

Children's Neuro Update

Welcome . . .

From Teresa Moss, Director National Specialised Commissioning Team



I would like to take this opportunity to thank Paul Chumas for all of his hard work as Steering Group Chair for the Safe and Sustainable review of Children's Neurosurgical Services over the last three years. I welcome Anne Moore, President of the Society of British Neurological Surgeons, to the role.

In the previous newsletter we focused on what parents had said was important for them about the service, with interviews and feedback from regional parent and charity workshops. This feedback together with emerging clinical evidence, contributions from professional associations and a large number of clinicians from a range of disciplines, has helped to define the needs and challenges for Children's Neurosurgical Services into the future. Meeting these needs and challenges will collectively make this service 'world class'.

More formalised networks are at the heart of the proposed solution to provide stronger coordination of care for patients and their families and to achieve 24/7 paediatric neurosurgical care.

Two Steering Group reports have been circulated to Professional Associations for comment on the approaches we are suggesting. This feedback will be reviewed by the Steering Group at its next meeting and following amendments, new documents will be circulated to the NHS, charities, parents and carers for wider comment in October.

The aim is to start implementation of these proposals in Spring 2012.

Children's Neurosurgical Services in England: A Framework for the Future
Children's Neurosurgical Specification Standards May 2011

are available on our website:

www.specialisedservices.nhs.uk/document/children-neurosurgical-specification-standards-may-2011

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Why the need for change?

As part of the review we have considered national and international evidence regarding children's neurosurgical services.

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 in the UK.
- The resection rate for some tumours is lower in the UK than international centres of excellence.
- 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*' suggests setting up Networks of Care or managed clinical networks.

It is proposed there should be about 8 Children's Neurosurgical Networks in England. Criteria for each network is currently being considered, for instance how big should each network be? 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. We can improve care, access and make the best use of rare specialist expertise with all services working closely together in a managed network.



So what's in a network?

Networks should help provide coherence and integration from the parent and family point of view (a 'joined up' service), from presentation, diagnosis, treatment, after care and finally ongoing support at home and at school.

Who does it involve?

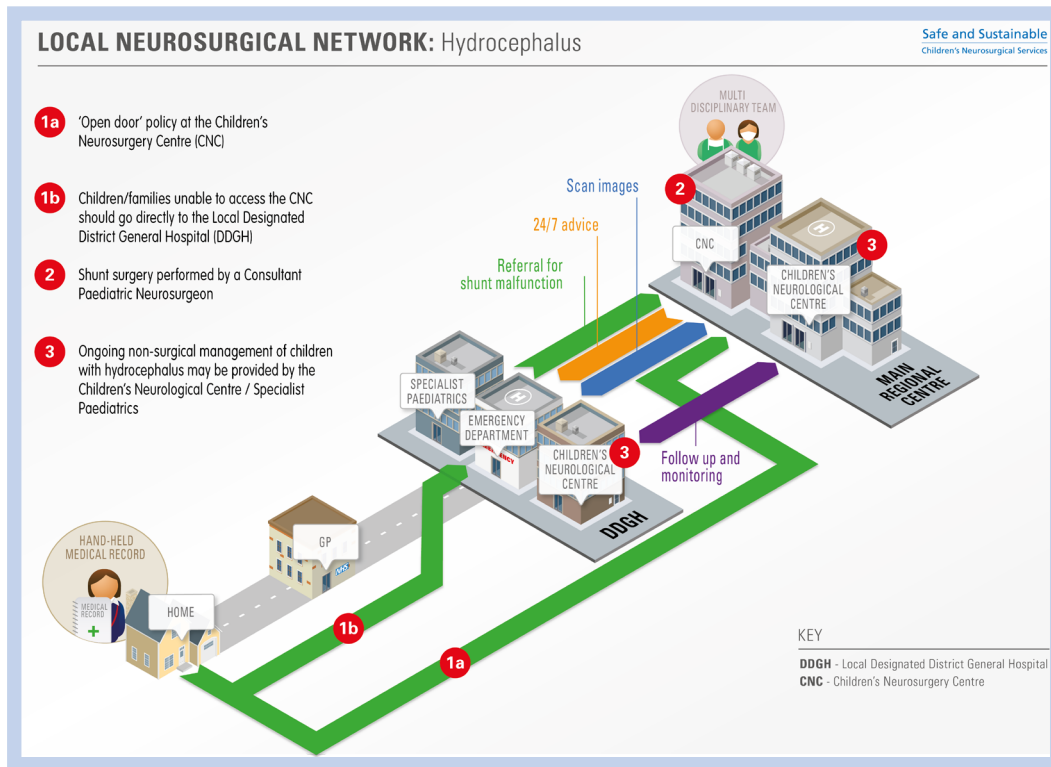
It involves a whole range of people from:

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

How do they work?

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.

An example of how a network for the care of children with hydrocephalus might look



Parent workshops coming soon . . .

