
CHILDREN'S NEUROSCIENCE
NETWORKS (FOR THE
NEUROSURGICAL CHILD)
SPECIFICATION STANDARDS

FEBRUARY 2012

INTRODUCTION

The National Specialised Services Safe and Sustainable Team have been working on a national review of paediatric neurosurgical services in England on behalf of the NHS Medical Director and the ten Specialised Commissioning Groups since 2009. 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 key areas. 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, and 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.

These standards support the model of care for these services and have been developed by the Standards Writing Group reporting to the Steering Group for Paediatric Neurosurgery Services. The first version of these standards was distributed widely for comment in November 2009 and those comments have been taken into account in this document, but they have also been changed to reflect the work on the service framework and the work on the exemplar pathways for brain tumour, brain trauma, epilepsy, hydrocephalus and spinal neural tube defects which now appear in Appendix A. The Steering Group has endorsed the proposal to establish regional children's neuroscience networks (for the neurosurgical child) to manage change in a proactive way. These standards will support this approach.

The following priorities have been used for each of these standards:

MANDATORY	Must be in place within the network at the establishment of the networks	These will be reviewed at 6 months to assess the effectiveness of implementation
MANDATORY ORANGE	Plans will be in place to achieve these standards within a time critical period - usually 6 months from the establishment of the network	These will be reviewed at the end of the first year to assess progress
YELLOW	Plans will be in place to achieve these in the second year of the network	These will be reviewed at the end of the second year
GREEN	These are important generic standards which are part of NHS 'Core' standards	

THE NETWORK APPROACH

A1	<p>The Children's Neuroscience Network - for the neurosurgical child, will have a formal and dedicated management group, with a lead consultant, nurse and administrator, for the management and coordination of the service, responsible for the continuous improvement of standards within the network as set out in this section. This group will be based at a Children's Neurosurgical Centre (CNC) having the management responsibilities for the network, and supported by relevant inter-trust agreements.</p>
A2	<p>All centres will provide clear leadership and participation in their children's neuroscience networks, with a formally nominated Clinical Lead and Lead Nurse in order to manage and develop further referral, care and treatment pathways, policies, procedures, performance monitoring and audit, relevant professional training and development in referring hospitals and primary care. The Clinical Leads may have a pathway/condition responsibility in which case all would need to be involved in the management of the network.</p> <p>The Children's Neuroscience Network will hold regular multi-disciplinary meetings across the network and local services for developing these issues.</p>
A3	<p>All regional Children's Neuroscience Network's will be co-ordinated and reviewed nationally by NHS Specialised Services; this will include comparative outcomes and measures as set out in this document, job plans and CPD activity of all consultant paediatric neurosurgeons. The number of annual surgical procedures per centre, the range of surgical procedures and the planning population required to achieve this will be reviewed regularly within each regional network to minimise occasional practice and maintain the skills of all paediatric neurosurgeons, in line with standard G1.</p>
A4	<p>The Children's Neuroscience Network of services will be responsible for the pathways of care that reflect the principle that as much care and treatment should be provided as close as possible to the child's home, while ensuring the best possible outcome for the child.</p> <p>The clinical leaders for the network will develop and coordinate the formal pathways for paediatric neurosurgical sub-specialities (as detailed in Appendix A), including trauma, hydrocephalus, tumours, epilepsy and dysraphism. They will identify key processes appropriate to the local network that cover the critical transition points along the pathway of care.</p> <p>There must be coordinated Safeguarding arrangements throughout the network.</p>
A5	<p>All centres must provide comprehensive care which is linked to local services, other tertiary centres, nationally designated specialist services and demonstrate compliance with requirements for networks for major trauma and children's cancer.</p>
A6	<p>Protocols must be developed for the delivery of emergency life-saving treatment that may be necessary at referring hospitals in accordance with the <i>Joint Statement from the Society of British Neurological Surgeons (SBNS) and the Royal College of Anaesthetists (RCOA) Regarding the Provision of Emergency Paediatric Neurosurgical Services (Appendix C)</i>.</p> <p>Emergency and urgent care pathways must be developed by each network and widely disseminated to referring clinicians and units.</p>

A7	<p>The pathway for children requiring life-saving surgery within the network area will be the formal responsibility of the Children's Neurosurgery Centre with the network management responsibility for the pathway. This must be clearly elaborated within the network. The on call paediatric neurosurgeon (PNS) for the network will be responsible for developing the management plan in conjunction with the referring hospital and will provide on-going definitive care and/or transfer when there is insufficient capacity in the children's neurosurgery centre. There will be a single point of contact responsible for co-ordinating care.</p>
A8	<p>Adult Neurosurgical Centres have an important role to play in the delivery of care for children with neurosurgical conditions:</p> <ul style="list-style-type: none"> • The adult neurosurgical centre will admit and treat children with life-threatening emergency conditions where early surgical intervention will improve the chances of a good outcome. The decision making to proceed will be achieved in collaboration with the on-call PNS. Usually after life-saving surgery the child will be subsequently transferred to the relevant CNC. However, there may be some circumstances following agreement where it is in the child's best interests to stay at the adult neurosurgical centre for continuing care. Where this is necessary the environment must meet the minimum standards outline in the RCN (2011) Health care service standards in caring for neonates, children and young People, London: RCN. • The adult neurosurgical centre must maintain availability of key equipment for emergency surgery on neonates and children agreed by the relevant CNC • This equipment must be checked by the CNC on an annual basis • There should be a named surgeon for paediatric neurosurgery liaison in the adult centre who is the link to the CNC • The annual audit of clinical outcomes (G9 standard) must include all cases operated on throughout the network [not just those at the main centre providing the child's care]
A9	<p>There will be specific guidelines within each network for the transfer of children requiring neurosurgery which will include a clear description of roles and responsibilities for the paediatric neurosurgeon leading the care of the child and the PICU retrieval service.</p>
A10	<p>The Children's Neuroscience Network will develop a training plan for their networks which will build on best practice including awareness of symptoms requiring investigation, escalation and the mechanisms for this.</p> <p>In particular this should include "Pathways to diagnosis" project, and the Diagnosis of Brain Tumours in Children, a Guideline for Health Professionals; neurological assessment in accordance with NICE guidelines: Head Injury: triage, assessment, investigation and early management of head injury in infants, children and adults. 2007.</p> <p>There should be written policy and guidelines for neurological observations for all wards in the network which reflect these.</p>
A11	<p>There should be evidence of good communication covering the different levels of interactions between clinicians, and between clinicians and parents / carers and between clinicians and children / young people. Protocols for communication will be developed and agreed with local referring paediatricians, paediatric neurologists, children's neurosurgical specialist nurses, clinical psychologists and patient groups.</p>

A12

Children transferring between services will be accompanied by high quality information, including a health records summary (with the responsible clinician's name) and an on-going management plan agreed and shared with carers.

A13

All referring hospitals (specialist DGHs, Children's Neurological Centres, Principal Treatment Centres, Trauma Units, Major Trauma Centres, and Adult Neurosurgical Centres) within the network must have imaging facilities and links which allow for immediate transfer of images to the Children's Neurosurgery Centre.

A14

Each Network will identify a named lead consultant in neuro-rehabilitation, who will provide rehabilitation services where required and act as the source of expert advice for network local paediatricians and GPs to facilitate the local delivery of services where possible.

B. MAKING CHOICES

B1	Information must be made available to children and their families in different formats. It must include information about the condition and the range of treatments appropriate to their needs at various points of the pathway. It should be clear, comprehensive, understandable, culturally sensitive, evidence based and include important procedures such as anaesthesia and radiology for example.
B2	<p>Parents/carers must be kept fully informed about their child's care (including care plan and progress) and be partners in decision making about their child's care.</p> <p>The family must be helped to understand the child's condition, the effect it may have on their child's health and future life and the treatment that they will receive. They must be encouraged to actively participate at every stage in their child's care.</p>
B3	Patients, parents and carers whose first language is not English must be provided with appropriate interpreting and translation services.
B4	<p>Where surgery is planned, the child and their parents or carers must have the opportunity to visit the centre and to meet the clinicians who will be responsible for their care, including an opportunity to discuss the planned operation with a consultant paediatric neurosurgeon or children's neurosurgical specialist nurse.</p> <p>Consent for planned procedures should normally be sought by the Consultant in advance of the admission and the status of consent re-checked before the operation, reflecting that the process of consent is continuous.</p>
B5	Parents, carers and all health professionals involved in the child's care must be given details of who and how to contact if they have any questions or concerns, including information on the main signs and symptoms of possible complications or deterioration and what steps they should take. They must have immediate 24-hour access to a member of the clinical team for advice, information and support.
B6	Parents and carers must be fully supported in obtaining further opinions when requested (both within the centre and from neurosurgeons outside the centre).

