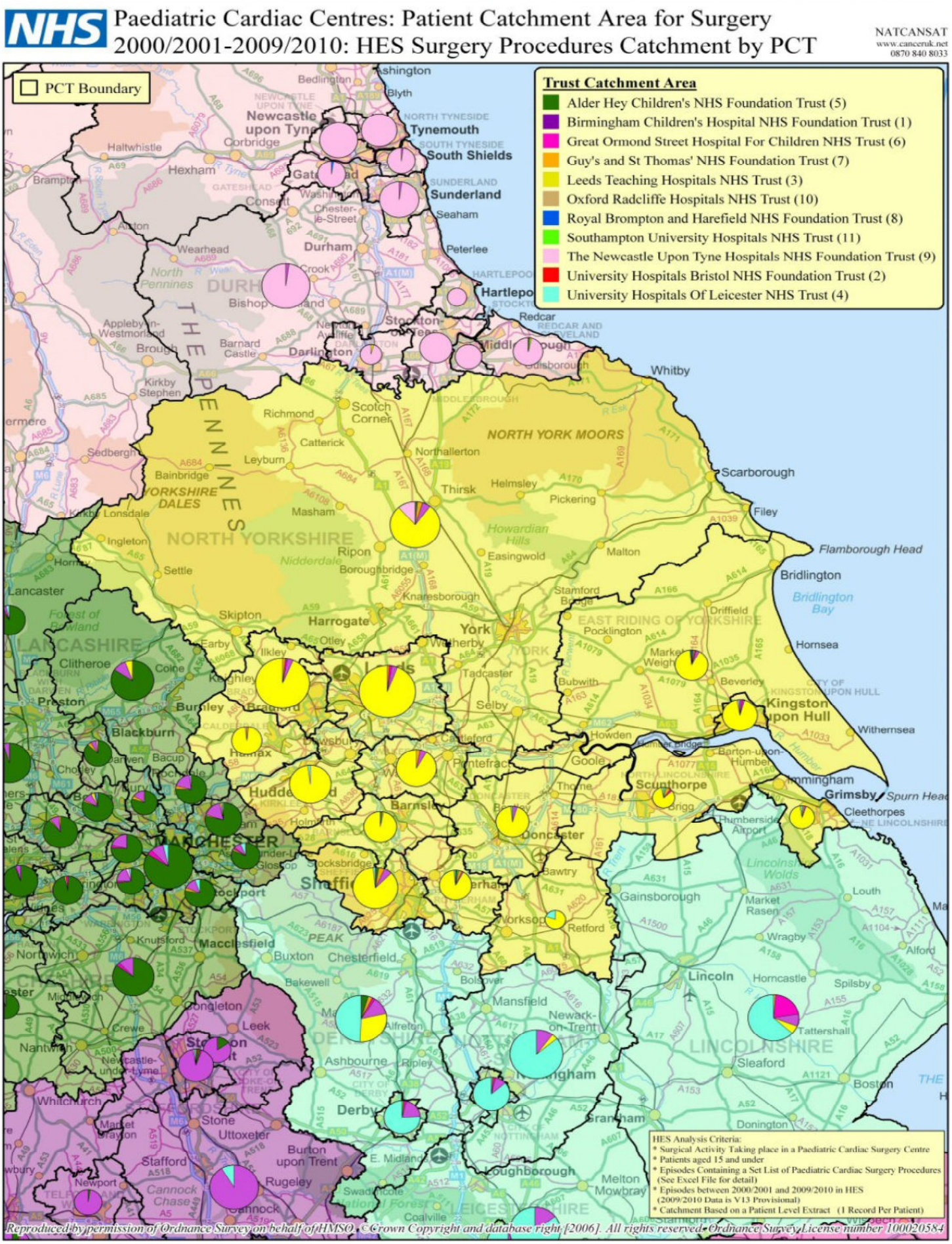
2. Surgical Flows 2000/01 – 2009/10

- Analysis included 1303 Y&H (Inc. Bassetlaw) patients treated surgically. Of these 126 (10%), were treated outside of Yorkshire and the Humber.

Table A1. Where have Yorkshire and Humber patients had their surgery if not at Leeds? (N=126)

	Surgical procedure	**Percent**
Birmingham	41	3%
Guys&Thomas	27	2%
Newcastle	20	2%
Leicester	14	1%
AlderHey	9	1%
GOSH	9	1%
Brompton	<5	0%
Southampton	<5	0%
Bristol	<5	0%
Oxford Radcliffe	<5	0%
Total out of Y&H	***126***	***10%***
Total in Leeds	1177	90%
Grand Total	***1303***	***100%***

Map 1. Where have Yorkshire and Humber patients had their surgery if not at Leeds?

