Kirklees COUNCIL

Regional Joint Health Overview & Scrutiny Committee – Children's Congenital Heart Services

FEEDBACK FROM PUBLIC CONSULTATION IN KIRKLEES

Background

Kirklees Council arranged two drop-in sessions for members of the public in May 2011 – one was held in Huddersfield and one held in Dewsbury. These sessions were publicised in the local press, on Kirklees Scrutiny's Twitter account, and on Kirklees Scrutiny's Facebook page. Eight people attended and shared their stories – all expressed concern about the potential loss of the unit in Leeds.

Two letters were also received.

Cllr Elizabeth Smaje, the Council's representative on the Regional Joint HOSC, also held a meeting with Dr Sara Matley from the Children's Heart Surgery Fund on 20 June 2011.

Key Themes

A number of key themes and messages emerged from the discussions, and these are set out below:

- **Pre-Natal Scans**

  Concern was expressed that congenital cardiac conditions were not always picked up during pre-natal scans. Several of those who attended had been aware of other serious health issues, for example, gastrological, and had therefore given birth at Leeds General Infirmary as they have units for other paediatric specialisms. Cardiac surgery was often then needed very quickly on a seriously ill baby.

- **Co-location of Services**

  The centralisation of children's hospital services at Leeds General Infirmary ensures that a wide range of paediatric services are co-located on the same site. A child can therefore have access to various specialists simultaneously and not need to be moved between sites. Concern was expressed that this would not be available at Liverpool or Newcastle.

  There was also concern that maternity services in both Liverpool and Newcastle are on different hospital sites from the children's heart unit, which could see mother and baby separated shortly after birth. In Leeds, both services are co-located on the same hospital site.

- **Number of Procedures**

  Concern was expressed that the projected number of procedures that would be carried out by a unit in Leeds did not take into consideration that population growth in the Yorkshire and Humber region is exceeding the national average.

  There was also concern that adult procedures had not been accounted for. There are an increasing number of people with congenital heart conditions surviving into adulthood and they are also operated on by the same surgeons, as they are specialists in congenital heart problems.

- **Travel Distance**

  Concern was expressed that the additional travelling time for Kirklees' residents to Liverpool or Newcastle could have significant adverse consequences. There was concern about rush hour traffic on the M62, M1 and A1 and the impact this would have on travel times. Concern was also expressed about the assumption of which postcode areas would attend which of the alternative hospitals and that a situation could arise where Liverpool was overwhelmed and Newcastle was unable to meet the minimum number of procedures.

- **Ambulance Service**

  Concern was expressed about the ability of Yorkshire Ambulance Service, and Embrace, to manage an increased number of neonatal, perinatal and paediatric transfers of critically ill children. Concern was expressed that the air ambulance did not fly in the dark and that it could also be grounded when foggy.

- **Impact on Paediatric Intensive Care Beds**

  In Yorkshire and Humber, Leeds and Sheffield provide the regional paediatric intensive care units and paediatric cardiac intensive care units. Dr Matley advised that the beds within the units are used flexibly and therefore the loss of 8 paediatric cardiac intensive care beds would impact across the region.

- **Staffing**

  Concern was expressed that there was an assumption consultants from the Leeds unit would take up positions at Newcastle or Liverpool if Leeds were to close. Newcastle currently has 2 consultants and Leeds has 3 and are looking to recruit a fourth. There was concern that consultants may not wish to relocate to Newcastle and that if a unit was located there and Leeds closed, there may be a period of time when there were insufficient surgeons available across the north of England.

- **Affordability**

  A number of parents were concerned about the costs they would incur if procedures were carried out at Liverpool or Newcastle. Expenses such as: travel, accommodation, and food were raised. It was recognised that the Children's Heart Surgery Fund in Leeds give assistance to families by providing nearby accommodation, helping with expenses, and providing kitchen facilities so parents can prepare their own food rather than incurring the expense of eating out. It was not known if similar facilities were available in Liverpool or Newcastle. There was particular concern about parents on low incomes.

- **Family Life**

  Many of those attending spoke about the impact on their family life of supporting a critically ill child through serious surgery. Several mentioned their other children and their needs, and the conflict they had faced in supporting the child in hospital but also being a parent to other children. Children were often kept in hospital for several weeks following surgery, and parents needed to be able to shuttle back and forward. Parents were often very reliant on assistance from their wider families and friends, which they felt would not be as easy if further distances had to be travelled.

- **Engagement Events**

  Those attending had been unhappy with the quality of engagement events at the Armouries, and did not feel that the correct people were presenting the information. They were also dissatisfied that there appeared to be a ‘done deal’.

  It was commented that those in attendance were predominantly white, middle class, and articulate people. A suggestion was made that engagement with mosques, for example, could have helped to reach a wider number of people.