C. THE PATIENT AND FAMILY EXPERIENCE

C1	There must be dedicated clinical facilities that are designed around the needs of children (diagnostic, ward, theatre, staffing, support).
C2	Each child must have named individuals (consultant and children's neurosurgical specialist nurse) responsible for coordinating their care, and who acts as a liaison between the clinical team and the child throughout their care.
C3	Parents and carers must be provided with accessible information about the service and the hospital, including information about amenities in the local area, travelling, parking and public transport.
C4	Children, their parents and carers should be encouraged to provide feedback on the quality of care and their experience of the service, and they should be encouraged to participate in national Patient Reported Outcome/Experience Measures (PROMS) and patient experience measures and surveys. Centres must make this feedback openly available, and they must demonstrate how they take this feedback into account when planning and delivering their services.
C5	<p>Centres must support patient and family support groups and networks.</p> <p>The children's neurosurgical specialist nurse should provide children and their families/carers with information about how to get in touch with patient groups.</p> <p>Additional information should be available for families on support groups and other parents who are willing to share their experiences.</p>
C6	<p>Centres must provide facilities that are easy and convenient for parents and carers to use.</p> <p>Facilities and support include: sufficient accommodation for the family to stay at the hospital and for parents to stay with their child in the ward 24 hours per day when appropriate, access to refreshments, and to be able to play and interact with their child (and their other children). There must be a quiet room available on the ward or centre completely separate from general family facilities. Access to care should not be inhibited by problems of parking facilities or cost.</p>
C7	There should be access to culturally appropriate support services including faith support, social workers, interpreters, clinical psychologists benefits advice and bereavement counsellors. These should be made available at the specialist centre and links to facilitate this at a local level should also be developed.

C8	There must be facilities that allow the mothers of new-born babies who are admitted as emergencies to stay with their baby. This should include access to maternity staff to support bonding, breast feeding and the emotional health of the mother and baby.
C9	Children should have access to general resources including toys, books, magazines, computers and other age-appropriate activity coordinated by play specialist teams.
C10	Staff in the multidisciplinary team should receive training in communication with children, young people and parents, which shall include training in conveying difficult information in a sympathetic way.
C11	Parents, carers and support groups will be regularly updated with appropriate information on issues of clinical governance and the results of local and national audits.
C12	Children's Neurosurgery Centres will develop and implement a hand held patient record which contains relevant neuro-images. This should include a clear concise summary of information that supports rapid assessment and treatment in local or more distant services, and include an anaesthetic summary where this is relevant to the emergency care of the child.
C13	There must be formal arrangements for addressing complaints and other comments made by children, parents and carers.

D. ACCESS TO SERVICES

D1	<p>All children must have access to consultant paediatric neurosurgical advice and care within a network on a 24 hour, 7 days per week basis, with a formal designated rota which is widely shared and understood within the network of referring hospitals and any other regional networks and services (such as trauma).</p> <p>A management plan for the acutely ill child must be agreed within an hour.</p> <p>All new admissions must be assessed by a consultant paediatric neurosurgeon within 24 hours of admission and all children requiring neurosurgical input (including ward, HDU and PICU) must be reviewed daily by a paediatric neurosurgeon. In occasional situations such as where emergency life-saving treatment precludes the child's transfer to a Children's Neurosurgery Centre within 24 hours these reviews will be undertaken by an adult neurosurgeon in discussion with the nearest on-call paediatric neurosurgeon.</p>
D2	<p>Relevant middle grade paediatric cover must be available on-site.</p> <p>Middle grade neurosurgical cover must be available within 30 minutes.</p> <p>A paediatric resuscitation team must be available on site 24/7.</p>
D3	<p>Each centre will be co-located with a paediatric intensive care unit and there must be access to a defined neurosurgical high dependency care area. (This is red/mandatory relationship within the Department of Health (DH) framework of critical inter-dependencies 2008¹).</p>
D4	<p>Each centre will have paediatric anaesthesia co-located with paediatric neurosurgery. (This is red/mandatory relationship within the DH framework of critical inter-dependencies 2008).</p> <p>Paediatric anaesthetists must demonstrate that they have continuing experience in paediatric neuroanaesthesia.</p>
D5	<p>Each centre will be co-located with 24/7 paediatric neurology services (This is a red/mandatory relationship within the DH framework of critical inter-dependencies 2008) and must include appropriate early rehabilitation services.</p>
D6	<p>Centres must be able to provide specialist services in accordance with the Framework of Critical Inter-Dependencies.²</p>

¹ Department of Health, Commissioning Safe and Sustainable Specialised Paediatric Services: A framework of Critical Inter-Dependencies, August 2008

² Ibid

D7

Centres must have access to a full range of diagnostic equipment, run by sufficient numbers of radiographers and neuro radiologists with dedicated children's sessions in their job plans:

- Computed Tomography (CT) Scanner, including CT angiography – this must be available at all times (24/7 access) and with quick access to the CT scanner from the neurosurgery theatre/s and from the Paediatric Intensive Care Unit (PICU) such that a scan must be completed and reported within 60 minutes of a request, where clinically indicated.
- Magnetic Resonance Imaging (MRI) scanner – available at all times (24/7 access).
- Functional Magnetic Resonance Imaging - available from Monday to Friday within normal working hours (5 day access).

It would be highly desirable for the centre to have access to a High gradient 3T neuro-optimised scanner with functional Magnetic Resonance Imaging – with capacity to undertake spectroscopy.

All out-patient neuro-imaging (including GA MRI scans) must be completed according to National neuro-radiological standards, or within current NHS wait-time targets.

The preferred model is for all services and resources to be dedicated for children's services, with close proximity to wards and theatres. Where children are being treated within an adult setting all staff must be trained in the care of children, in accordance with the Royal College of Nursing (RCN) Health care service standards in caring for neonates, children and young People, (2011) and the investigations carried out using specifically designed policies and procedures for paediatric patients.

D8

Centres must have access to a full range of diagnostic procedures and have the anaesthesia sessions to support this if required:

- 24/7 access to intra-cranial monitoring is mandatory and access to CSF infusion studies desirable
- Biplane angiography & interventional neuroradiology – available 5 days a week from 9 am to 5 pm (7 day access desirable)
- EEG Electroencephalography – available as a minimum from Monday to Friday from 9 am to 5 pm. (7 day access preferred)
- EMG Electromyography – available from Monday to Friday from 9 am to 5 pm (5 day access)
- EEG Videotelemetry – available from Monday to Friday from 9 am to 5 pm (5 day access)(7 day access for an epilepsy centre)
- EEG ambulatory – available from Monday to Friday from 9 am to 5 pm (5 day access) (7 day access for an epilepsy centre)
- NCS Nerve Conduction Studies – available from Monday to Friday from 9 am to 5 pm (5 day access)

Neuropathology reporting service - available from Monday to Friday from 9 am to 5 pm (5 day access) and available for frozen section and smears

D9

Centres must have access to a full range of intraoperative techniques:

- Spinal cord monitoring (SSEPs and MEPs) - 5 day access
- EEG/cortical monitoring - 5 day access
- Evoked potentials - 5 day access
- Intraoperative image guidance system 24/7 access
- Neuro-endoscopy - 24/7 access
- Imaging ultrasound - 24/7 access
- Ultrasonic aspirator - 24/7 access

And it would be desirable for centres to have access to:

- Single Photon Emission Computed Tomography (SPECT) and Positron Emission Tomography (PET)
- Advanced radiotherapy techniques (e.g. IMRT) (5 day access)
- Intraoperative MRI, CT and advanced intraoperative ultrasound (5 day access), depending on support from any emerging cost-effectiveness data (these new technologies currently lack sufficient evidence to advocate routine usage).

D10

All children requiring neurosurgical investigation, treatment and care must receive that care from staff trained in looking after children and trained specifically in neurosciences according to the requirements for their profession/discipline.

Children must be admitted to a dedicated neurosurgical ward or a neuroscience ward which is staffed by nurses trained in the care of children with acute neurological problems.

The senior nurse in charge of the ward out of hours will be required to provide telephone advice to parents in the region. This is in accordance with the Royal College of Nursing (RCN) Health care service standards in caring for neonates, children and young People, (2011) and RCN Defining safe staffing levels for children and young people's services (2003).

When required, there must be daily delivery of the management plan for children's rehabilitation.

D11

Centres must ensure that they plan sufficient capacity (resources and bed capacity) to accommodate expected and unpredictable peaks in demand. Neurosurgical patients must not be "lodged" on wards staffed by nurses who are not trained in the care of paediatric neuroscience patients; support and advice from staff with the relevant expertise must be available at all times.