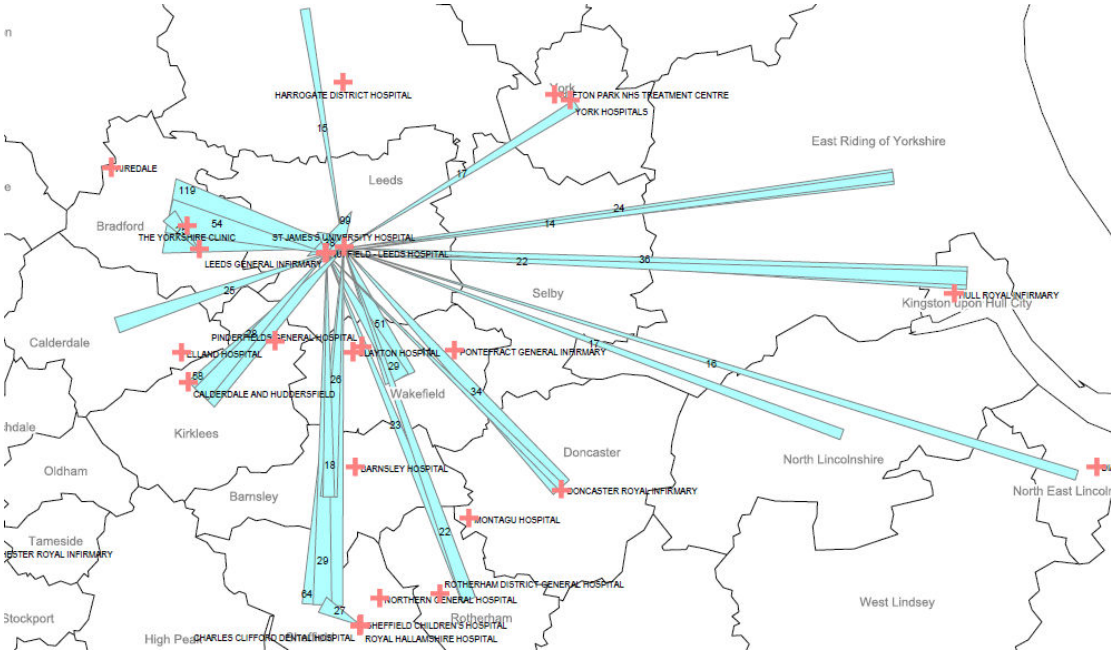


3. Multiple health needs flows 2007/08, 2008/09, 2009/10 pooled.

Map 2. Yorkshire and Humber patient flows inside and outside of the region (n=1200 patients)

Hospital Episode Statistics (HES), The NHS Information Centre for health and social care

Map 3. Patient flows within Yorkshire and the Humber (n=1200 patients, small numbers, and hence out of region flows, are suppressed)



Hospital Episode Statistics (HES), The NHS Information Centre for health and social care

Safe and Sustainable: Updated 2010-11 Paediatric Cardiac Surgical Activity by PCT in Yorkshire and the Humber

1. Surgical Procedures 2010-11

1.1. This briefing presents the 2010-11 CCAD figures for Leeds Teaching Hospitals by PCT, superseding the 2009-10 figures presented and discussed in the YHSCG Regional Impact Assessment.

Table 1. Surgical procedures performed at LTHT by age-group and PCT 2010/11.

PCT	Total Paediatric	Rate/ 10,000 pop
Calderdale	21	5.58
Bradford and Airedale	57	5.29
Kirklees	39	4.99
Rotherham	20	4.38
Wakefield District	23	4.13
Hull	17	3.87
Leeds	46	3.69
Sheffield	23	2.63
North Yorkshire and York	32	2.55
North Lincolnshire	7	2.55
Barnsley	9	2.27
Doncaster	11	2.12
East Riding of Yorkshire	9	1.70
North East Lincolnshire	4	1.41
PCTs Outside Region	18	-
Grand Total	**336**	

1.2. 336 surgical procedures were performed at Leeds in 2010-11. Table 1 shows these figures by Primary Care Trust (PCT).

1.3. This represents an increase of 20 surgical procedures compared to the 2009-10 data.

1.4. The numbers of surgical procedures per 10,000 paediatric population show that Calderdale has the highest rate per 10,000 population for this years worth of data.

Table 2: Surgical procedures 2010-11 by ethnic group

Ethnic Group	Grand Total	Percentage
White British	225	67%
Asian or Asian British	63	19%
Unknown	23	7%
Black or Black British	13	4%
Mixed	6	2%
Any Other White Background	3	1%
Other Ethnic Groups	3	1%
Total	**336**	**100%**

1.5. The most common group of patients were of ‘White British’ ethnicity.

1.6. 19% (63/336) of the surgical cases treated at Leeds in 2010/11 were from an 'Asian' or 'Asian British' ethnic group.

2. Discussion / Questions from JHOSC

2.1. **The increase increases year on year from 2009-10 to 2010-11 is within what is predicted for the region.**

The YHSCG original impact assessment assessed the impact of the increasing population in the Region and predicted 5-6 cases per year for patients with Asian ethnicity. For the non-Asian paediatric population, which is also expected to increase in Yorkshire and the Humber, Analysis suggests this population could account for an extra 201 to 268 cases up to 2031. This equates to between 10 and 13 cases per year over this time period.

2.2. **Why does Calderdale suddenly have the highest rate?**

There is an increase for Calderdale on the 2009-10 figures. 10 extra cases were seen in Calderdale in 2010-11 compared to 2009-10, and coupled with the relatively small paediatric population this is driving the higher rate seen this year. The change in rate from 2009-10 is not statistically significant and this type of fluctuation is common when we are looking at year on year changes for rare diseases or conditions such as congenital heart disease.

2.3. **Why has there been an increase of x cases in my area?**

Eight of the 14 PCTs experienced an increase in surgical cases compared with 2009-10 figures. Six PCTs experienced a decrease in cases. For these PCTs, the change in rate from 2009-10 is not statistically significant and this type of fluctuation is common when we are looking at year on year changes for rare diseases or conditions such as congenital heart disease.

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August 2011