

Specialised Services

CHILDREN'S NEUROSCIENCE NETWORKS (FOR THE NEUROSURGICAL CHILD):

A FRAMEWORK FOR SERVICES IN ENGLAND

STEERING GROUP REPORT

FEBRUARY 2012

EXECUTIVE SUMMARY

The provision of children's neurosurgical services is not only about neurosurgeons, but also about a wide ranging team of people with skills and expertise to support the individual child and their family in a caring atmosphere that creates confidence and safety for that child and their family. These services need to work together for the emergency or urgent condition but they also need to provide care and support to the child and their families for long term conditions such as hydrocephalus and spina bifida. It is because of this wide ranging diversity of professions who are involved in the care of these children, the term 'neuroscience' - rather than 'neuroscurgery' - is more appropriately used in this document.

Families expect care to be as local as possible, so that they can manage as best they can the challenges of long hospital stays whilst trying to maintain some stability for the rest of the family. Families also expect to be able to access the 'best there is' for very rare conditions that may only affect a handful of children every year. This is why the NHS in England proposes that the surgical care of some of these very complex conditions, (a very small proportion of all children's neurosurgical procedures) should be concentrated in a smaller number of units than is presently the case.

There are key points from the review of current services (Steers and Stower report September 2010) that support the need for change and these issues were reinforced by parents, carers and their representatives:

- There is considerable variation in the infrastructure, resources, people and skills for these services across the country and this includes variability in access and support along the pathway for different conditions from local hospitals, emergency departments, diagnosis, imaging, the care environment, accommodation and support for families.
- A high quality, effective multi-disciplinary team (MDT) is a crucial factor for services. Paediatric MDTs for both formal meetings and the wider MDT for the whole pathway of care from the initial concern raised by parents, through assessment, diagnosis, treatment and after care, all of this requires an enormous range of expert professional skills and these are essential for a 'world class' service.
- Rehabilitation and re-ablement services emerge as a priority for the future and it is included as a key area in the exemplar pathways and standards. However, current services are variable and patchy within the different geographical areas around the country, and this was identified as a significant area of need by wide ranging groups of clinicians and parents of clinicians and parents

Some of the clinical evidence supporting the need for change includes:

- There tends to be a longer time between the onset of symptoms and diagnosis of brain tumours than other childhood tumours^{1, 2}
- The resection rate for some tumours is lower in the UK than international centres of excellence.³
- 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.⁴
- International evidence exists to suggest centres performing more ventricular shunt procedures have better outcomes than lower volume centres.⁵
- Shunts performed by a consultant out-of-hours fare better than those performed by a trainee⁶
- The 30 day shunt revision rate in the UK may be higher than international centres of excellence⁷
- 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: from between 8.1% in some units and 18.8% in others.⁸
- Wide variation is reported in the process of care for children with severe traumatic brain injury, with potential impacts on survival.⁹
- Internationally, lower mortality rates have been demonstrated for children with traumatic brain injury treated in paediatric trauma centres than for those treated in adult trauma centres.¹⁰

The NHS recommends that children should expect to be treated by a paediatric-trained neurosurgeon, with access to care, advice and support *24 hours a day, 7 days* a week. The recent NHS Clinical Advisory Group guidance for the Management of Children with Major Trauma¹¹, sets out the expectations for children's neurosurgery in providing care and support to the child with a major head injury, that paediatric neurosurgical consultants should be available for consultation and care to the Trauma Network 24/7. This rota for advice and care should be widely available throughout the network of referring hospitals and clinicians caring for children with the other wide ranging neurosurgical conditions.

The NHS recommends that the service in the future needs all parts of the care system to work closely together in a managed network in order to make the best use of rare specialist expertise, standardising care, improving access, and reducing any distance delay effects that can result from the concentration of specialist services in large centres. These networks should be called 'Childrens Neuroscience Networks' (for the neurosurgical child) (CNNs) and together, those working in the network, can improve services and share learning. The networks must provide coherence and integration from the parent and family perspective,

¹ Wilne S.H. et al, 2006. The presenting features of brain tumours: a review of 200 cases. Archives of Disease in Childhood, 91, pp. 502-506.

² Wilne S et al, 2007. Progression from first symptoms to diagnosis in childhood brain tumours: A multicentre study. Archives of Disease in Childhood, 92(Suppl.1), p.A69.

Bouffet E., 2007. Recent advances in ependymoma management. Liverpool ISPN.
 Paediatric Neurosurgery Evidence National Specialised Commissioning 2011

⁵ ibid (4)

Richards H, et al 2009. Who should perform shunt surgery? Data from UK Shunt Registry. Cerebrospinal Fluid Research, 6(Suppl 1), p.S31

⁷ Paediatric Neurosurgery Evidence, National Specialised Commissioning 2011

⁸ Tasker R.C., Fleming T.J., Young A.E.R., Morris K.P., Parslow R.C., 2011. Severe head injury in children: intensive care unit activity and mortality in England and Wales. British Journal of Neurosurgery 25, pp.68-77.

⁹ Morris K.P.et al (2006) UK Paediatric Traumatic Brain Injury Study Group intra-cranial pressure complicating severe traumatic brain injury in children: monitoring and management. Intensive Care Medicine, 32, p1606-1612

¹⁰ Paediatric Neurosurgery Evidence National Specialised Commissioning 2011

¹¹ Management of Children with trauma NHS Clinical Advisory Group Report 2011 http://www.excellence.eastmidlands.nhs.uk/welcome/improving-care/emergency-urgent-care/major-trauma/nhs-clinical-advisory-group/

from presentation, diagnosis, treatment, after care and finally ongoing support at home and at school. Whilst the best management of the condition is paramount, the impact on the child and the consequence for the family should not be forgotten and should therefore form an integral part of the therapeutic package for the family.

In proposing managed Children's Neuroscience Networks (CNNs) are the vehicles for change and developing these services; they will need to demonstrate that they can provide: a management structure for the network, user involvement, excellence in clinical practice, supported by research training and development. It is envisaged that there will need to be a number of networks who meet the geographical and service criteria described in this document, across England. All centres and services that are currently part of delivering neurosurgical care to children will be involved. CNNs will involve at least 2 children's neurosurgical centres working closely together and in this situation one will take the a management role for the network supported by clinical leaders from the Children's Neurosurgical Centres (CNC) and/or clinical leaders who are responsible for specific pathways or subspecialties across the network. Some children's neurosurgical services, such as the very rare brain cancers and complex epilepsy surgery in younger children, will require these networks to work together over a wider geographical area.

