

Children's Neuroscience Networks (for the Neurosurgical Child) - Questionnaire

Introduction

Feedback from parents, contributions from Professional Associations and emerging clinical evidence has helped to define the needs and challenges for Children's Neurological Services into the future. 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.

Meeting these needs and challenges will collectively make this service 'world class'.

The NHS is proposing Children's Neuroscience Networks (for the Neurosurgical Child) will provide stronger coordination of care for patients and their families and achieve 24/7 paediatric neurosurgical care. It is envisaged that there will need to be a number of networks across England. All centres and services that are currently delivering neurological care to children will continue to provide services and be active participants in the network. At least two Children's Neurosurgical Centres will work closely together so they can develop shared clinical guidelines and protocols and benefit from shared audit, research, training and development.

More information about the proposals can be found within two Steering Group documents:

- 1) Children's Neuroscience Networks (for the Neurosurgical Child): A Framework for services in England – February 2012
- 2) Children's Neuroscience Networks (for the Neurosurgical Child): Specification Standards – February 2012

These documents can be found on the Safe and Sustainable website using the following link:

www.specialisedservices.nhs.uk/document/steering-group-reports

The current documents have been developed following detailed ongoing discussions and feedback from a wide range of Professional Associations. However it is important that the views of different organisations are sought including NHS Trusts, clinicians local authorities, families and carers. All comments received and the results of this questionnaire will be discussed by the Steering Group with the aim of finalising the documents by early summer. We do recommend you read the documents before completing the questionnaire.

The proposed model of care

Obstetricians, Perinatologists and Neonatologists who will be involved in investigation, diagnosis and counselling during pregnancy, the planning and management of delivery and the care of the new-born baby.

GPs play a key role in the early recognition of the condition, appropriate referral, support and follow up

Paediatricians and Specialist Paediatricians in Child Health in services in local DGHs are often the first point of contact in hospital following the initial presentation of the child's condition. They are likely to initiate further investigations and seek the advice and support from the Paediatric Neurosurgeons and Radiologists in the Children's Neurosurgery Centre. They also play a key role in after care and support.

Children's Neurological Centre/Services. This Centre or Service may also be the point of specialist advice following the initial presentation or involved in support of specialist paediatrics to agree a diagnosis. They also play a key role in after care and support.

Children's Neurosurgery Centre (CNC). The CNC has 24/7 advice and support provided by Paediatric Neurosurgeons (PNs) who can discuss diagnosis and treatment plans with clinicians in the network. They will undertake the neurosurgical procedure and agree the management plan for follow up and after care. They may also seek the support of clinical and behavioural psychologists.

Principal Treatment Centres for Children's Cancer (PTC). The Paediatric Oncologist (who has received appropriate training in the management of brain tumours) and the multidisciplinary team will be involved in agreeing the management plan for children with brain cancer, together with the PNs. They will be integral to the monitoring and review of the treatment plan and the child's after care and support.

Trauma Unit. When a child has been involved in an accident, this unit, which is part of the Major Trauma Network, may be responsible for stabilising the child's condition, undertaking urgent scans, discussing treatment plans with the Major Trauma Centre (MTC)

Major Trauma Centres (MTC) and/or Children's MTC. These are the Major Trauma Centres (MTC) in the Trauma Network. In some places they will be combined caring for adults and children, and in others they will be dedicated children's services. There will be a trained trauma team present 24/7. They will assess, investigate, stabilise and prioritise the treatments required and agree the immediate and ongoing management of head injuries with the PNs.

Adult Neurosurgical Centre (ANC). These centres have an important role to play in the delivery of care for children with neurosurgical conditions: they will admit and treat children with life-threatening emergency conditions in discussion with the PNs. After life-saving surgery, the child will be transferred to the lead Children's Neurosurgery Centre. They will also play a key role in the transition to adult services.

Rehabilitation. The comprehensive multidisciplinary assessment starts in the CNC, and includes a holistic goal setting approach with individually designed programmes focussing on specific, physical, cognitive, and behavioural function. This may include services provided in a rehabilitation centre and service provided in the community based around the child's home and school.

1. Does the proposal make adequately clear the separate and distinct roles for:
 - specialist district general hospitals Yes/No/Don't know
 - specialist paediatricians Yes/No/Don't know
 - children's neurological services Yes/No/Don't know
 - children's cancer and oncology services Yes/No/Don't know
2. What is not clear?
 - specialist district general hospitals
 - specialist paediatricians
 - children's neurological services
 - children's cancer and oncology services

A Paediatric Neurosurgeon is defined within the proposed standards document (G1) and is a consultant neurosurgeon who has undertaken a one-year GMC recognised Fellowship in a recognised paediatric neurosurgical centre as recommended in *Safe Paediatric Neurosurgery* (2001). If accepted, this standard will be applied to all new appointments, and it is recognised that some existing consultants with substantial paediatric practice may not have undertaken formal fellowships. A substantial proportion of the consultant's job plan (minimum of 50% or 5 PAs) should be allocated to paediatric neurosurgery and there should be evidence of regular Continuing Professional Development (CPD) in paediatric neurosurgery.