D12	<p>Children requiring high dependency level care (HDC) must be looked after within a high dependency unit or within a paediatric intensive care unit (PICU) – providing that the HDU capacity is protected and not disadvantaged by surges in PICU requirements. All hospitals admitting children for neurosurgical care must be able to deliver HDC.</p> <p>Children requiring HDC must be looked after by nurses who have received formal training in HDC, and with a nurse to patient ratio of 1:2 (or 1:1 if the patient is looked after in a single occupancy cubicle) in line with the RCN documents in D10.</p> <p>Children requiring HDC must be reviewed by both paediatric neurosurgical and medical teams (general paediatrics, paediatric neurology, and PICU or paediatric anaesthesia), with consultant-led ward rounds at least twice a day. There must be access to on-site middle grade paediatric cover, and if required an anaesthetic / PICU registrar, at all times.</p> <p>Episodes of HDC must be documented on a daily basis using the Paediatric Critical Care Minimum Dataset (PCCMDS). Data must be submitted by Trusts to the Secondary User Service (SUS).</p>
D13	<p>All paediatric neurosurgery (for a planned operation or for an emergency procedure) must be carried out in a dedicated theatre specifically equipped and staffed for paediatric neurological surgery. Ideally, this would occur in a paediatric theatre suite.</p> <p>When undertaken in an adult theatre suite the facilities (including the recovery area) must be in keeping with those found in paediatric settings and must include care provided by appropriately trained staff. However, the theatre staff (scrub nurse and “runner”) for emergency and elective cases must be neurosurgically trained and be involved in neurosurgical operations on a daily/frequent basis.</p> <p>Centres must ensure that they have sufficient theatre capacity for children requiring unplanned operations (these emergency operations can be up to 70% of the workload).</p>
D14	<p>Centres must provide sufficient theatre capacity and related resources to ensure a low cancellation rate for planned operations. The cancellation rate must be no more than 0.5% over a 6 month period and there must be immediate access to a theatre for life-threatening cases.</p>
D15	<p>Theatres will be equipped with the specialist equipment required for paediatric neurosurgery.</p> <p>This includes a specialist table and headrest, an image-guidance system, ultrasonic aspirator, imaging ultrasound, EEG, spinal cord monitoring, and at least one theatre must be equipped with C-arm X-ray imaging.</p>
D16	<p>Paediatric anaesthetic cover in the CNC must be provided according to standards set out in Appendix B.</p>
D17	<p>Paediatric Intensive Care Units must comply with the PICS (Paediatric Intensive Care Society) Standards and the RCN (2011) Health care service standards in caring for neonates, children and young people.</p>

D18	Paediatric Intensive Care Units must have sufficient capacity (beds, staff, equipment, transport) to meet the needs of their catchment population and to accept all emergency paediatric neurosurgical referrals in their catchment area.
D19	<p>Centres must have sufficient capacity (beds, staff, equipment, transport) for the expected number of children requiring high dependency care.</p> <p>There must be sufficient high dependency capacity to ensure acceptance of all emergency paediatric referrals and a cancellation rate of no higher than 0.5% over 6 months for planned operations.</p>
D20	Centres must ensure that the job plans of the paediatric neurosurgeons have a balance of emergency paediatric and elective direct clinical care, as well as time for supporting professional activities.
D21	<p>Centres must have access to consultant paediatric neuro-oncology opinion 7 days a week. A paediatric neuro-oncologist is defined as a paediatric oncologist who is on the GMC specialist Register for Paediatrics (Paediatric Oncology).</p> <p>The preferred model would be for principal treatment centres for children's cancer dealing with brain tumours, to be co-located with paediatric neurosurgery.</p> <p>This is an Amber 3* relationship according to the Department of Health framework of critical inter-dependencies³ which is essential to provide a full specialised service.</p> <p>There must be discussion between the oncologist and surgeon of the management plan for all tumour cases on presentation.</p>
D22	<p>Centres providing specialist care will have a nurse specialist/s covering each of the relevant areas:</p> <ul style="list-style-type: none"> • Hydrocephalus • Paediatric neuro-oncology • Epilepsy • Children's traumatic brain injury • Spinal dysraphism

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

D23

Nursing care must be provided by a dedicated team of nursing staff trained in the care of children and in paediatric neurosurgery in line with RCN (2003) Defining safe staffing levels for children and young people's services, London: RCN.

Staff within the High Dependency Unit (HDU) and PICU must have specialist training in the care and management of patients with high dependency/PICU needs, as well as the neurological care of children.

High dependency care will be staffed by competent nursing staff at a ratio of 1 nurse to 2 children, unless physical layout (e.g. cubicles) requires consideration of 1:1 nursing.

D24

Centres will ensure that, as a minimum, the on-site multi-disciplinary team includes the following specialist staff members with specialised training in managing patients within paediatric neurosurgery and paediatric neuro-rehabilitation:

- Data collection manager
- Neuropsychology
- Neuroradiology
- Dietician
- Play specialists
- Physiotherapists
- Occupational therapist
- Speech and language therapist
- Paediatric pharmacist – access to advice at all times
- Hospital school teacher – access to service

Some of these specialist staff may be members of teams working across paediatric neurology and neurosurgery.

The MDT must also have access to an orthotist, neuro psychology, Child and Adolescent Mental Health Services at the relevant stages in the child's care.

D25	<p>There must be access to other specialist opinions with specialist training in paediatrics:</p> <ul style="list-style-type: none"> • Neuropsychology and child psychiatry (CAMH) opinion based on clinical needs • Immediate access to Neuropathology diagnosis for frozen section or smear • Easy access to Neuropathology opinion for case discussion and multi-disciplinary team meetings <p>The attendance of a Neuropathologist at multi-disciplinary team meetings</p>
D26	<p>Each Centre will have access to dedicated neuro-rehabilitation facilities either on site or as part of the care pathway; they will be responsible for managing the early rehabilitation plan.</p> <p>The Centre will provide early involvement of rehabilitation and neuropsychology teams in assessing a child's and family's needs in a care package and in providing support in reintegration to the community and to education.</p> <p>All children must have equal access to any neuro and physical rehabilitation services they require, regardless of where they receive their acute care.</p> <p>The Centre will have ongoing involvement and responsibility in following up and monitoring this process and assessing longer term outcomes and quality of life in survivors. They will link closely with the Network lead consultant in neuro-rehabilitation and lead therapist who will provide rehabilitation services where required and act as the source of expert advice for network local paediatricians and GPs to facilitate the local delivery of services where possible.</p> <p>The Centre will ensure that multidisciplinary follow up is provided with continuing access to the service via care co-ordinators, clinic systems and/or key worker both at the Children's Neurosurgery Centre and in some cases at an involved shared care centre more locally and this will be agreed with carers. Early and regular contact must be made with local paediatricians and GPs so that they can be involved in the planning of care at the earliest stage.</p> <p>Transition arrangements will be in place for age appropriate continued follow up.</p>
D27	<p>There must be an appropriate mechanism for arranging safe retrieval and transfer of patients in accordance with the Joint Statement from the Society of British Neurological Surgeons (SBNS) and the Royal College of Anaesthetists (RCoA) Regarding the Provision of Emergency Paediatric Neurosurgical Services (Appendix C) and the designation standards for Paediatric Intensive Care services.</p> <p><i>Transfer and retrieval arrangements must include the ability to receive patients by helicopter.</i></p>
D28	<p>All delays to transfers/retrievals (as defined by PIC Standards for the Care of Critically Ill Children 2010) must be monitored and reported to NHS Specialised Services as part of contract monitoring and performance.</p>

E. AGE APPROPRIATE CARE

E1	<p>Planning the transition from children's to adult services should start at 14 years of age. There should not be a fixed age for transition from children's to adult services which will vary according to the needs of the child and their family.</p> <p>Centres will be responsible for developing a transition plan that will include the close involvement of the adult neurosurgeon; full discussion with the child/adolescent and their parents/carers about the clinical issues, their views, opinions and feelings. Ideally this will occur through joint paediatric/'adult' neurosurgical out-patient clinics.</p> <p>During the period of transition continuity of care with the paediatric neurosurgical team will be maintained, including the delivery of non-emergency care in the adult setting.</p> <p>This should also be in accordance with RCN (2004) Adolescent transition care. Guidance for nursing staff, London: RCN (2011) Health care service standards in caring for neonates, children and young People, London.</p>
E2	<p>For safety reasons the immediate peri-operative care of adolescent patients will be delivered in either the adult or paediatric neurosurgical setting – whichever is the most appropriate for each particular patient.</p>
E3	<p>Paediatric neurosurgeons should have sufficient flexibility in their job plans to provide advice and surgical care to adults with relevant neurosurgical conditions, such as congenital spinal dysraphism and complex hydrocephalus.</p>
E4	<p>The patient's management plan must be reviewed at each consultation to make sure that it continues to be relevant to their particular stage of development.</p>
E5	<p>Young people should have the opportunity to be seen by the consultant for part of the consultation without a parent being present.</p>