CNNs will need to provide the infrastructure which brings all the component parts of the service together in a collaborative rather than a competitive way. Although there will be a national model for children's neurosurgical services underpinned by a framework of standards for commissioning services, the delivery of the model will lead to different configurations depending on local circumstances and therefore CNNs need to be established as a 'best fit' for local people.

This framework document builds on work undertaken with professional associations, clinicians, charities, parents and families over the past 2 years. Over the summer 2011, it has been distributed to professional associations involved who sought the feedback of their members, and their views have been incorporated into this latest version of the document and the service specification standards.

There is ongoing work with the professional associations to develop an outline assessment process for CNNs, based on the draft criteria in this document and the standards document, with a view to creating a measurable, transparent framework by which future CNNs can be judged. This should be completed by summer 2012. The Steering Group and professional associations have supported the proposal to use 'peer reviews' of CNNs with clinicians recognising that such approaches have a proven track record in contributing to improvements in clinical practice across different organisations. Prior to network 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 would be agreed within the commissioning framework developed for these services.

1. INTRODUCTION

Around 4,200 paediatric neurosurgery operations are performed in England each year, of which 70% are emergency and 30% are elective. Most emergency operations are performed on children with hydrocephalus, head injury or brain tumours. Hydrocephalus accounts for about 1,700 procedures each year and central nervous system tumours, craniofacial disorders and epilepsy each account for about 400 cases every year. The remaining caseload comprises children with spinal dysraphism and other disorders.

There are currently 14 NHS hospitals in England recognised as providers of paediatric neurosurgery. Most of these operations are carried out by trained paediatric neurosurgeons or neurosurgeons with a paediatric interest. However, they are mostly based in general neurosurgical centres and only 5 centres in England have a dedicated paediatric neurosurgery consultant rota. Others rely on joint rotas with emergency competent adult surgeons.

The NHS proposes that in the future there will be a number of Children's Neuroscience Networks (for the neurosurgical child) (CNN) across England who meet the geographical and service criteria described in this document. These will comprise at least two Children's Neurosurgical Centres (CNC), one of which will be responsible for the management role for the network supported by clinical leaders from the CNC and/or clinical leaders who are responsible for specific pathways or subspecialties across the network. This document explains the proposed network model of care.

2. BACKGROUND

Safe and Sustainable (within the National Specialised Commissioning Team), has been working on a review of paediatric neurosurgical services in England on behalf of the NHS Medical Director and the ten Specialised Commissioning Groups since 2009. The review was commissioned to address three key concerns:

- Children's neurosurgical services have developed in England but in an ad hoc way with no strategic oversight for this specialty service nationally.
- Children and their families expect a 'world class service' for the challenging conditions these children have and current services are not sustainable nor able to meet future requirements and developments in the field, and may not be able to match the best outcomes when compared internationally.
- Few of the current children's neurosurgical services are able to provide access to specialists 24/7.

The provision of children's neurosurgical services is not just about neurosurgeons, but about a wide ranging team of people with skills and expertise to support the individual child and their family in a caring atmosphere that creates confidence and safety for that child and their parents.

Part of the challenge for these services is their complexity; they need to work closely with the different services that come together to care for a child with a Traumatic Brain Injury (TBI) on the one hand, whilst also meeting the requirements for the different services that come together to care for a different child with a brain tumour. They also need to provide care and support to the child and their families for 'life time' conditions such as hydrocephalus and spina bifida, and the challenges for emergencies, urgent and elective care - 24/7. Families expect care to be as local as possible, so that they can manage as best they can the challenges of long hospital stays whilst trying to maintain some stability for the rest of the family. Families also expect to be able to access the 'best there is' for very rare conditions that may only affect a handful of children every year

Throughout the review, the aim has been to combine clinical evidence of best practice, expert advice from clinical leaders in the field, with national policies and guidelines on standards in the key areas such as children's cancer. This has been brought together with the insights of parents of children who have experienced brain or spinal cancer, brain trauma and conditions such as epilepsy, hydrocephalus and spina bifida, as well as the views of clinicians in the fields of neuroscience, paediatric medicine and rehabilitation in order to provide a framework and strategy for developing these services in England for the future.

The review has been developed and managed through a Steering Group comprising the relevant professional associations and lay people, a Standards Writing Group - who have produced and tested draft service standards, and a Models of Care Group who have further tested and developed care pathways and best practice for some conditions. Committee memberships and minutes from all these meetings can be found on the specialised services - safe and sustainable children's neurosurgery section of the website.¹²

12 http://www.specialisedservices.nhs.uk/safe_sustainable/childrens-neurosurgical-services

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3. LINKS TO NATIONAL POLICY

The NHS White Paper *Equity and Excellence - Liberating the NHS* (2010)¹³ explained that all NHS services must be focused on outcomes and the quality standards that deliver them. The focus to reduce mortality and morbidity, increase safety, and improve patient experience and outcomes for all is the basis of the NHS Outcomes Framework 2011/12¹⁴ which is developed to provide that national level accountability for the outcomes that the NHS delivers; to provide a national level overview of how well the NHS is performing, wherever possible in an international context; and to act as a catalyst for driving quality improvement and outcome measurement.





The 'duty of quality' is set out in figure 1: The NHS Commissioning Board will commission the National Institute for Health and Clinical Excellence (NICE) to develop Quality Standards (2) which will set out the evidence-based characteristics of a high quality service for a particular clinical pathway or condition. These standards will, where appropriate, look across several or all five domains of the NHS Outcomes Framework. Drawing on these Quality Standards, the NHS Commissioning Board will translate the national outcomes into outcomes and indicators that are meaningful at a local level in the Commissioning Outcomes Framework (3).

 The NHS White Paper Equity and Excellence - Liberating the NHS 2010 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353
 NHS Outcomes Framework 2011/12

 $http://www.dh.gov.uk/en/Publications and statistics/Publications/PublicationsPolicyAndGuidance/DH_122944$

In this way this document 'Children's Neurosurgical Services in England - A Framework for the Future' and the associated standards document for children's neurosurgery services, sits across all domains of the outcomes framework and will provide best practice for commissioning these services.

Considerable progress has also been made nationally in describing and developing networks for paediatricians and specialist paediatricians, neonatologists and neurologists. All these (trauma, cancer, paediatrics, neurology), provide essential elements to build on for the future.

