CHILDREN'S NEUROLOGICAL SERVICES: ADDITIONAL INFORMATION FROM LEEDS TEACHING HOSPITALS NHS TRUST

Leeds Teaching Hospitals

Children's Neurosurgery Review

Information provided for the Leeds HOSC re the above as at 16th January 2012.

Service Profile - The service based at the Leed's Children's Hospital, LTHT delivers care to approx 2,500 children per annum.

This service provides 500 day case and inpatient operations/procedures and supports 2,000 outpatients per year.

1) Timetable

The timetable for the review is currently unclear and has not been made generally available. The most recent Newsletter stated Spring 2012 for the start of implementation.

1.1) History to date:

Over the course of the review there are three distinct work streams that have evolved. The first is the proposal to establish Children's Neurosurgical Networks, the second is the need to provide additional complex epilepsy surgical treatments supported by strong multi-disciplinary team assessments, and the third is establishing a national/regional multi-disciplinary team review to agree the clinical plan for rare and complex Brain Tumours which would support treatments provided in centres across the country. Detail of these work streams is provided within this briefing.

Safe and Sustainable first published draft standards in November 2009. Yorkshire and Humber OSC were invited (and attended) an engagement event on 30 November 2009. OSC's were asked to provide comments on the draft standards.

2010 - The Model of Care Group was established to develop exemplar pathways and standards for brain tumour, brain trauma, hydrocephalus, spinal dysraphism and epilepsy

2010 - Steers and Stower undertook a fact finding visit of the current children's neurosurgical centres and published a report.

November 2010 - Parents interviews and workshops were held around the country and report published with key findings.

November 2010 - A clinical workshop was held to agree the model of care and pathways held in November

June 2011 - The Steering Group agreed the circulation of two documents for comments from Professional organisations

- Children's Neurosurgical Services in England: A Framework for the Future
- Children's Neurosurgery draft service specification standards May 2011

These documents have been amended and are due for wider circulation and comment in January 2012 - these have not been received as yet.

1.2) Epilepsy Procurement

The Advisory Group for National Specialised Services (AGNSS) has agreed the case made for commissioning additional complex epilepsy surgical treatments supported by strong multidisciplinary assessment teams. The process for procuring these services is currently underway with recommendations for national designation being made to AGNSS in February 2012.

Leeds submitted a joint consortia bid with Sheffield and Newcastle against the Epilepsy procurement - this was successful at Stage 1 but unfortunately did not progress beyond Stage 2. The parties in the consortia withdraw the bid as we could not agree on all aspects of the bid.

This does mean that pending the recommendations from AGNSS in February that children and families from Leeds and West Yorkshire may have to travel outside of the Yorkshire and Humber region to access complex Epilepsy surgery.

2) Profile of service users

The Children's Neurosurgical review encompasses children from 0-18 years, (up to the 19th birthday). Some aspects of the review do include antenatal diagnosis. The review focuses on 4 main patient pathways;

- Hydrocephalus
- o Brain Tumours
- Epilepsy
- o Brain Trauma

The average length of for a patient undergoing care for a Neurosurgical condition is 3.4 days. However much of the child's care is undertaken by the Paediatric Neurologists and the extended multidisciplinary team, whereby there are much longer pathways involved for children and their families. The inpatient aspect of care can for example many months in the case of children undergoing rehabilitation following brain trauma.

3) Access to services

Currently there are services based in;

- Leeds Teaching Hospitals NHS Trust on the Leeds General Infirmary site
- Sheffield Children's Hospital NHS Foundation Trust and Sheffield Teaching Hospitals NHS Foundation Trust Royal Hallamshire Hospital site.
- Hull and East Yorkshire NHS Trust Hull Royal Infirmary site. The numbers of Paediatric Neurosurgical operations undertaken in Hull are very small and SCG have advised that the service in Hull should not be viewed as a stand alone service. The Hull service is strategically aligned to the Leeds service.

ITEM 10

4) Numbers and patient flows

The Paediatric Neurosurgical review has concluded that the evolution via a managed network approach consisting of all current children's neurosurgical centres working to agreed standards of care is the best way forward.

- 1. All the different hospitals and trusts contributing to the child's care will have formal agreement to work together with an identifiable leadership team.
- 2. They have a shared approach to collecting information, measuring quality and improvement in care.
- 3. They share policies, clinical guidelines and protocols for care.
- 4. They share common aspects of training and development.
- 5. There is a regular shared assessment and review against standards.
- 6. There is common record keeping.
- 7. They can share and transfer images and scans between the different hospitals so that the right expert can see and advise about care and treatment. They must have an education and training plan for different staff groups within the centre and across the network.
- 8. They can develop co-ordinated approaches to audit, and research.

What this actually means in terms of patient flows is unclear since it is envisaged that all the current centres will remain.

5) Facilities

The service based on the Leeds General Infirmary site benefits from vertical integration with all of the Children's services on one site, and horizontal integration with the adult neurosurgical service. This ensures that children with these life long conditions can be transitioned to care as an Adult in an optimum service model. The Leeds service provides services across the full range of conditions included in the scope of the review.

6) Impact on related services

It is not feasible to assess at this stage of the review, it will depend upon the outcome of the networks and the procurement of the highly specialist clinical services highlighted in this paper.

It is of some concern to Leeds Teaching Hospitals that when you consider not only this review, but other similar reviews e.g. the Congenital Cardiac Review/s for children and Adults there could be a significant knock impact to a range of other services provided from the Leed's Children's Hospital.

Losing specialist services does have wider impacts on critical care, other medical and surgical specialities. This is something that needs to be kept under review as the detail of the specific service reviews and their implementation emerges.

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January 2012