F. PRENATAL SCREENING

F1	Centres will agree and establish protocols with maternity and neonatal units in their catchment area for the care and treatment of pregnant women whose foetus has been diagnosed with a CNS condition. Any protocols must comply with the NHS 18+-20+weeks Fetal Anomaly Standards and Guidance 2010.
F2	The protocols must ensure that pregnant women are referred to the relevant specialist as early as possible when appropriate, and that accurate diagnosis is made promptly with the aid of a foetal MRI scan where appropriate and in line with the NHS FASP guidelines.
F3	Parents who have been told that their expected child has a CNS anomaly must have access to non-directive counselling and support to help them interpret the diagnosis and possible outcomes. Parents must also be given contact details for relevant local and national support groups at this point.
F4	A consultant paediatric neurosurgeon must be available for antenatal counselling related to congenital central nervous system anomalies as soon as possible.
F5	At diagnosis, a plan must be agreed between the centre, the maternity unit, the neonatal team and the parents about arrangements for the delivery of the baby, minimising the possibility of separation of mother and child after delivery.
F6	There should be a facility to deliver the baby close to the centre if necessary (for example, at a linked obstetric unit). If the plan is for the delivery of the baby at the local maternity unit, this should include arrangements for the transfer of the baby to the neurosurgical centre if required. A neonatal team must be available at delivery and to care for the baby whilst awaiting transfer by a neonatal transfer team.
F7	If need for Neonatal Intensive Care is anticipated, delivery should be planned at a Unit where this can be provided. This unit should have links with a local Children's Neurosurgical Centre.

G. EXCELLENT CARE

G1	<p><i>Children must be treated by a paediatric-trained neurosurgeon. A Paediatric Neurosurgeon is defined as 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)⁴. 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.</i></p> <p><i>A substantial proportion of the consultant's job plan (minimum of 50%), or 5 PAs, must be allocated to paediatric neurosurgery and there must 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 CNC team according to particular paediatric or adult sub-specialist interests.</i></p> <p><i>In addition, paediatric neurosurgery consultants undertaking epilepsy and craniofacial surgery must have undertaken a period of attachment to a recognised epilepsy surgery centre or craniofacial surgery centre (as appropriate) either in the United Kingdom or abroad.</i></p> <p><i>It should be noted that all qualified neurosurgeons are competent to undertake life saving care for children in an emergency situation.</i></p>
G2	<p>There will be dedicated time allocated within each consultant paediatric neurosurgeon's job plan for training of junior staff, update education of adult neurosurgeons within the network and mentoring of new consultant paediatric neurosurgeons.</p>
G3	<p>There are some rare conditions in children which require the input of adult-trained neurosurgeons with specialist expertise. In these cases the adult-trained neurosurgeons would not need any specific training in paediatric neurosurgery. However the care of these children must be co-ordinated jointly with a paediatric neurosurgeon in order to ensure that the other paediatric aspects of the case are appropriate for the child's needs.</p>
G4	<p>Centres will assist in maintaining core competences in all adult neurosurgical services to continue safe provision of immediate treatment and stabilisation of children with life threatening intracranial conditions (e.g. insertion of a drain for acute hydrocephalus).</p>
G5	<p>Centres will develop and maintain a training programme and training register for all members of the multi-disciplinary team (MDT). This training would include the care of children, life support and infection control. All members of the multi-disciplinary team will take part in continuing education and CPD.</p>
G6	<p>Centres will have a nominated consultant with responsibility for trainee medical education in coordination with the regional Training Programme Director.</p>

G7	The training programme must also include the competences to recognise child maltreatment and to take effective action as appropriate to their role and responsibilities as described in the Intercollegiate Document September 2010: Safeguarding of Children and Young People In Roles and Competences For Health Care Staff.
G8	Children must be anaesthetised by paediatric anaesthetists with Royal College of Anaesthetists approved training in paediatric anaesthesia (in line with Appendix B).
G9	<p>Within each centre, there must be a lead radiologist with a special interest in paediatric neuro-radiology who is responsible for arranging cover of the relevant MDTs, prioritising imaging protocols (in accordance with national guidelines and studies), and standardising imaging protocols across the network. Such a post must allow provision for appropriate CPD. Providing additional specialist imaging advice and support to the network must also be recognised within the job plan of the relevant staff.</p> <p>Centres must ensure there is access to GA imaging in a timely fashion and relevant training for staff.</p>
G10	All clinical teams will operate within a robust and documented clinical governance framework that includes morbidity and mortality reviews, clinical incident reporting and review, clinical audit and improvement measures.
G11	<p>All Centres must undertake an annual audit of clinical outcomes, using appropriate benchmark comparators, and must produce a report for the clinical network and the commissioner. The annual audit of clinical outcomes must include all cases operated on throughout the network not just those at each centre.</p> <p>This annual audit will cover all key subspecialty areas including CSF Disorders, neuro-oncology, craniofacial surgery, traumatic brain injury, epilepsy surgery, dysraphism and miscellaneous categories. The proposed performance and outcome measures for each subspecialty are set out below.</p> <p>Results will be monitored and compared against national outcome statistics in particular 30 day mortality figures, and 30 day readmission rates for all Paediatric Neurosurgical cases. Action plans will be developed and improvements made.</p>

G12	<p>Centres treating children with Cerebral-spinal fluid (CSF) disorders will monitor performance and outcomes using the following measures:</p> <ul style="list-style-type: none"> • Primary shunt infection rates in children under 16yrs • Primary shunt one year failure rates • Shunt revision rate for any reason including infection within 30 days post operation • Open access to ward for parents of children with hydrocephalus • Rate of success of ETV at 1 year <p>All units undertaking treatment of children with hydrocephalus must be involved in national audit</p>
G13	<p>Centres treating children for tumours of the central nervous system will monitor performance and outcomes using the following measures:</p> <ul style="list-style-type: none"> • Contribution of data to national audit (morbidity, mortality and pre- & post-resection radiology) • 30 day intervention-related mortality rate, with all deaths formally externally peer-reviewed • Five-year survival rate for all children with brain tumours • Five-year independently mobile, tracheostomy-free survival rate for children with brain tumours • Children registered with CCLG - more than 95 per cent compliance • Fresh tissue taken for storage and cytogenetics of more than 90 per cent compliance
G14	<p>Centres treating children with craniofacial conditions will monitor performance and outcomes using the following measures:</p> <ul style="list-style-type: none"> • Compliance with relevant NHS Specialised Services craniofacial standards and data collection • Mortality from craniofacial surgery (non-syndromic) less than 1 per cent
G15	<p>Centres treating children with traumatic brain injury will monitor performance and outcomes using the following measures:</p> <ul style="list-style-type: none"> • All units undertaking treatment of children with traumatic brain injury must be involved in national audit and formal mandatory reporting to a national database • Mortality rate for severe head injury (30 day and 1 year mortality) • All children with severe traumatic brain injury (Glasgow Coma Score less than 9) must be managed in PICU co-located with paediatric neurosurgery services. • Children with severe traumatic brain injury requiring prolonged ventilation <i>must be managed</i> using Intra Cranial Pressure (ICP) monitoring and their surgical management led by paediatric neurosurgeons. • Formal mandatory reporting to a national database of: <ul style="list-style-type: none"> - Transfer times: time to reach first hospital, time to reach tertiary neurosurgical centre, mode of transfer (referring hosp vs. retrieval), time to surgical procedure - Survival in specific diagnostic groups e.g. non accidental injury (NAI), SDH, EDH, diffuse head injury - along with confirmed post-resuscitation Glasgow Coma Score (GCS) - Length of stay in relation to severity