The document on the future of children's health services produced by the Royal College of Paediatrics and Child Health¹⁵ identifies the challenges for specialist paediatric services describing the widespread support amongst paediatricians for greater cooperation between teams and organisations working in a geographical area. This includes sharing clinical protocols, working in managed networks and rotating staff between services.

Defining the specialties that need 24/7 hands-on consultant delivery and developing better on-call consultation. All these services are also essential components for children's neurosurgical services as in many instances local paediatric services, specialist paediatric services and or paediatric neurologists are essential at the early presentation of the condition, and involved in supporting the longer term conditions, preventing or minimising complications and supporting after care.

There are other imperatives that have considerable impact on children's neurosurgery services. The recent NHS Clinical Advisory Group guidance for the Management of Children with Major Trauma¹⁶ builds on the earlier NHS report on regional networks for major trauma¹⁷ and sets out the expectations for children's neurosurgery in providing care and support to the child with a major head injury. Most importantly that paediatric neurosurgery consultants should be available for consultation and care to the Trauma Network 24/7 and should be involved in creating a management plan for children with severe head injury together with a consultant in paediatric intensive care within one hour of CT imaging.

All the specialist centres and units contributing to the network of care for children with brain tumours have an obligation nationally to comply with the NICE Children and Young People with Cancer Improving Outcomes Guidance (CYPIOG).¹⁸ This is essential for units delivering any aspect of treatment/care (diagnostics, surgery, chemotherapy, radiotherapy, supportive care) to children with these conditions and is subject to cancer Peer Review against the children cancer measures arising from the IOG. Progress against these measures are published annually as part of the National Cancer Peer Review Programme.¹⁹

19 An overview of the findings from the 2009/2010 National Cancer Peer Review of Cancer Services in England National Cancer Action Team Report 2009/2010

¹⁵ Modelling the Future, A consultation Document on the future of children's health services - Royal College of Paediatrics and Child Health September 2007

¹⁶ Management of Children with trauma NHS Clinical Advisory Group Report 2011 http://www.excellence.eastmidlands.nhs.uk/ welcome/improving-care/emergency-urgent-care/major-trauma/nhs-clinical-advisory-group/

¹⁷ Regional Networks for Major Trauma NHS Clinical Advisory Group Report September 2010 http://www.excellence.eastmidlands. nhs.uk/welcome/improving-care/emergency-urgent-care/major-trauma/nhs-clinical-advisory-group

¹⁸ National Institute for Health and Clinical Excellence 2005 Improving Outcomes in Children and Young People with Cancer

3. THE CASE FOR CHANGE

3.1 The current service

There are 14 Children's Neurosurgery Centres (CNC) in England:



In 2010, each of the 14 paediatric neurosurgical centres submitted detailed information about the service they provide and this was followed by centre visits by Mr James Steers, retired neurosurgeon and past president of the Society of British Neurological Surgeons, and Sharon Stower, senior children's nurse representing the Royal College of Nursing. The purpose of these visits was to clarify the information provided by the centres, understand policies, procedures and ways of working, gather evidence of good practice relating to patient/family centred care including support services, environment and facilities, and identifying the range of paediatric expertise linked to the service and the networks of care. This information is available in a separate report.²⁰

20 Safe and Sustainable Paediatric Neurosurgery -Report of the Unit Visits Mr. James Steers and Ms Sharon Stower September 2010 The following table shows the activity undertaken by each of the children's neurosurgery centres, this is based on the audit undertaken by British Paediatric Neurosurgical Group²¹, it uses data from 2008-09 and is annualised. There are (approximately) 4,200 neurosurgical procedures performed each year in England. The activity is grouped into categories for *'Major'* (for example craniotomies, spinal fixations and cranioplasty); *'Moderate'* (for example burr hole surgery and shunts; and *'Minor'* (for example shunt removal and intra cranial pressure monitoring).

- Units performing more than 300 cases each year are: Great Ormond Street, Liverpool, Birmingham, Bristol, Manchester and Kings College Hospital.
- Units performing between 200-300 cases each year are: Oxford, Nottingham, Leeds and Cambridge; and
- Units performing under 200 cases each year are: Sheffield, Southampton, Newcastle and St George's.



Childrens Neurosurgery Centre

However, in summary the following conclusions are made in the Steers and Stower report:

- There is considerable variation in the infrastructure for these services across the country and this includes variability in access and support along the pathway for different conditions from local hospitals, emergency departments, diagnosis, imaging, the care environment, accommodation and support for families, training for staff, rehabilitation and after care. Some variation in the infrastructure (people, skills, buildings, linked services) is inevitable, but children and their families should expect a 'child friendly' environment with room for the families to be at the bedside, room for play and a room for privacy when difficult discussions concerning their child need to take place.
- To improve children's neurosurgical services for the future, 24/7 advice and care from a paediatric neurosurgeon needs to be available across a network. Five units provide a 24/7 paediatric neurosurgical on call rota; three units where cover for paediatric neurosurgery relies on adult neurosurgeons who have an 'official' written rota for the available paediatric neurosurgeon. Seven units have no identifiable rota for paediatric neurosurgery relying on the on call adult neurosurgeon to find/ contact an available paediatric neurosurgeon when necessary. This means that clinicians from outside hospitals are disadvantaged if an urgent discussion about a child or young person is required.
- Paediatric neurosurgery throughout the UK has not been planned systematically and has developed incrementally. The visits highlighted the different ways in which units are resourced both in terms of structure and personnel. There are key elements which must be the foundations for a world class service for the future:
 - The development of an academic paediatric neurosurgical structure;
 - Opportunities for continuing professional development (CPD) in all units;
 - Consistent approaches to Specialist Registrar (SpR) training which provide sufficient experience;
 - Formally recognised training in paediatric neurosurgery in the UK.
- A high quality, effective multi-disciplinary team (MDT) is a crucial factor for services and parents reinforced this. Paediatric MDTs for both formal meetings and the wider MDT for the whole pathway of care from the initial concern raised by parents, through assessment, diagnosis, treatment and after care, all of this requires an enormous range of expert professional skills and these are essential for a 'world class' service.

'Whilst there is not yet consensus on the future shape of paediatric neurosurgical services in England, it is clear that there is broad agreement on the need to seize the opportunity that the Safe and Sustainable review provides for addressing longstanding areas of concern and debate'

REPORT OF MR JAMES STEERS AND SHARON STOWER, 2010

3.2 Clinical evidence for change

This review has generated widespread and variable comments from different clinicians.