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INFORMATION PROVIDED BY KIRKLEES COUNCIL'S DIRECTOR OF PUBLIC HEALTH

Background

Cllr Elizabeth Smaje, the Council's representative on the Regional Joint HOSC, sought clarification from Dr Judith Hooper, Director of Public Health for Kirklees Council, on the likely impact on infant mortality in Kirklees, if children's cardiac provision was to be moved further away.

The following comments were received:

- The infant mortality rate is unlikely to be affected if children's heart surgical services are further away. Evidence suggests that pooling surgical expertise into fewer larger centres ensures they perform the necessary number of procedures a year to maintain and develop their expertise. This results in better outcomes.

- The child does not need to reach a surgical centre in the shortest possible time but the specialist intensive care retrieval teams should get to these children, and stabilise them correctly so that surgery can then be carried out in the best possible circumstances. A letter by Dr Ian Jenkins (the immediate past president of the Paediatric intensive Care Society) describes this http://www.specialisedservices.nhs.uk/news/view/32

- The distance from home and travel to centres further away could have an impact on the parents and siblings. Newcastle is one of the sites proposed as a centre. Yorkshire & Humber has double the child population of the North East region, and is growing much faster. Within this, the BME population is growing fastest. The Pakistani population has more congenital abnormalities and cardiac abnormalities form a significant proportion of these. (In Kirklees almost a quarter of the infant deaths due to congenital abnormalities (2006-8) had cardiac abnormalities observed at time of birth. In addition a small proportion who died of other causes had cardiac abnormalities observed at time of birth and there may also be those cardiac problems picked up some time after birth). The Pakistani population has large families and is more deprived, so a disproportionately high burden is placed on these families by imposing additional travel. However the number of major heart operations needed by a child should be small and much of the rest of the care can be delivered nearer home by networks built around the specialist centre.

- Some children with congenital heart disease will have other complex service and care needs. There may be issues around cardiac surgery being at a separate centre from where other care needed by the child is provided e.g. in Liverpool cardiac would be at Alder Hey and maternity at Liverpool Women's. Newcastle services are actually spread over 3 sites, whilst Leeds is on a single site. The importance of such co-location is not easy to quantify. More information may be available in the impact assessment.

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Kirklees Joint Strategic Needs Assessment 2010 – Information on Vulnerable Groups identified by Health Impact Assessment: Interim Report

In the Health Impact Assessment: Interim Report, published August 2011, information was outlined on the population groups that will be disproportionately affected by reconfiguration proposals due to their higher susceptibility of experiencing congenital heart disease and, therefore, needing children's heart surgery services.

The population groups identified included:

- People who experience socio-economic deprivation;
- People from Asian ethnic groups, particularly those with an Indian, Pakistani, Bangladeshi and other Indian subcontinent heritage;
- Mothers who smoke during pregnancy;
- Mothers who are obese during pregnancy.

The Joint Strategic Needs Assessment for Kirklees 2010, published July 2011, provides the following data relevant to these population groups:

Socio-economic deprivation

The Index of Deprivation 2007 identified Kirklees as one of the 50 most deprived local authorities in England for both the income and employment domains – Kirklees is ranked 12th worst in England. More than 70,000 people (about 1 in 6) were classed as income deprived and 27% of the Kirklees population live in the top 20% of most deprived areas, nationally.

Asian ethnic groups

Over 1 in 8 people are of south Asian origin, Pakistani and Indian primarily. Over 1 in 3 young people in the north of Kirklees are of south Asian origin, especially in Dewsbury and Batley.

Smoking during pregnancy

19% of white women smoke during pregnancy – with variations from 33% in Dewsbury to 7% in Denby Dale & Kirkburton (17% national average). No south Asian women said they smoked during pregnancy and this led to a figure of 10% of all women who smoked during pregnancy.

49% of 130 teenage mothers enrolled in the Kirklees Family Nurse Partnership programmes smoked at enrolment with 38% continuing to smoke in their 36th week of pregnancy.

Obesity during pregnancy

48% of mothers were at least overweight, especially Pakistani origin mothers (60%). Obesity was worse in north Kirklees with 23% of mothers obese.

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Assumptions have been made by the Safe and Sustainable Team on the patient flows that would arise from each of the proposed configurations of surgical centres. In the event of Options A, B or C being agreed, it is anticipated that the postcode flows within the Kirklees boundary would be as follows: BD to Liverpool; HD to Liverpool; and WF to Newcastle.

Analysis of each of the postcode areas has been undertaken, and it is acknowledged that for patients with an HD or BD postcode, Liverpool would be the natural destination if Option D was not selected. However, the analysis shows that for patients with a WF postcode, Newcastle would not be the natural destination, with travel times nearly double that of Liverpool. This would therefore affect the assumed numbers of patients that would attend each hospital.