G16	<p>Centres treating children with epilepsy will monitor performance and outcomes using the following measures:</p> <ul style="list-style-type: none"> • Mortality (peri-surgical and late) with cause • Peri-operative surgical morbidity (within 30 days) • Late surgical morbidity • Seizure outcome 1 and 5 years (related to procedure and pathology) • Neurological outcome (Better/no change/worse /expected/unexpected) • Neurodevelopment/cognitive/neurobehavioral outcome at 2 and 5 years (better/no change/deterioration) • Re-operation rate • Quality of life • Patient satisfaction
G17	<p>Centres treating children with spinal dysraphism will monitor performance and outcome using the following measures:</p> <ul style="list-style-type: none"> • 30 day re-operation rate for post-operative CSF leakage • Continence and mobility status at 1 and 5 years post-op
G18	<p>Centres must contribute to existing/new national databases, registries and audits, with defined minimum data sets, including:</p> <ul style="list-style-type: none"> • Registration of patients to the Children's Cancer and Leukaemia Group • Shunt registry • Paediatric Intensive Care Audit Network data • British Paediatric Neurosurgical Group (BPNG) basic numbers audit and morbidity / mortality audit
G19	<p>Systems will be in place to allow the managed introduction of new treatments and techniques into the centre. Centres will follow mandatory NICE guidance and work within the constraints set within relevant NICE Interventional Procedures Guidance⁵.</p>
G20	<p>Centres will collaborate nationally at a clinical, audit, research and administrative level, and will take part in formal inter-unit and inter-network peer review.</p> <p>For research activity there must be a focus on contributing to a few high-quality multi-centre research projects, rather than single centre case series. Paediatric Neurosurgeons with proven academic experience will be expected to initiate and coordinate these multi-centre studies and must peer-review new research-proposals from other Centres.</p>

APPENDIX A

HYDROCEPHALUS: AREAS OF CARE, PRINCIPLES AND BEST PRACTICE



Context

Until relatively recently, paediatric hydrocephalus was treated by both neurosurgeons and paediatric general surgeons. Today it is generally accepted that all hydrocephalus management must be co-ordinated by the paediatric neurosurgical team. The mainstay of treatment of hydrocephalus remains insertion of a ventriculo-peritoneal shunt but unfortunately studies show that in children approximately 30% of shunts will require revision within a year of insertion (this figure being higher for neonatal patients). After the first year, the risk of shunt malfunction is approximately 5% per year. Likewise, from the literature, the infection rate after primary shunt insertion is 5% to 10%. Unfortunately, each year a number of children die as a result of hydrocephalus. These are often preventable deaths and usually result from a delay in diagnosis. Endoscopic Third Ventriculostomy (ETV) is an alternative treatment option in some patients with obstructive hydrocephalus. The use of ETV has increased dramatically since the 1980's and while the failure rate for ETV (in carefully selected patients) is still of the order of 30%, it is felt that the long term malfunction rate of a functioning ETV is significantly lower than that seen with shunts. Use of ETV in patients who have previously been shunted is receiving increasing interest in the paediatric neurosurgical community and it is likely that a significant percentage of patients who present with shunt blockage are potential candidates for ETV.

Examination of data from HES shows a significant drop off in the number of shunts performed on the weekend. Furthermore funnel plots from the UK Shunt Registry show that children having their shunt revised on a Sunday have a significantly higher risk of subsequent failure of the shunt than shunts inserted/revised on any other day of the week. From the Shunt Registry data, it seems likely that there is a difference in treatment received by children on a weekend compared to the rest of the week. A more robust (case controlled) study undertaken by the UK Shunt Registry compared the outcome of shunts performed by a trainee as opposed to those undertaken by a consultant. This study showed a significant benefit for patients treated by a consultant rather than a trainee out of hours.

Access	
A1	Local pathways for hydrocephalus care must be developed in each Children's Neuroscience Network (CNN) supported by the Children's Neurosurgery Centre (CNC) and there needs to be a clear referral pathway for urgent and emergency care.
A2	An 'open door' policy needs to be available in every CNC with all contacts (direct and telephone) recorded and audited. In Networks where this is not feasible then robust alternative arrangements which avoid unnecessary delays in referring from designated District General Hospital (DGH) must be demonstrated.
A3	Children/families unable to access the 'open door' policy at the CNC, with a suspected shunt blockage must go directly to designated DGHs local to them in the first instance. These hospitals must be part of a network of care where consultant paediatric neurosurgical advice and care is available 24/7.
Principles of care	
P1	Shunt surgery must be a consultant delivered service and whenever possible this must be performed or directly supervised by a Consultant Paediatric Neurosurgeon (PNS) at a CNC.
P2	Where life-saving surgical management is deemed necessary locally then surgery must be performed or directly supervised by an emergency competent Neurosurgeon available following discussion with the PNS at the CNC.
P3	Consultant Paediatric Neurosurgeons will undertake 'peripheral' out-patient (OP) clinics which, when appropriate, will allow patients to be reviewed and have surveillance imaging closer to home.
P4	All units undertaking treatment of paediatric patients with hydrocephalus must be involved in national audit.
Diagnosis and assessment	
D1	Each CNN must have designated DGHs who can respond urgently to scanning and imaging requests from clinicians. Such DGHs must notify the CNC when a child with a shunt is admitted acutely in order for the investigation and management to be co-ordinated. Notification of a possible shunt malfunction must occur at the point of triage in A&E or admission to the ward if a direct GP referral has been made.
D2	The designated DGH must have an image exchange portal for transfer and remote viewing of scans so that specialist advice can be given urgently.

D3	There must be an agreed transfer plan for each child depending on their clinical condition - and this needs to be agreed in consultation with the Consultant Paediatric Neurosurgeon, the local Paediatrician and Anaesthetist and the PICU Consultant. This should be done through conference call facilities managed through PICUs who can arrange calls between various lead clinicians managing the child's care.
D4	Children's Neurosurgery Centres (CNC) must have CT, MRI (with or without GA) and ultrasound available for children 24/7 in an appropriate timeframe dictated by clinical need.
The Multi-Disciplinary Team (MDT) and Management Plan	
M1	The management plan for children with a suspected blocked shunt needs to be agreed with the Consultant Paediatric Neurosurgeon providing advice and support 24/7 at the CNC; the local Paediatrician and local Ophthalmologist in some instances.
M2	The Management Plan needs to be agreed with the family and shared with them on an ongoing basis as the needs of the child changes.
M3	Where hydrocephalus is caused by tumour then the ongoing management plan will be agreed in consultation with the neuro-oncology MDT and care managed by the Principal Treatment Centre (PTC).
M4	Adult Neurosurgical Centres have an important role to play in the delivery of care for children with neurosurgical conditions associated with hydrocephalus. Transition to adult hydrocephalus services at the relevant point in the young person's care must be to a named neurosurgeon in the adult service. Ideally, this transfer to adult services must be undertaken at a transition out-patient clinic attended by both a paediatric and "adult" neurosurgeon. There should be an agreed policy around shunt technology that spans the period of transition.
Interventions and Procedures	
I&P 1	The child should arrive in the neurosurgical centre within 4 hours of initial referral. Children in coma or with a deteriorating conscious level should be transferred within 1 hour. In the latter situation the Consultant Paediatric Neurosurgeon may suggest that the child has emergency surgery in an adult neurosurgical centre if this is closer. The Consultant Paediatric Neurosurgeon might also suggest that Cerebral Spinal Fluid (CSF) be aspirated under aseptic conditions from the shunt reservoir in order to 'buy time'.
I&P 2	The child with a suspected blocked shunt must be accepted by the closest Children's Neurosurgery Centre regardless of whether there is a PICU or ward bed available at the time of referral.

I&P 3	If clinically indicated, direct transfer from DGH to the operating theatre within the Children's Neurosurgery Centre must be arranged for a child with a suspected blocked shunt.
I&P 4	Any child with a suspected shunt problem must be reviewed by a member of the neurosurgical team and be discussed with the consultant neurosurgeon within 1 hour of arrival in the neurosurgical centre.
I&P 5	Any child with a suspected shunt problem must be seen and assessed by a Consultant Paediatric Neurosurgeon within 24 hours of hospital admission.
Rehabilitation, ongoing care and support	
R1	A full time nurse specialist(s) in paediatric hydrocephalus providing advice and support must be available in hours to help co-ordinate the care of children with hydrocephalus in their network.
R2	The ongoing non-surgical management of children with hydrocephalus may be provided by the Children's Neurological Centre or by a designated service more locally within the CNN.
R3	There will be agreement within the CNN where ongoing reviews, including eye checks, may best be managed, and this will be agreed with the carers.
R4	Baseline scans must be made available to parents/carers so that comparisons can be made when potential problems arise, particularly for those going on holiday.