Many clinicians agree that a strategic framework for the service is necessary in order to:

- *improve* the care and safety provided for children,
- *improve* the experience those children and their families have from the point of the initial concern, diagnosis, through to aftercare (including rehabilitation) and support at home.
- *improve* the outcomes of care through the robust collection of nationally agreed information.

Clinicians also support the fact that services need to be 'world class' and that services can improve on what is offered to children and families now. They have spent considerable time reviewing evidence and developing standards which will be the foundation of improvements in service quality. It is fundamental that any change is managed carefully so as to avoid destabilising care, harnessing improvement approaches which introduce systematic and incremental change, whilst transforming parent and family experiences along the whole pathway and system of care.

A number of reviews have examined the relationship between hospital and/or physician volume and outcomes, demonstrating an association between high volume and better outcomes for a range of procedures and conditions, but this evidence is more marked for more high-risk procedures including surgery for pancreatic and oesophageal cancer, abdominal aortic aneurysms and paediatric cardiac surgery²². The Department of Health (DH) document *Commissioning Safe and Sustainable Specialised Paediatric Services*²³ states that centres providing specialised paediatric services must have a sufficient volume of specialised care to ensure that they can provide sustainable and comprehensive support services.

The clinical evidence has been summarised in a separate document.²⁴ It has been shared with clinical members of the various working groups, the challenge has been in the interpretation of the published data taking account of the very different contexts of children's neurosurgical services in this country or internationally.

From the evidence the following conclusions can be drawn:

- There tends to be a longer time between the onset of symptoms and diagnosis of brain tumours than other childhood tumours.^{25, 26}
- That the resection rate for some tumours is lower in the UK than international centres of excellence.²⁷
- That 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 this²⁸
- International evidence exists to suggest centres performing more ventricular shunt procedures have better outcomes than lower volume centres.²⁹

²² Halm E.A., Lee C., Chassin M.R., Is Volume Related to Outcome in Health Care? A Systematic Review and Methodological Critique of the Literature. Annals of Internal Medicine 2002; 137: 511-520.

²³ Department of Health, Commissioning Safe and Sustainable Specialised Paediatric Services: A framework of Critical Inter-Dependencies, August 2008

²⁴ Paediatric Neurosurgery Evidence National Specialised Commissioning 2011

²⁵ Wilne S.H. et al, 2006. The presenting features of brain tumours: a review of 200 cases. Archives of Disease in Childhood, 91, pp. 502-506.

²⁶ Wilne S et al, 2007. Progression from first symptoms to diagnosis in childhood brain tumours: A multicentre study. Archives of Disease in Childhood, 92(Suppl.1), p.A69.

²⁷ Bouffet E, 2007. Recent advances in ependymoma management. Liverpool ISPN.

²⁸ Paediatric Neurosurgery Evidence National Specialised Commissioning 2011

²⁹ Ibid (28)

- That shunts performed by a consultant out-of-hours fare better than those performed by a trainee³⁰
- That the 30 day shunt revision rate in the UK may be higher than international centres of excellence³¹
- 1 in 10 admissions for children to an intensive care unit with traumatic brain injury has a fatal outcome. Outcomes across England and Wales varies considerably for these severe cases: from between 8.1% in some units and 18.8% in others.³²
- Wide variation is reported in the process of care for children with severe traumatic brain injury, with potential impacts on survival.33
- Internationally, lower mortality rates have been demonstrated for children with traumatic brain injury treated in paediatric trauma centres than for those treated in adult trauma centres34

The experience of parents and carers 3.3

Understanding more about the experience that parents, carers and their representatives have had of services has been undertaken in two main ways. Firstly, parents were interviewed on an individual basis or in small focus groups at each centre as part of the centre visits. This information was thematically analysed and reported by Robert Hughes, Chairman of the Charity, Anna's Hope, and Steering Group member, in July 2010. Secondly, using the exemplar pathways developed by the Models of Care Group, these themes were tested with parents in a series of six regional workshops that took place in November 2010, engaging participants with the review, its progress, and the developing pathways and drawing upon their experience and insight to help design safe and sustainable neurosurgical services for children for the future.

This important work is available in two separate reports^{35, 36} and some key points are reflected below:

- Specialist treatment, knowledgeable support and advice are highly valued by parents. The support and advice needs to be accessible by phone 7 days a week for parents and 24/7 for professionals working in local health services.
- The importance of local care, where possible.
- Providing fast access this is about providing information to by-pass local gatekeepers when necessary because parents are trusted, their child's records are 'red-flagged' or they have their own electronic copy of records, and scans.
- Being known and trusted is a vital two-way part of the relationship between a family and an excellent service provider.

Richards H, et al 2009. Who should perform shunt surgery? Data from UK Shunt Registry. Cerebrospinal Fluid Research,

³⁰ 6(Suppl 1), p.S31.

Paediatric Neurosurgery Evidence National Specialised Commissioning 2011 31

Tasker R.C., Fleming T.J., Young A.E.R., Morris K.P., Parslow R.C., 2011. Severe head injury in children: intensive care unit activity 32 and mortality in England and Wales. British Journal of Neurosurgery 25, pp.68-77

³³ Morris K.P.et al (2006) UK Paediatric Traumatic Brain Injury Study Group, Intracranial pressure complicating severe traumatic brain injury in children: monitoring and management. Intensive Care Medicine, 32, pp.1606-1612

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³⁵ Emerging themes on the pathway design based on patients' and parents' experiences

http://www.specialisedservices.nhs.uk/library/31/15_July_2010_Parent_and_patient_experiences_paper_1.pdf Report from Regional Charity/parent Workshops November 2010 36

http://www.specialisedservices.nhs.uk/library/31/Regional_ParentCharity_Workshops___November_2010.pdf

- There are several crucial transition stages in most family's experiences:
 - From noting symptoms to finding a diagnosis,
 - Diagnosis to treatment options and perhaps surgery,
 - Managing frequent and/or long periods of treatment in hospital,
 - Transition into care at home.

These can be complex and parents need information, participation and a key worker to help them negotiate and co-ordinate these complex changes.

• Essentially parents were reflecting the challenges posed by three stages along the pathway of care (Figure 2)³⁷; from presentation through to initial diagnosis and treatment; living with the on-going condition and the repeat cycles necessitating further identification, assessment and treatments preventing other complications; and the transition either back to normality, through to adult services or sadly death.



Figure 2: Diagrammatic representation of a pathway illustrating three stages, an initial pathway, a cyclical pathway and a transition pathway.