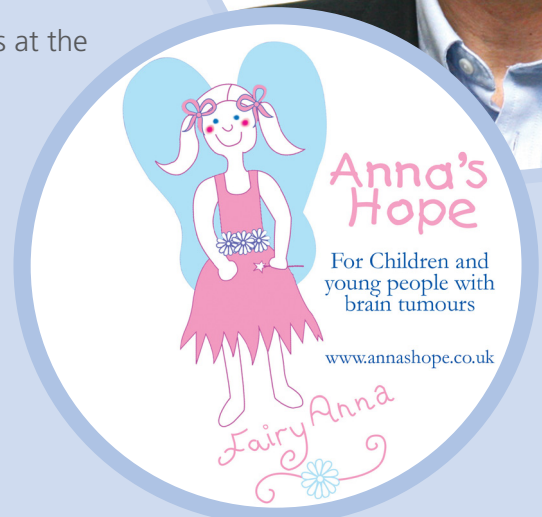
Building on the success of the November events we are planning another round of workshops around the country.

The purpose of these workshops is to share with parents, carers and charities how their views have been taken into account in developing the model of care and standards, describe what children's neurosurgical networks might mean for them and to seek input on what will make these networks work in practice.

It would be great to see the same level of participation as at the last round of workshops.

Robert Hughes

Chairman of Anna's Hope charity and patient and parent representative on the review's Steering Group



Dates and venues

12th October	(11:00 – 14:30)	Warrington (Village Hotel)
12th October	(18:30 – 21:00)	Leeds (Queens Hotel)
13th October	(11:00 – 14:30)	Sheffield (Hilton Hotel)
13th October	(18:30 – 21:00)	Nottingham (Hilton Hotel)
17th October	(11:00 – 14:30)	Taunton (Holiday Inn Hotel)
18th October	(11:00 – 14:30)	Oxford (Conference Centre)
19th October	(11:00 – 14:30)	London (Victoria Park Plaza)
20th October	(11:00 – 14:30)	Southampton (Grand Harbour De Vere Hotel)
1st November	(11:00 – 14:30)	Newcastle (Hilton Gateshead)
3rd November	(11:00 – 14:30)	Birmingham (Maple House)

You can register at: www.eventsforce.net/childneuroworkshops

Other news

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 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 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 December this year.

Rare and Complex Brain Tumours

It has been identified that establishing a multi-disciplinary case review system to agree the clinical plan for rare and complex Brain Tumours would develop the service 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 in the neurosurgical community will be starting in the autumn about how this might work in practice. The Children's Cancer and Leukaemia Group has been asked to nominate representatives for this working group.



The Steering Group update

The Steering Group is currently drafting principles to underpin the future service development and network implementation. These should be the foundations for the service going forward:

1. For the service to be safe, sustainable and world class the status quo is not an option.
2. The service should be delivered by fellowship trained consultant paediatric neurosurgeons (PNs) who have a strong on-going commitment (50% of their jobs with ongoing professional development) to Paediatric Neurosurgery.
3. Children, their families and other clinicians and services should have access to advice and treatment from a PN 24/7. Likewise every child who is an in-patient should be seen every day by a PN.
4. Surgeons may have a "mixed practice" (across adults and children) - recognising that some skills apply to both.
5. However some conditions in children are rarely seen in adults, these patients should be operated upon in fewer units and by fewer surgeons than at present in order to increase experience and improve outcomes. The Steering Group recognises that different arrangements may suit local requirements and changes may emerge as services develop and expertise changes.
6. There is a need for a national collection of agreed data, including outcome data so that comparisons can be made.
7. The national shortfall in paediatric rehabilitation needs to be addressed.
8. Paediatric Neurosurgical Services will come under the remit of The National Commissioning Board (subject to legislation). There should be a review mechanism through this in order to evaluate the success of the Children's Neurosurgical Managed Networks in achieving these principles and standards.
9. Each Network should be in a position to offer their population a world class service for virtually the whole range of paediatric neurosurgical conditions – although there will remain a need for some rarer conditions to still be managed in fewer national centre(s). In order to achieve this over time, these service might need to be concentrated in one hospital within the network.
10. An increase in the number of paediatric neurosurgeons (in order to offer 24/7 cover) in isolation from these other recommendations is likely to dilute expertise and leave services unsustainable.

Staying in touch

We want to hear your views on the future of the national services. If you have any comments, views or suggestions, you can contact Stephanie Stanwick, Programme Manager for the Safe and Sustainable Children's Neurosurgical Services review:

- **Email:** Stephanie.Stanwick@nsct.nhs.uk
- Write to her at: **NHS Specialised Services 2nd Floor, Southside, 105 Victoria Street, London SW1E 6QT**
- **Telephone:** 0207 932 3958

For further details about Safe and Sustainable go to:
www.specialisedservices.nhs.uk/safeandsustainable