BRAIN TRAUMA: AREAS OF CARE, PRINCIPLES AND BEST PRACTICE



Context

Traumatic Brain Injury (TBI) is the most common cause of morbidity, mortality and disability in children over 1 year of age. In the UK there are over 500 cases of severe TBI admitted to Paediatric Intensive Care (PIC) each year. For those that reach hospital, mortality varies with the severity and injury type. Average mortality rates in children after severe TBI admitted to PICU are between 9 and 10%. Severity of TBI is most commonly related to a post-resuscitation Glasgow Coma Score (GCS) at presentation. Severe TBI is defined as a GCS of less than 9 and a moderate TBI as a GCS of 9-12. The need for urgent neurosurgical decompression is rare in children. However, there is an equivalent urgency to access intracranial pressure monitoring, as more children than adults suffer diffuse brain injuries with associated cerebral oedema. The key elements for the care of these children include: high quality trauma resuscitation; neuro-imaging; emergency decision making; surgical skills relating to trauma and 24/7 expert children's neurosurgical advice with the ability to transfer these children safely to the nearest Children's Neurosurgery Centre (CNC). There are currently no formalised or nationally agreed clinical guidelines in the UK for the use of ICP monitoring, surgical management including de-compressive craniectomy, hyperventilation, osmotic diuretics or the use of barbiturates in children with TBI.

Access	
A1	Local trauma pathways need to be developed for each Trauma Network. There are two options, children either follow the same pre-hospital pathway as adults and are managed in the combined Major Trauma Centre (MTC) or the destination is a dedicated Children's MTC.
A2	The seriously injured child needs to be transferred to the Combined MTC or Children's MTC directly (if the transfer time is less than 45 minutes); but if transfer times are more than 45 minutes, it may be necessary for treatment to be initiated in an Adult or Combined MTC or Trauma Unit. Paediatric Neurosurgeons must be available 24/7 for consultation and care to the Trauma Network and must be involved in all decisions to operate for TBI in children.
Principles of care	
P1	Good communication, coordination and clarity of team roles are essential for clinicians and parents understanding of networks and the relationships between different elements of their child's care. This information must be clearly provided to families.
P2	All units undertaking treatment of children with moderate or severe head injury must be involved in relevant national audit. They must be able to provide emergency management of children with spinal cord injuries.
Diagnosis and assessment	
D1	Each Trauma Network must have designated DGHs/Trauma Units who can respond urgently to scanning and imaging requests for children with major trauma.
D2	These services must have Consultant Radiology Support available 24/7 for neuroradiological imaging and an ability to provide paediatric anaesthesia to a standard specified by the Royal College of Anaesthetists.
D3	The designated DGH must have an image exchange portal for transfer and remote viewing of scans so that consultant paediatric neurosurgical and paediatric intensivist advice can be given urgently.
D4	Children's Neurosurgery Centres (CNC) must have CT, MRI, ultrasound and general radiology available for children 24/7.
D5	CNCs will develop a training plan for their CNNs which will build on best practice including awareness of symptoms requiring investigation, escalation and the mechanisms for this. In particular this must include, neurological assessment in accordance with NICE guidelines: head injury: triage, assessment, investigation and early management of head injury in infants, children and adults.

The Multi-Disciplinary Team (MDT) and Management Plan	
M1	A management plan must be created for children with severe brain injury by the paediatric neurosurgeon and consultant in paediatric intensive care within an hour of CT imaging. This must address surgical treatment, Intra-Cranial Pressure (ICP) monitoring and paediatric intensive care.
M2	Ongoing care of children with severe head injury (GCS≤8) must be managed in the CNC and transfer should occur after life-saving critical interventions.
M3	<p>There will be a lead consultant/neurologist in children's neuro-disability responsible for the rehabilitation management plan. They will provide specialised rehabilitation services and act as a source of expertise and advice to the network.</p> <p>The MDT for neuro-rehabilitation must be included at relevant discussions for developing the plan; Paediatric Intensivist, Paediatric Neurosurgeon, Paediatric Neurologist, Neuroradiologist with expertise in paediatric neuroradiology, Paediatric Neuropsychologist, Children's Neurosurgical Specialist Nurse, Therapy; Paediatric Physiotherapist, Paediatric Occupational Therapist, Paediatric Speech and Language Therapist, Play Specialist, Dietician, and access to orthotics, pharmacy, educational and social work support</p> <p>There must be access to multidisciplinary neuro-rehabilitation provided by specialist paediatric neuro-rehabilitation staff as soon as the child is medically stable.</p> <p>Each relevant member of the MDT must complete an appropriate assessment to determine the child/family's needs.</p>
M4	The rehabilitation management plan will be discussed and agreed at the MDT with the relevant Paediatric Neurosurgeon in attendance.
M5	The Management Plan needs to be agreed with the family and shared with them on an ongoing basis as the needs of the child changes.

Interventions and Procedures	
I&P 1	<p>The receiving hospital, whether a Children's MTC, Combined MTC or designated Trauma Unit, depending on the condition of the child, must be able to achieve:</p> <ul style="list-style-type: none"> • Intubation within 10 mins • CT scan report and management plan within 1 hour of CT scan, after discussion with Paediatric Neurosurgeon and PIC consultant. This must include scan reporting and image transfer.
I&P 2	<p>The Children's Neurosurgery Centre/CMTC will take responsibility for the child and accept for surgery. If there is no PIC capacity then they will accept for surgery and take responsibility for post operative PIC placement. Transfer should achieve surgery at the CMTC within 3 hours of injury.</p>
I&P 3	<p>Where the child has a GCS of between 9-13 and a normal CT scan, a management plan must be agreed between local clinicians and the Paediatric Neurosurgeon. Formal review of this plan must occur at no more than 6 hours after injury.</p>
I&P 4	<p>The child should arrive at the CMTC within 3 hours from the time of the injury and must be transferred with the referring hospital anaesthetist. PIC retrieval should only be considered in exceptional circumstances.</p>
I&P 5	<p>Where a child is being cared for in an Adult/Combined MTC, and the condition is acutely deteriorating then immediate surgery should be undertaken by an Adult Neurosurgeon in discussion with the CNC/Children's MTC on-call Paediatric Neurosurgeon, and then once stable transfer to the CNC should be achieved as soon as possible.</p>

Rehabilitation, ongoing care and support	
R1	Each CNN must identify a named lead consultant/neurologist in children's neuro-disability who will provide specialised rehabilitation services and act as a source of expertise and advice to the network, co-ordinating early rehabilitation, developing the management plan and discharge plan for discussion and agreement at the MDT.
R2	A key worker/children's neurosurgical specialist nurse must be identified within the CNN providing an important role in supporting children and families; they will also provide information advice and reassurance.
R3	<p>A care package must be identified prior to discharge from the CNC which identifies ongoing care rehabilitation and support in the community; this might include clinical care at home, information and training for the family, the needs for supporting education, and strategies for learning and concentration.</p> <p>Early contact/referrals must be made with local paediatricians, multidisciplinary teams, and GPs and childrens community nursing team so that they can be involved in planning the long-term care.</p>
R4	The local Children's Neurological Centre will provide a key network role for specialist rehabilitation and support. At particular points in a child's treatment specialised emotional and psychological support might be required and needs to be provided by the CNN.
R5	Early contact must be made with local paediatricians, multidisciplinary teams, GPs and children's community nursing team so that they can be involved in planning the long-term care.
R6	The Children's Neurological Centre will be responsible for monitoring and reviewing the rehabilitation plan and planning delivery of key service locally to where the child lives.
R7	There will be agreement within the CNN where ongoing reviews may best be managed, and this will be agreed with the carers.
R8	There should be a CNN-wide school re-integration policy for children following Traumatic Brain Injury.

BRAIN TUMOURS: AREAS OF CARE, PRINCIPLES AND BEST PRACTICE



Context

There are approximately 500 cases of new Central Nervous System (CNS) tumours in children and adolescents each year in the UK. The majority (75%) present as emergencies via Paediatric A&E or as urgent referrals from general paediatrics to paediatric neurology, and limited imaging will have been done at the point of presentation. The degree of urgency is dependent on: conscious level (altered by hydrocephalus and tumour size), pace of disease (altering focal neurology) to this point, and the degree of hydrocephalus. The time between the onset of the first symptom and the diagnosis of childhood brain tumour is considerably longer than other childhood cancers. The varied symptoms, relative rarity of CNS tumours and difficulties in prioritising access to brain scanning combine to explain this delay. Neurosurgical services will provide specific components of highly specialist diagnostic, disease management and follow up services. These will be part of commissioned CNNs comprising identified providers of different components of care required by children and their families. Children's Neurosurgery Centres (CNCs) will be required to work closely with other providers to deliver coordinated multidisciplinary, multi-modality treatment and holistic family-centred care. This will include primary care, paediatric oncology Principal Treatment Centres (PTC), paediatric oncology shared care units (POSCUs) and children's community services or palliative care services to deliver care from first presentation, throughout treatment and beyond to long term survival or palliative and end of life care.