37 Child Health Services in Europe, Wolff I ed. (anticipated publication date 2011), Chapter: Integrated care, informatics and improvement for children's services, Lenton S, European Public Health Observatory

4. DEVELOPING STANDARDS

The more detailed work on developing standards and pathways has been entirely reliant on clinicians from wide ranging professional bodies. They have led the work at every level in particular:

- Lead clinician(s) chaired the Standards Group and led the development of the standards.
- They led the fact finding visits to every centre.
- They contributed to the development of sub-specialty papers identifying best practice for the Models of Care, published evidence and the development of pathway principles for epilepsy, hydrocephalus, trauma, tumours and spinal dysraphism.
- They presented key evidence and findings to the Models of Care group's consideration.
- Lead clinicians supported the regional workshops for charities, parents and carers.
- They drafted the key areas of care documents for each specialty and commented frequently on their iterations and development.

The standards are broken down into key areas relating to the following:

Α	The network approach			
В	Making choices			
С	The patient and family experience			
D	Access to services			
Ε	Age appropriate care			
F	Prenatal Screening			
G	Excellent Care			

The standards are prioritised by importance for implementation in the networks and include best practice principles for the pathways of care for epilepsy surgery, hydrocephalus, brain tumours, brain trauma and spinal dysraphics.

This work was discussed further in November 2010 in a workshop for over 200 clinicians including specialist nurses, anaesthetists, ambulance staff, neurosurgeons, paediatric neurologists, paediatric intensive care unit (PICU) staff, therapists, theatre staff, radiologists and oncologists. One of the aims of the workshop was to seek input and contributions to the development of this work on brain trauma, brain tumours, epilepsy and hydrocephalus and explore other aspects of service development and provision such as networks for paediatric neurosciences, education and training, research and development, audit and outcome measures. All comments from the workshops were reviewed by the Models of Care Group and comments have been taken into account in the subsequent work.

Throughout the review rehabilitation and re-ablement services emerge as a priority for the future and it is included as a key area in the exemplar pathways and standards. However, current services are variable and patchy within the different geographical areas around the country. This was identified as a significant area of need by wide ranging groups of clinicians during the site visits. Rehabilitation and re-ablement should be an integral part of the planning process for the managed care of the injured child, and for children with other neurosurgical conditions. Social, behavioural, mental health and educational needs of the child must be explicitly addressed in designing services for children as well as the needs of families especially where the child has ongoing complex healthcare needs or requires palliative care.

As part of developing the work for the Standards Group and Models of Care the National Specialised Commissioning Team commissioned a review of acquired brain injury in children including rehabilitation models and systems of care³⁸. Rehabilitation services described in the literature mostly appear successful and have been designed around five key principles:

- a systematic approach for delivering the service
- a philosophy of enhanced participation in line with WHO concepts of disability
- high levels of communication, coordination and clarity of roles within the team
- a focus on the needs of families and the future educational potential of children
- formal evaluation of the service and a desire to improve the quality of care

This includes: comprehensive multidisciplinary assessment; a holistic goal setting approach with individually designed programmes focussing on context specific physical, cognitive, and behavioural function; strong links to outside agencies, particularly in the education and social care sectors, especially where there are safeguarding concerns. Important components specific to the rehabilitation of children include programmes that focus on memory and behavioural problems (including long lasting and severe problems that may need inpatient care), education liaison and outreach services, and programmes that target support for families.

This approach provides a rehabilitation framework for the future and should form part of the network of services for children's neurosurgery and it needs to be a discrete focus for multiagency commissioners of these services in the future.

38 Acquired Brain Injury in Children: A rapid review of post-acute rehabilitation models and systems of care, a literature review to inform policy for commissioning rehabilitation services following traumatic brain injury and neurosurgical procedures in childhood September 2010 Bazian

5. THE MODEL OF CARE -A FRAMEWORK FOR THE FUTURE

The quality of the paediatric neurosurgery service is dependent on a common purpose, values and practice shared between the various multi-disciplinary teams providing care. This purpose is to improve the care and safety for children, to improve the experience that children and their families have of services, and improve the outcome of care. It relies on wide ranging skills and expertise within these different teams.

The model of care for the services is described in the following sections and builds services around the journeys that children and families take through the various services involved, and common journeys are grouped together in pathways that share common components. Each component is delivered by a competent team and these teams work within a managed network striving for continuous improvements in the quality, safety, experience and outcomes of the service they provide. It relies on wide ranging skills and expertise within these different teams.

In developing the model of care, five exemplar pathways were used to describe the various elements of the services that would need to come together initially and these are: oncology, trauma, hydrocephalus, epilepsy and spinal dysraphism (spinal neural tube defects). The services covered are found not just in the specialist centre providing neurosurgery but in paediatric departments, Principal Treatment Centres for children's cancer, neurological centres, behavioural and psychological services, emergency departments, paediatric intensive care units, and diagnostic and imaging departments in a number of different hospitals and trusts across a regional area.

The service in the future needs all the component parts of the care system to work closely together in a managed network in order to make the best use of rare specialist expertise, standardising care, improving access, and reducing any distance delay effects that can result from the concentration of specialist services in large centres. The teams in these networks can actively work together to improve services and share learning. A network is described as a virtual organisation which drives continuous quality improvement; they need to provide coherence and integration from the parent and family perspective, from presentation, diagnosis, treatment, after care and support at home and at school.

The focus on rehabilitation services (as described in the previous section), from both a multidisciplinary perspective in specialised units, the community and schools, reinforces (amongst other things) the need for a systematic approach to delivering rehabilitation services within the network, high levels of communication, continuity, co-ordination and clarity of roles within the team, a focus on the needs of all family members and the future educational potential of children.

In proposing that managed networks are the vehicle for developing the services in the future, providing the mechanisms which brings all parts of the service together in a collaborative rather than a competitive way; it is clear that though there will be a national model for children's neurosurgical services, the delivery of the model will lead to different configurations depending on local circumstances and therefore networks around specialist centres need to be established as a 'best fit' for local people.

6. THE EXEMPLAR PATHWAYS AND AREAS OF CARE

Following the clinical workshop in November 2010 where the focus of the discussion was on pathways for brain tumour, brain trauma, hydrocephalus, epilepsy, an additional pathway for spinal dysraphism (spinal neural tube defects) has been developed with a total of 5 exemplar pathways to shape the model of care. Standards have been developed for each describing the key principles and best practice in care in the following domains:

- access,
- the principles of care,
- · diagnosis and assessment,
- the MDT and the management plan,
- Interventions and Procedures,
- · rehabilitation ongoing care and support

These standards are in Appendix A of the Children's Neurosurgery Specification Standards document.

