

## Paediatric Neurosurgical Services – Briefing

### Background

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 ready for wider circulation and comment in January 2012

### Why the need for change?

As part of the review we have considered national and international evidence regarding children's neurosurgery. This is what we found:

- There tends to be a longer time between the onset of symptoms and diagnosis of brain tumours than other childhood tumours.
- The resection rate for some tumours is lower in the UK than international centres of excellence. (This relates to the clear surgical removal of tumour cells.)
- The 30 day, 1 year and 5 year survival rates for some brain tumours in the UK may be lower than in the US and there are potentially many reasons for this.
- International evidence exists to suggest services performing more ventricular shunt procedures have better outcomes than services performing fewer procedures.
- Shunts performed by a consultant 'out-of-hours' fare better than those performed by a trainee.
- The 30 day shunt revision rate (those that need to be re-done within 30 days) in the UK may be higher than recognised international centres of excellence.
- 1 in 10 admissions for children to an intensive care unit with traumatic brain injury has a fatal outcome. Outcomes vary considerably across England and Wales for these severe cases.
- Wide variation is reported in the detailed processes of care for children with severe traumatic brain injury, with potential impacts on survival.

### **The Solution?**

The document 'Children's Neurosurgical Services in England: A Framework for the Future' (a steering group report) proposes setting up networks of care or managed clinical networks.

It is proposed there should be a number of Children's Neurosurgical Networks in England. Criteria for the networks are currently being considered, for instance how big should each network be and what population should they cover. The challenge will be for Networks to show that whatever the time of day or night, it is possible for any child in England to have advice from or be seen and treated by a consultant paediatric neurosurgeon and associated team, as well as make sure every child that needs it, has access to the same high quality service across the country.

### **What's in a network?**

The Steering Group's report concluded that 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, and that by all services working closely together in a *managed network* we can make the best use of rare specialist expertise, improving care and access.

### **So what's in a network?**

Networks should help provide coherence and integration from the parent and family point of view, from presentation, diagnosis, treatment, after care and finally ongoing support at home and at school.

### **Who does it involve?**

It involves a whole range of people from:

GPs, Paediatricians in Child Health services, Obstetricians, Children's Neurologists, Radiologists, Neurosurgeons and the multi-disciplinary team with nurses and therapists, Principal Treatment Centres for children's cancer, Major Trauma Centres and local Trauma Units , Adult Neurosurgeons, Specialist Anaesthetists, Rehabilitation Teams and local District General Hospitals

### **How do they work?**

1. They have formal agreements to work together across all the different hospitals and trusts contributing to the child's care, 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 the right expert can see and advise about care and treatment. 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 .

An example of how a network for the care of children with hydrocephalus might look is attached at Annex A.

### **Children's Epilepsy Surgery Service**

During the Children's Neurosurgical Services review, clinical evidence has emerged which suggests that there are significant advantages with early epilepsy surgery performed during the first 5 years of life. When examining the current activity for epilepsy surgery in England against international benchmarks, the Steering Group concluded that England performs fewer than half the number suitable procedures in comparison with other countries. 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.

### **Rare and Complex Brain Tumours**

As part of the review, it has been identified that establishing a multi-disciplinary team review to agree the clinical plan for rare and complex Brain Tumours would support the services provided in centres across the country. The Steering Group has suggested that there should be a multi-professional team working across larger geographical areas and across current centres with a view to developing skills and improving clinical management and outcomes for these conditions. Discussions with clinicians will be starting in 2012 about how this might work in practice. The Children's Cancer and Leukaemia Group has been asked to nominate representatives for this working group.

#### Next steps:

- Revised framework and standards document will be issued widely in January for 3 month feedback and comments.
- Comments will be reviewed by the Steering Group at the end of that period.
- Proposals for networks will be developed by regional commissioners together with local services, and reviewed nationally for coherence and fit with other networks.
- Network self assessment against standards will start in early autumn 2012 followed by a peer review process across networks. The self assessment and peer review process will be developed and finalised by summer 2012.

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