	By Car (source: google maps)			**By Public Transport (source: transportdirect.info)**		
	To Leeds General Infirmary	**To Newcastle Freeman Hospital**	**To Alder Hey Children's Hospital**	**To Leeds General Infirmary**	**To Newcastle Freeman Hospital**	**To Alder Hey Children's Hospital**
HD1 Central Huddersfield	31 mins	2 hrs 21 mins	1 hr 6 mins	41 mins	3 hrs 32 mins	2 hrs 6 mins
HD9 Rural Huddersfield (Holmfirth)	44 mins	2 hrs 33 mins	1 hr 19 mins	1 hr 25 mins	4 hrs 5 mins	2 hrs 46 mins
WF12 Dewsbury	25 mins	2 hrs 8 mins	1 hr 15 mins	34 mins	4 hrs 9 mins	2 hrs 18 mins
WF17 Batley	21 mins	2 hrs 8 mins	1 hr 18 mins	40 mins	4 hrs 10 mins	2 hrs 31 mins
BD11 Birkenshaw	18 mins	2 hrs 10 mins	1 hr 10 mins	37 mins	2 hrs 46 mins	3 hrs 4 mins
BD19 Cleckheaton	19 mins	2 hrs 9 mins	1 hr 8 mins	46 mins	3 hrs 5 mins	2 hrs 55 mins

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VISIT TO LEEDS CHILDREN'S HEART SURGERY UNIT, LEEDS GENERAL INFIRMARY

On 22 August 2011, Cllr Smaje (Kirklees representative on the Joint HOSC) visited the Children's Heart Surgery Unit at Leeds General Infirmary. Cllr Mulherin from Leeds Council was also present on the visit. Stacey Hunter, Divisional General Manager for Children's Services, and Karl Milner, Executive Director – External Relations, accompanied the visit.

During the visit, Cllr Smaje and Cllr Mulherin spoke with staff in the Children's Heart Surgery Unit, and they raised a number of issues:

- Travelling time to Newcastle or Liverpool if the Leeds unit were to close.
- Continuity of care – many patients had been attending the unit since they were small babies.
- Siblings at home – parents facing difficult situations if siblings were at school.
- Travel costs – many patients seek assistance with travel expenses already.
- Co-location with other services.

Cllr Smaje and Cllr Mulherin also spoke with the grandmother of a young patient on the Children's Heart Unit. She explained that she travelled by public transport 3 or 4 times a week to Leeds General Infirmary to help provide her daughter with a short break. She had been undertaking this journey for the last 7 weeks. She was concerned that this would not be possible if she had to travel to Liverpool or Newcastle.

Concerns raised by Leeds Teaching Hospitals Trust during the visit:

- The decision not to include the number of adult procedures and cardiac interventions within the figures. Intervention cardiology is a growing area and around 550 paediatric interventions are undertaken a year – 200 pacemaker/defibrillator; 200 structural; 150 a combination of the two. The Trust advised that the cardiologists undertaking intervention procedures had stated that they would not undertake them without a cardiac surgeon on standby, as this would not be safe.

- The lack of an evidence base for the 400 procedures figure – it is argued that some surgeons will not undertake as many procedures due to the complexity of the surgery they undertake, however they will still be undertaking a sufficient number to sustain competency. There is no evidence linking the number of procedures to clinical outcomes.

- 17 outreach clinics are run by Leeds, which are attended by sonographers. Around half of these are surgical clinics, which would not continue if Leeds was to close. Leeds did not believe that surgeons would be able to run outreach clinics from Newcastle or Liverpool into the Yorkshire & Humber region, as they would need to be in theatre or on site, and not considerable distances from the hospital.

- Concern was expressed about the separation of obstetrics and cardiology. The Trust have undertaken work in hospitals around the region to ensure that scans can be undertaken in more local settings so that patients do not have to always travel to Leeds.

- The impact on other services, for example, the kidney service. This is hard to quantify, but cannot be ignored.

- The number of paediatric intensive care cots would be reduced by approximately 6-8, as the funding will not be available.

- Leeds is the biggest teaching hospital in the country but would be unable to train in this speciality.

- Concern was expressed about recruitment of high quality staff. It was felt that the most experienced cardiac consultants and cardiac anaesthetists would be drawn to the hospitals where surgery was being performed.

- Concern was expressed that many patients did not just have to attend the hospital once for the procedure, but attended regular appointments. It was estimated that the majority of patients who are maintaining their condition will attend the hospital once every 3 months; a smaller number whose condition was stable would attend the hospital once every 6 months for a check-up. Following a procedure, monthly check ups would be put in place. Liaison nurses are in regular contact with patients, by phone calls where necessary.