Proposed quality measures are being developed for each pathway in order to support the improvements in service provision. It is important that services in the future can demonstrate continuous improvement in the care and safety provided for children; the experience that children and their families have and the outcomes of care through the robust collection of nationally agreed information. Some measures can be used to demonstrate improvement in the processes of care along the pathways within the networks and would feature as part of a network audit/improvement plan. Other measures are based on the systematic collection of agreed information on morbidity for example and can demonstrate comparative information about children's neurosurgery centres and networks in a way similar to that used by the national cancer programme.

The proposed elements of the service for children's neurosurgery are described in the following sections and are a commitment to the future. It will take a number of years to be realised and progress will be incremental.

7. THE MODEL OF CARE, UNDERPINNING PRINCIPLES

7.1 The network of care

The Children's Neuroscience Network (for the neurosurgical child) (CNN) will have clearly identified clinical leaders responsible for developing and agreeing the pathways of care with their local services. The core aim for these networks is that care and treatment should be provided as close as possible to the child's home, while ensuring the best possible outcome for the child. They will be required to develop formal pathways for paediatric neurosurgical sub-specialties (as described in the Standards document, Appendix A) identifying key processes appropriate to the local network, covering routine, urgent and emergency care, including the critical transition points along the pathway of care. Diagramatic representations of the condition specific pathways are set out within this section and show the complex relationships between the different organisations. It is imperative that there are clear routes into the Children's Neurosurgical Centre's for all emergencies which are clearly understood by all.

The CNN's clinical leaders will be responsible for developing plans for improving skills across the network and demonstrating improved care outcomes in line with national requirements.

The network of care includes:

Obstetricians, Perinatologists and Neonatologists	Involved in investigation, diagnosis and counselling during pregnancy, planning and management of delivery and care of the newborn baby.				
GPs	Plays a key role in the early recognition of the condition, appropriate referral, support and follow up.				
Paediatricians and Specialist Paediatricians in Child Health 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	May also be the point of specialist advice following the initial presentation or involved in support of specialist paediatrics to agree a diagnosis. They may also seek the support of clinical and behavioural psychologists.				
Children's Neurosurgery Centre (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.				
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 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 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 Services	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.

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)³⁹. 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 it is recommended that this should translate into being involved in approximately 80 operative cases per year. It is accepted that this individual operative workload may vary within a CNC team according to particular paediatric or adult sub-specialist interests. There should be evidence of regular Continuing Professional Development (CPD) in paediatric neurosurgery.

It should be noted that all qualified neurosurgeons are competent to undertake life saving care for children in an emergency situation.

39 Safe Paediatric Neurosurgery 2001 – A Report from the Society of British Neurological Surgeons (2001)

		Trauma	Hydrocephalus	Spinal neural tube defects	Tumours	Epilepsy
Obstetricians Perinatologists Neonatologists	 Antenatal investigation and diagnosis. Counselling and planning. Management of delivery and stabilisation and care of newborn. 		~	~		
GPs	 Early presentation of the condition. Longer term condition's. Cycles of care supporting after care. 	V	~	~	~	~
Paediatricians and Specialist Paediatricians in Child Health services in local DGHs	 First point of contact. Initiate further investigations. Advice and support from PNs in CNC after care and support. 	~	v	v	v	v
Children's Neurological Centre/Services	 Point of specialist advice. Support of specialist paediatrics to agree a diagnosis . After care and support. 	~	V	~	v	~
Children's Neurosurgery Centre (CNC)	 24/7 PNs advice and support. Discuss diagnosis and treatment plans with clinicians in the network. Agree the management plan follow up and after care. 	V	~	v	~	v
Principal Treatment Centres for Children's Cancer (PTC)	• Multidisciplinary team agree management plan with the monitor & review treatment plan with PNs after care and support.		V		~	
Trauma Unit	• Stabilise child's condition, urgent scans, discuss treatment plans with the MTC.	~				
Major Trauma Centres (MTC) and/or Children's MTC	• Trained trauma team present 24/7 assess, investigate, stabilise prioritise agree management of head injuries with PNs.	V				
Adult Neurosurgical Centre (ANC)	 Treat children with life- threatening emergency conditions. Key role in the transition to adult services. 	~	~	~		
Rehabilitation Services	 Individual programmes focussed on physical, cognitive, and behavioural functions. A rehabilitation service in CNC and around the child's home and school. 	~	~	~	~	~











7.2 Children's Neuroscience Network (for the neurosurgical child) - The Network Management Role

There are 14 centres currently across the country as described in section 3.1 It is envisaged that there will need to be a number of networks across England each covering a defined population and who meet the service criteria described in this document. CNNs need to involve at least 2 Children's Neurosurgical Centres working closely together so that they can develop shared clinical guidelines and protocols; benefit from shared audit, research, training and development. One of the Children's Neurosurgical Centres (CNC) will take a management role for the network supported by clinical leaders from the network who are responsible for specific pathways or subspecialties across the network.

Children's Neuroscience Networks need to have:

- a) clear governance structures supported by agreements with participating organisations
- b) an identifiable management team and support for the network provided by an NHS trust with a Children's Neurosurgical Centre;
- c) clinical leaders with defined roles, responsibilities and accountabilities either for the network overall or for clinical pathways or subspecialties across the network;
- d) active user involvement;
- e) robust clinical governance arrangements;
- *f*) processes to achieve excellence, including assessment and review against standards, shared policies and guidelines, audit;
- *g)* research, training and development, including supported continuing professional development processes and a programme of shared learning across the organisations.

7.3 Network criteria

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 the range of provision over time, these services might need to be concentrated in one hospital within the network taking account of the skills and experience of the local children's neurosurgical multidisciplinary teams. This needs to be agreed locally within the networks and with service commissioners, taking account of the particular neurosurgical skills and the need to maintain expertise for specialist conditions and avoid occasional practice.