It is recommended that this should translate into being involved in approximately 80 operative cases per year on children, *although it is accepted that this individual operative workload may vary within a Children's Neurosurgery Centre (CNC) team according to particular paediatric or adult sub-specialist interests.*

3. Do you agree with the proposed definition of a paediatric neurosurgeon?

Yes/No/Don't know

4. Do you want to comment on the definition?

24/7 Specialist cover

5. Do you support the proposal that a rota of named consultant paediatric neurosurgeons must be available for advice, care and support to each network of referring hospitals on a 24/7 basis?

Yes/No/Don't know

6. Do you support the proposal that each network of referring hospitals and the named consultant paediatric neurosurgeon must be able to transmit and receive real time brain scans/imaging on a 24/7 basis?

Yes/No/Don't know

7. Do you think that the network proposals will improve access to services for parents in an emergency?

Yes/No/Don't know

8. Do you think that the proposals will improve access to services for parents to obtain earlier diagnosis and treatment for their children?

Yes/No/Don't know

Patient-held records

9. Do you think that parents should be provided with summary records and scans of the child's condition?

Yes/No/Don't know

10 Please rank your preferred methods for doing this? (put your most preferred method first and so on)

- ☐ Paper files
- ☐ A computer memory stick
- ☐ A data file on your mobile phone
- ☐ A secure computer link

Care Quality Assurance

It is proposed to develop an outline assessment process for Children's Neuroscience Networks (CNNs), based on the draft criteria within the Steering Group documents, with a view to creating a measurable, transparent framework by which future CNNs can be judged. This should be completed by summer 2012.

This will be assessed and 'peer reviewed' by clinicians of CNNs recognising that such approaches have a proven track record in contributing to improvements in clinical practice across different organisations.

11. Do you agree that networks should each provide data on the outcomes of their treatment and care within a national framework and definitions, so that comparisons can be made?

Yes/No/Don't know

12. Do you agree with the proposal for networks to use self-assessment followed by peer review, as the main way of ensuring treatment and care quality standards?

Yes/No/Don't know

13. What, if any, are your concerns with this approach to ensuring high standards of treatment and care?

14. Should referral policies and pathways for key conditions be the same for all networks nationally or should there be freedom to design these locally? Please indicate which you believe to be the correct balance.

Referral policies and pathways should....

- be identical for all networks nationally
- be mostly the same with only minor variation locally where necessary
- be based upon national approaches but adjusted to local circumstances
- be determined mostly by the local network, with reference to others' nationally
- be determined by the circumstances in each local network

Arrangements between Networks

Trauma Unit When a child has been involved in an accident, this unit, which is part of the Major Trauma Network, may be responsible for stabilising the child's condition, undertaking urgent scans and discussing treatment plans with the MTC.

Major Trauma Centres (MTC) and/or Children's MTC. These are the Major Trauma Centres (MTC) in the Trauma Network. In some places they will be combined, caring for adults and children, and in others they will be dedicated children's services. There will be a trained trauma team present 24/7. They will assess, investigate, stabilise and prioritise the treatments required and agree the immediate and on-going management of head injuries with the Paediatric Neurosurgeons (PNs).

15. Should Children's Neuroscience Networks (for the Neurosurgical Child) provide real time advice and support by a consultant paediatric neurosurgeon to the major trauma networks for children in your location?

Yes/No/Don't know

16. What local difficulties are you aware of, in achieving this?

Arrangements within Networks

Children's Neuroscience Networks need to have:

- clear governance structures supported by agreements with participating organisations;
- an identifiable management team and support for the network provided by an NHS Trust with a Children's Neurosurgical Centre;
- clinical leaders with defined roles, responsibilities and accountabilities either for the network overall or for clinical pathways or subspecialties across the network;
- active user involvement;
- robust clinical governance arrangements;
- processes to achieve excellence, including assessment and review against standards, shared policies and guidelines, audit;

- research, training and development, including supported continuing professional development processes and a programme of shared learning across the organisations.

17. In a network where there is more than one Children's Neurosurgery Centre, is it important to have clearly identified leaders?

Yes/No/Don't know

18. Would it be beneficial to have identified leaders for each pathway such as for children with tumours or with hydrocephalus?

Yes/No/Don't know

19. Why do you think this?

Commitment and implementation

There will be a national review of all network and clinical leadership proposals to ensure 'best fit' with national policies and criteria; to ensure appropriate access is available across all children's neurosurgical services, and to assess the impact these proposals may have on other linked services and networks such as trauma and cancer.

Subject to legislation, the implementation of network proposals and plans will be overseen by the NHS Commissioning Board and local development priorities will be agreed within the commissioning framework developed for these services.

20. Do you believe that a managed network which coordinates all health services will improve the quality of care provided to patients in your region?

- ☐ Significantly improve care
- ☐ Somewhat improve care
- ☐ No effect either way
- ☐ Some risk to quality of care
- ☐ Significant risk to quality of care

21. Do you agree the proposed implementation process for establishing networks?

Yes/No/Don't know

22. How long will it be before the network is fully implemented in your region?

- 2 years
- 3 years
- 4 years
- Longer than 4 years
- Don't know