The broad Children and Young People's (CYP) cancer pathway and requirements of commissioned services is detailed in the NICE CYPIOG (2005) which must be fully implemented and to which this work aligns. Therefore re-stating all the components of paediatric oncology care outlined in CYPIOG is unnecessary and beyond the scope of this project. This document concentrates on those aspects that have been identified as specifically and additionally pertinent to neurosurgery and the role played in the MDT. All the specialist centres and units contributing to the network of care for children with brain tumours must comply with the NICE Children's and Young People with Cancer Improving Outcomes Guidance (CYPIOG). 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's cancer measures arising from the IOG.

Access	
A1	<p><i>Awareness</i></p> <p>Networks must demonstrate that they are supporting the national campaign to raise awareness of symptoms requiring investigation and the mechanisms for this. ('Pathways to diagnosis' project http://www.rcpch.ac.uk/Research/ce/Guidelines-frontpage/Guideline-Appraisals-by-Organisation/Pathways-to-Diagnosis ; and in particular Diagnosis of Brain Tumours in Children, a Guideline for Health Professionals.)</p>
A2	<p><i>Pathways to diagnosis</i></p> <p>Each CNN supported by the CNC must provide clear information for referring clinicians about appropriate local routes and urgency of investigation for children with symptoms and signs suggestive of CNS tumour.</p> <p>The CNN will have access to advice on management from the paediatric neurosurgical team at the CNC 24/7.</p>
Principles of care	
P1	<p><i>Communication</i></p> <p>CNNs which include incorporating the CNC, the PTC and referring hospital, must provide information about the network based approaches to care, emphasising clarity of roles and communication between different centres within the network, between individual team members within centres, and with parents.</p> <p>There will be an identified key worker for each patient to coordinate care and ensure good communication.</p>
P2	<p><i>Continual Audit, Research and Service Development</i></p> <p>All CNCs must be involved in national audits of activity and outcomes from surgery and following adjuvant treatments.</p> <p>Tumour banking and involvement in available relevant clinical trials or observational studies should be encouraged for all patients with central notification of reasons for failure to enrol patients into such studies.</p> <p>Developing techniques such as intrathecal therapies and targeted biological therapies will be delivered in centres with specific expertise and research support.</p>

Diagnostics and Assessment	
D1	<p><i>Neuroradiology</i></p> <p><i>All referring hospitals within the CNN must have imaging facilities and links which allow for immediate transfer of images to the CNC.</i></p> <p><i>Definitive tumour imaging will be conducted pre and post operatively at CNC, with appropriate anaesthetic support, according to nationally agreed protocols and will be reported by radiologists with expertise in children's CNS tumours.</i></p> <p><i>These paediatric radiologists will attend all the MDTs.</i></p>
D2	<p><i>Neuropathology</i></p> <p><i>CNCs will have rapid reliable access to intra-operative smear reports.</i></p> <p><i>Reporting will be undertaken by neuropathologists with expertise in Children's CNS tumours with peer review and central standardisation of reporting.</i></p> <p><i>These neuropathologists or their cover will attend all the MDTs.</i></p> <p><i>There must be facilities for tumour banking, release and transfer to other centres.</i></p>
D3	<p><i>Endocrinology</i></p> <p><i>CNCs must have sufficient endocrinology expertise available for the initial MDT assessment and ongoing management for midline tumours and good access to advice for the peri-operative management of these children.</i></p>

The Multi-Disciplinary Team (MDT) and Management Plan	
M1	<p><i>MDT Working</i></p> <p><i>There must be the facility for urgent MDT discussion between core members at any time; all cases at some stage must be discussed at formal MDT meetings with all core members attending, in line with cancer peer review requirements. Selected difficult or unusual cases will be discussed at a supra-regional level across a network of centres.</i></p>
M2	<p><i>Where possible with planned surgery a pre-surgical evaluation should be undertaken by members of the MDT to establish current level of function regarding communication, cognition and mobility.</i></p>
M3	<p><i>Adult Neurosurgical Centres have an important role to play in the delivery of care for children with neurosurgical conditions: Transition to adult neuro-oncology services at the relevant period in the young person's care should be to a core neurosurgical member of the CNS tumours MDT.</i></p>

Interventions and Procedures	
I&P1	<p><i>Surgery</i></p> <p><i>Emergency life-saving surgery, such as for associated hydrocephalus, must be provided without delay by an appropriately skilled neurosurgeon.</i></p> <p><i>Definitive surgery must be conducted by a Consultant Paediatric Neurosurgeon experienced in paediatric CNS tumours, a member of the MDT, and when necessary supported by another surgeon with specialist skills for lesions in certain anatomical sites.</i></p>
I&P2	<p><i>Complex Cases</i></p> <p><i>For certain rare tumour types where neurosurgery is required, more specialist advice may be sought and this surgery may then take place at a supra-regional level centres. This might also be required where second or subsequent surgery is being considered. In these cases centres will collaborate closely involving carers in all discussion. They may be managed following discussions at a supra-regional level and if necessary in centres with established expertise in managing that particular problem.</i></p>
I&P3	<p><i>Radiotherapy</i></p> <p><i>Appropriately sited and resourced services with all of the facilities, personnel and anaesthetic support will deliver paediatric radiotherapy and this must meet the IOG.</i></p> <p><i>MDT mechanisms must ensure selected children are managed appropriately with specialist treatments such as stereotactic radiosurgery or proton beam therapy where this is beneficial for them.</i></p>

Rehabilitation, ongoing care and support	
R1	<p><i>End of Life Pathways</i></p> <p><i>Within each CNN there must be available pathways for the transition into supportive end of life services for the child and their family in appropriate cases.</i></p>
R2	<p><i>A post surgical evaluation must be undertaken by relevant members of the MDT to evaluate any change in presentation and guide rehabilitation and care package decision making.</i></p>
R3	<p><i>Care Package and Follow-up</i></p> <p><i>As soon as the child is medically stable, the CNC working with the PTC will provide early involvement of rehabilitation and neuropsychology teams in assessing a child's and family's needs in a care package. They will also identify the child's and families ongoing needs and provide support in reintegrating to the community, local services and education.</i></p> <p><i>The CNC will have ongoing involvement and responsibility for following up and monitoring this process and assessing longer term outcomes and quality of life in survivors, adhering to specifically identified cancer measures.</i></p> <p><i>The CNC will ensure that multidisciplinary follow up is provided with continuing access to the service via clinic systems / key worker both at the CNC and in some cases at an involved shared care centre more locally and this will be agreed with carers.</i></p> <p><i>Transition arrangements will be in place for age appropriate continued follow up.</i></p>
R4	<p><i>CNNs must provide agreed hand held records about the child's care for the carers. This may include scans where relevant so that parents can provide key information if they are going away or when potential problems arise.</i></p>
R5	<p><i>There should be a network wide school re-integration policy for children with CNS tumours.</i></p>

EPILEPSY SURGERY: AREAS OF CARE, PRINCIPLES AND BEST PRACTICE



Context

Epilepsy surgery is increasingly recognised as beneficial in selected children. There is also evidence that children should be considered earlier rather than later in view of the consequence of ongoing seizures on brain development, and greater ability for brain reorganisation in the young, as well as the likely long term psycho-social consequences of ongoing seizures. There is no evidence to suggest that surgery is deleterious in appropriately selected candidates and therefore no benefit to waiting once drug resistance has been demonstrated. Indeed emerging evidence suggests there are significant advantages with early surgery (in children under 5). There is scant data available addressing the number of children who might benefit from surgery. A recent study from Connecticut, USA followed children newly diagnosed with epilepsy for 10 years (10). From this it estimated that in the USA 127/1,000,000 children present with drug resistant epilepsy per year and that 52/1,000,000 children should undergo a pre-surgical evaluation and 27/1,000,000 a resective surgical procedure. This suggests that in the UK 780 children should be evaluated per year and 405 should have a resective surgical procedure. During 2008, 392 children were evaluated and 106 underwent resective surgery. Twelve had required invasive EEG monitoring. In addition to resective surgery, 105 vagal nerve stimulators were implanted. The number of resective procedures performed was one quarter the numbers of procedures estimates predict 'should' have been performed. Only 4 centres performed more than 10 resective procedures during the year and only 4 centres undertook more than 4 resective procedures in children under 5 years of age.

Access	
A1	Local review and epilepsy surgery referral pathways need to be developed for each CNN supported by the CNC designated as an epilepsy surgery centre and disseminated widely to referring clinicians.
A2	All children with a recent onset suspected seizure must be seen by a paediatrician with training and expertise in epilepsies (within 2 weeks) and they will have a regular structured review managed by the local services. Local pathways must be in place which reflect this.
A3	Children must be referred to the Paediatric Neurologist at the Children's Neurological Centre in their local network: in line with NICE guidelines below;
	<p><i>Children's referral for more specialist care (NICE Clinical Guideline)</i></p> <p>Where there is:</p> <ul style="list-style-type: none"> • behavioural or developmental regression, • unidentifiable epilepsy syndrome, • when they are under 2 yrs of age, • seizures are not controlled within 2 yrs, • 2 anti-epileptic drugs have been unsuccessful, • there are unacceptable medication side effects, • a unilateral structural lesion, • psychiatric co-morbidity, • diagnostic doubt.
A4	Parents and children must have high quality information about their child's condition and the choices available to them, this must include options for second opinions and the choice of centre to be referred to.
A5	The referral must be made to the epilepsy team at the Children' Neurological Centre where there will be an initial outpatient review and an admission for further investigation.