These are the overarching principles of care for services across the network:

- 24/7 advice and support will be provided by Consultant Paediatric Neurosurgeons (PNS) to the relevant regional networks providing care for trauma (Major Trauma Centres and Trauma Units), cancer and other clinical neurosurgical services as required. This information about rotas will be shared widely with services within the network.
- Local referral pathways for urgent review and assessment, diagnosis and treatment need to be developed for each network for each condition, developed by the Clinical Leads in the Children's Neuroscience Network in conjunction with the wider clinicians involved in the care of children and disseminated widely to referring clinicians. However even though there are different specific clinical issues for the different conditions, and complex relationships within the network for these conditions, it is imperative that there are clear routes into the CNC's for all emergencies which are clearly understood by all.
- Networks need to clearly appraise the balance of consultant paediatric neurosurgical skills available to them. They will need to assess the type of procedures being undertaken by the network for the ranges of surgical subspecialties provided and collectively agree how that develops and changes over time to ensure the best service available for their children and families.
- Networks will need to develop plans for training and continuing professional development (of both medical and non-medical staff) which will be agreed by the network and supported by the different organisations.
- The network for care will be underpinned by good communication, co-ordination and clarity of role. These are essential for both clinicians and parents to understand the networks and the relationships for different elements of their child's care. This information should be provided to families.
- Neurosurgical networks should provide agreed hand held records with key information about the child's care. This may include scans and other information where relevant so that parents can provide this in situations, for example family holidays or when problems arise.
- In an emergency and 24/7, a management plan will be agreed with the referring hospital within an hour; and there would be access to emergency procedures undertaken by Consultant Paediatric Neurosurgeons as required according to the needs of the child.
- The management plan is a fundamental part of every child's care and needs to be agreed with the family and shared with them on an ongoing basis as the needs of the child changes. This should include the appropriate prevention of secondary complications for long term conditions such as shunt management and potential behaviour problems associated with brain injury.
- All designated services within the various networks must have an image exchange portal for transfer and remote viewing of scans for specialist advice and support.

- There are good working relations between the Children's Neuroscience Network (CNN) and 'adult' neurosurgery. This is important not only for access to relevant clinical expertise (from the adult to the children's service and vice versa), but also to underpin neuroscience research, and to support the transition to adult services whenever that is appropriate for the child.
- Some rarer and more complex procedures, such as those for some rare brain cancers and complex epilepsy surgery in young children may not be undertaken in every network and therefore will require networks to collaborate across a wider geographical area.

7.4 The Designated Local DGH

These are the overarching principles of care for services for the Designated DGH:

- These services would play a key role in the network and provide a specialist role as first point of access for most conditions. They would have access to 24/7 advice and support from the consultant Paediatric Neurosurgeons (PNS) based in the Children's Neurosurgery Centres (CNC) and from the Children's Neurological Service and network. The nature of the services required for these more specialised DGHs will mean that there will not be one in every local DGH.
- These services would be the local Trauma Unit and part of the paediatric trauma network and would be able to provide appropriate scanning to support initial diagnosis and referral following discussion with Major Trauma Centres (MTCs).
- The lead clinician(s) would play a key communication and coordination role in the networks for cancer, trauma and neurology. They would support the Children's Neurological Centre and CNC and provide appropriate after care and support.

7.5 Children's Neurological Centres and Networks

Childrens Neurological networks are already a fundamental part of the services for children with wide ranging different neurological conditions that don't require neurosurgical input. These networks link to local specialist paediatric services with many specialist children's neurologists providing outpatient clinics locally for children and their families. The proposals in this document strengthen and build on this approach.

These are the overarching principles of care for the Children's Neurological Centres:

- The Children's Neurological Centre will have a specialist role in the network providing diagnosis, expert advice and treatment of a range of conditions. Within any particular neuroscience network there will be Children's Neurological Centres co-located with the CNC and others will not be co-located but will continue to play a key role in providing specialist neurological care. Over time these services will also be co-located with some specialist designated DGHs.
- The Children's Neurological Centre will play a leadership role in the provision of specialised paediatric neurology services across the network, with 24 hour availability of a Consultant Paediatric Neurologist.

- The Children's Neurological Centre would be expected to manage children with most acute neurological disorders not requiring intensive care. Paediatric Neurology input for most would be provided by a combination of 24 hour on-call telephone advices from the linked CNC with a greatly enhanced day-time out-reach service.
- In-patient acute neurological care provided by paediatric neurologists would only be undertaken at the CNCs and some other larger specialist centres.
- The Children's Neurological Centre with be a focus for the multi professional team required to support rehabilitation and would ensure the care is age and needs appropriate managing the transition to adult services when that is most appropriate for the individual and their family.
- The Paediatric Specialist in Neuro-disability with specialist therapists would provide a key role in these services and networks.
- Behavioural and clinical psychological services are important part of the services available to the network both for the specialist interventions at the CNC /Children's Neurological Centre and the more local support for the family.

7.6 Principal Treatment Centres for Children's Cancer

The services that need to come together for the care of the child with brain cancer are many, requiring close co-ordination between the different elements. These include: the Principal Treatment Centres (PTCs) and the Shared Care Units (POSCUS) which may be involved in giving chemotherapy more locally to the child's home. All the specialist centres and units contributing to the network of care for children with brain tumours should comply with the National Institute for Health and Clinical Excellence (NICE) Children's and Young People with Cancer Improving Outcomes Guidance (CYPIOG).⁴⁰ This is essential for units delivering any aspect of treatment/care (diagnostics, surgery, chemotherapy, radiotherapy, supportive care) to children with these conditions and will be subject to cancer Peer Review against the children cancer measures arising from the IOG.

These are the overarching principles of care for Principal Treatment Centres for children's brain cancer:

- The Children's Neurosurgery Centres (CNC) must be co-located with Principal Treatment Centres (PTC) for childhood cancer. In line with the Service Inter-Dependency Framework⁴¹ co-location is essential to provide a full specialised service; otherwise a very close clinical network would be essential.
- Not every Principal Treatment Centres (PTC) would provide care for children with brain cancer. At diagnosis children would be admitted directly from their local hospital to the CNC with its associated PTC for diagnosis and surgery. If there is a more local PTC they would not be admitted there first as this may result in unacceptable delays in care. Once the condition is stable following surgery, children may be transferred from the specialist CNC to a more local PTC for chemotherapy and other treatment.

40 National Institute for Health and Clinical Excellence 2005 Improving Outcomes in Children and Young People with Cancer
 41 Department of Health, Commissioning Safe and Sustainable Specialised Paediatric Services: A framework of Critical Inter-Dependencies, August 2008

- The specialist MDT at the PTC co-located with the CNC would be responsible for the diagnosis, decision making, treatment plan and review for the individual child as well as co-ordinating the provision of the care provided within the network, either with the more local PTC (if there is one) and Shared Care Unit
- For some very rare cancers a regional specialist MDT may be established which operates across a number of networks to agree the decision making, treatment plan co-ordinating monitoring and reviewing the provision of the care.
- The local PTC working with their Children's Neurological Centre would be responsible for the rehabilitation plan for children within their local area.

7.7 Adult Neurosurgery

These are the overarching principles of care for the adult neurosurgery services working closely with children's services. Adult Neurosurgical Centres have an important role to play in the delivery of care for children with neurosurgical conditions:

- The Adult Neurosurgical Centre will admit and treat children with life-threatening emergency conditions where the timing of surgery will improve the chances of a good outcome. The decision to proceed is achieved in discussion with the Children's Neurosurgery Centre (CNC)
- Usually after life-saving surgery the child will be subsequently transferred to the CNC, there may be some circumstances where it is in the child's best interests to stay at the adult neurosurgical centre for some elements of their continuing care.
- All neurosurgeons on the emergency rota should maintain competence in emergency surgery for babies and children requiring such care. Support for the continuous professional development for these surgeons should be provided by the CNC.
- There must be close working relationships between the Adult Neurosurgery Centre and the CNC. Some PNS will also work with adults and this will be formalised in the consultant's job plans. A named Adult Neurosurgeon will be the link with the CNS and vice versa.
- There will clear transition plans for young people moving into adult services with a named neurosurgeon for key conditions.

7.8 Children's Neurosurgery Centre (CNC)

The pathways and services described for in all the diagrams of the services show the key role that Children's Neurosurgery Centres (CNCs) play in the networks for these services.

These are the overarching principles of care for services across the network:

- 24/7 care would be provided by Consultant Paediatric Neurosurgeons. A definition of a Consultant Paediatric Neurosurgeon is someone who spends 50% of time (equivalent to 5 programmed activities) in paediatric neurosurgery. This should translate into being involved in approximately 80 operative cases per year, it is accepted that this individual operative workload may vary within a CNC team according to particular paediatric or adult sub-specialist interests.
- 24/7 advice and support would be provided by Consultant Paediatric Neurosurgeons to the relevant regional networks for trauma, cancer and other clinical neurosurgical conditions as required. In an emergency a management plan would be agreed with the referring hospital within an hour and there would be access to emergency procedures as required according to the needs of the child.
- All new admissions should be seen by a Consultant Paediatric Neurosurgeon within 24 hours of admission and all children requiring neurosurgical input (including ward, HDU and PICU) should be reviewed daily by a Paediatric Neurosurgeon.
- The Children's Neurosurgery Centres (CNC) may have a minimum of 4 such surgeons some of whom may spend 100% of their time in caring for children; others may have a mixed adult and children's practice.
- Trauma and shunt procedures would be core to every Paediatric Neurosurgeon.
- The CNC would provide most surgery but some very specialist tumours or epilepsy surgery for example will take place in a more limited number of more specialised centres.
- The CNC will be co-located with the Children's Neurological Centre supporting the network for children's neurological services.
- The key worker role would be provided by the CNC in order to provide help and support to parents during active treatment for the particular pathway. This support may pass to the PTC or Children's Neurosurgical Centre as appropriate during different phases of the child's care.
- Specialist consultant neuroradiologists are integral to the MDT at the CNC and will be required to support the network advisory role. This needs to be properly resourced within the job plan together with the leadership and professional development roles.
- The CNC would be responsible for providing agreed outcome data for key procedures and responsible for the contribution of the network to national audit. National comparative outcome data analysis will occur on a regular basis as part of the national commissioning process.

7.9 Specialist Neuro-rehabilitation Services

These are the overarching principles of care for these services:

- Rehabilitation and re-ablement services should be an integral part of the planning process for the managed care of the injured child, and for children with other neurosurgical conditions.
- There must be a systematic approach to delivering rehabilitation services with high levels of communication, co-ordination and clarity of roles within and between teams, focusing on the needs of families and the future social and educational potential of children.
- 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 functions.
- There should be a lead consultant in rehabilitation who provides leadership in developing the child's management and rehabilitation plan who also provides advice and support for the care required through the network of services.
- A key worker must be identified within the network providing an important role in supporting children and families and a care package must be identified prior to discharge from the CNC which identifies ongoing care rehabilitation and support in the community around the child's home and school. This might include clinical care at home, information and training for the family, the needs for supporting education, and strategies for learning and concentration.
- Early contact/referrals should be made with local paediatricians, multidisciplinary teams, and GPs so that they can be involved in planning the long-term care.

8. CONCLUSIONS

Doing nothing is not a viable option. This document reminds us that children's neurosurgical services are very complex with areas of care linked to complicated networks such as cancer and trauma. These services need to provide care and support to the child and their families for 'long term conditions' such as hydrocephalus and spina bifida, and the challenges for emergencies, urgent and elective care - 24/7. In the 21st century parents expect that their child can be treated by a paediatric-trained neurosurgeon, with access to care and support 24 hours a day, 7 days a week.

The proposals to establish managed Children's Neuroscience Networks allows these services to continue to evolve within a national framework of standards and approaches. As they do so they will become better at demonstrating improvements in the services' care and safety, the experience children and their families have of the whole pathway of care and improvements in the outcomes of care through the robust collection of national information. They will also clearly appraise the balance of consultant paediatric neurosurgical skills available to them, assessing the type of procedures being undertaken by the network for the ranges of surgical subspecialties provided and collectively agree how that develops and changes over time to ensure the best service is available for their children and their families.

Children's Neuroscience Networks provide the opportunity to develop these services in a cost effective way, sharing knowledge and learning. This is not the 'easy' option for managing change; it is the most comprehensive approach providing improvement challenges from referral to treatment and aftercare, whether this takes place locally or in more specialist regional services. If we want a world class, safe and sustainable service that we can rely on to provide the very best standards of care for these children for the future, this year on year improvement should be systematic, comprehensive and transparent, providing coherence and integration from the parent and family perspective. The review has been led by a Steering Group with representatives from the following:

Lay representation British Paediatric Neurosurgical Group Society of British Neurological Surgeons British Paediatric Neurology Association Children's Cancer and Leukaemia Group Paediatric Intensive Care Society Royal College of Paediatrics and Child Health **Royal College of Anaesthetists** Neuroanaesthesia Society of Great Britain & Ireland Association of Paediatric Anaesthetists Royal College of Nursing NHS commissioners NHS in Scotland and Wales NHS public health doctors NHS Strategic Health Authorities Department of Health



Specialised Services

Comments

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