Principles of care	
P1	Good communication, coordination and clarity of team roles are essential for both clinicians and parents to understand the networks and the relationships for different elements of their child's care. This information must be provided to families so they can better understand this.
P2	CNCs must demonstrate that arrangements are in place that allow parents, carers and children to actively participate in decision making at every stage in their child's care.
P3	All units undertaking treatment of paediatric patients with epilepsy must be involved in national audit.
Diagnosis and assessment	
D1	The data required pre-surgery evaluation is set out below and this will be discussed by the epilepsy MDT as part of the epilepsy surgery pathway;
	<p style="text-align: center;"><i>The pre-surgical evaluation:</i></p> <p>Interictal sleep EEG recording, Video EEG recording of seizures, MRI with specified protocol including serial scans, access to Functional imaging, age appropriate neuropsychology assessment including neuropsychiatry.</p>
D2	The designated DGH and centres within the CNN must have an image exchange portal for transfer and remote viewing of scans so that specialist advice can be given when required.

The Multi-Disciplinary Team (MDT) and Management Plan	
M1	This is a complex process requiring a number of specialist staff with different essential expertise as set out below;
	<p><i>The Multidisciplinary Team required:</i></p> <p>Paediatric Epileptologist, Neurosurgeon with expertise in paediatric epilepsy, Neurophysiologist with an expertise in Paediatric Neurophysiology, Neuroradiologist with expertise in paediatric Neuroradiology, Paediatric Neuropsychology, Paediatric Neuropsychiatrist, dedicated children's epilepsy specialist nurse, Therapy: Paediatric OT, SLT, Physiotherapy, Paediatric Neuroanaesthetist, Neuropathologist and Paediatric Ophthalmologist.</p>
M2	The pre-surgical evaluation will be undertaken and discussed and reviewed by the epilepsy MDT.
M3	The Management Plan needs to be agreed with the family and shared with them on an ongoing basis as the needs of the child changes.
Interventions and Procedures	
I&P1	All epilepsy surgery will take place in designated centres. Where surgery is to be undertaken at a Children's Neurosurgery Centre not co-located with the Children's Neurology Centre undertaking the review then this must be discussed fully with the MDT including the Paediatric Epileptologists and paediatric neurosurgeon, so that repeat investigations may be avoided.
I&P2	Definitive surgery must be undertaken by a Consultant Paediatric Neurosurgeon experienced in epilepsy surgery.
Rehabilitation, ongoing care and support	
R1	<p>Post-operative evaluation must be undertaken by relevant members of the MDT (minimum of speech and language therapist, occupational therapist and physiotherapist) to identify any change in presentation and rehabilitation which needs to guide discharge planning.</p> <p>In discussion with the parents post operative after-care and rehabilitation (where required) could be undertaken at a Centre closer to the family; this could be on a shared care basis with the CNC.</p>

R2	A care package must be identified prior to discharge which identifies ongoing care rehabilitation and support in the community; this might include clinical care at home, information and training for the family, the needs for supporting education, and strategies for learning and concentration.
R3	The Children's Neurosurgery / Neurological Centre will have a children's epilepsy specialist nurse who will demonstrate appropriate knowledge and skills in this area and provide information, support and advice for the parents and their children about the condition, the surgery and the services and support available to them in their local network.
R4	CNNs will have clear information and protocols in place for shared care arrangements with designated DGHs with a paediatrician with training and expertise in the epilepsies.
R5	Centres will have access to specialist advice and support within the CNN for cognition and behaviour management for children and their carers where this is needed for particular children.
R6	There should be a CNN-wide school re-integration policy for children following epilepsy surgery.

SPINAL NEURAL TUBE DEFECTS: AREAS OF CARE, PRINCIPLES AND BEST PRACTICE



Context

Neural Tube Defects (NTDs) comprise a group of developmental disorders of the brain and spinal cord that have their embryological origin in the initial stages of central nervous system formation early in the first trimester of pregnancy. These are broadly divided into the open NTDs that may affect the brain (encephaloceles, meningoencephaloceles) or the spine (myelomeningocele, meningomyelocele, spina bifida aperta) and the closed NTDs (spinal lipomas, split spinal cord anomalies, dermal sinus tracks etc).

Urgent surgery within 48 hours of birth is usually required for newborns with open NTDs to prevent the onset of meningitis, whereas the surgery for closed NTDs (often called spinal cord 'de-tethering') is planned on an elective basis and can be complex and time-consuming.

The incidence of open NTDs has declined over recent decades due most likely to a combination of antenatal diagnosis, improved general nutrition and the wider use of folic acid supplementation. The change in incidence has however not been seen in the closed NTDs. For open NTDs improvements in antenatal and initial post natal care have led to reduced mortality from these conditions. Furthermore advances in the multidisciplinary management of these conditions means that functional outcomes have improved significantly for both open and closed NTDs.

There were 246 operations for open dysraphism performed in the UK children's neurosurgical centres, based on the average of 2008/2009 BPNG audit data. 70% of babies with NTD also have hydrocephalus.

Until relatively recently, NTDs were treated by both neurosurgeons and paediatric general surgeons. Today it is generally accepted that surgical treatment of spinal dysraphism must be conducted by paediatric neurosurgeons and ongoing management be co-ordinated through a multidisciplinary teams consisting of paediatrician, urologist, orthopaedist and physiotherapist as a minimum.

Access	
A1	Local pathways for assessment and diagnosis need to be developed for each CNN supported by the Children's Neurosurgery Centre (CNC) and disseminated widely to referring clinicians. This must include pathways for referral by paediatricians for urgent referrals and transfers for open dysraphism, and dysraphism associated with hydrocephalus and also for the referral of closed dysraphism for further evaluation and surgical treatment where necessary.
A2	Each CNN for children with NTDs must have designated DGHs who can respond urgently to scanning and imaging requests from clinicians. This unit must be part of a network with a Children's Neurosurgery Centre where consultant paediatric neurosurgical advice is available 24/7.
A3	Children/families need to have clear information about how and where to access services should problems arise whether this involves contacting a children's neurosurgical specialist nurse, going to designated DGHs, or the Children's Neurological Centre more local to them.
Principles of care	
P1	Good communication, coordination and clarity of team roles are essential for both clinicians and parents to understand the networks and the relationships for different elements of their child's care. This information must be provided to families so they can better understand this.
P2	All units undertaking treatment of NTDs must be involved in national audit.
Diagnosis and assessment	
D1	Each network will have appropriately trained staff who can perform and report on spinal ultrasounds in the neonatal period and until approximately 3 months of age.
D2	The designated DGH must have an image exchange portal for transfer and remote viewing of scans so that specialist advice from the CNC can be given urgently.

The Multi-Disciplinary Team (MDT) and Management Plan	
M1	The immediate management plan for the child needs to be agreed between the referring clinician and the Consultant Paediatric Neurosurgeon (PNS) at the Children's Neurosurgery Centre.
M2	The pre-surgical evaluation will be undertaken and discussed and reviewed by the epilepsy MDT.
M3	The management plan needs to be agreed with the family and shared with them on an ongoing basis as the needs of the child changes.
M4	The neurosurgical and urology teams must work closely together in the management of these children. Agreed guidelines must be in place to assess and monitor the upper and lower renal tracts of these patients and mechanisms in place to respond in a timely manner to changes in bladder or renal function.
M5	A Specialist Physiotherapy assessment is essential to provide a record of muscle function before treatment and in the course of follow up. The role of the physiotherapist should also include coordination of care between physiotherapy services and the specialised centre and locally.
M6	The Specialist MDT at the CNC should follow up the child at regular intervals after initial surgery and agree shared care arrangements within the network, including monitoring for urological and motor deterioration as well as hydrocephalus or Chiari complications in the case of open defects.
Interventions and Procedures	
I&P1	Ideally surgical repair for open dysraphism should be undertaken within 48 hours of birth because of the risk of infection, chronic CSF leakage and for reasons of cosmesis and ease of care. Complex closed dysraphic conditions (e.g. lipomyelomeningocele) should be treated in specialist centres.
I&P2	Babies with open dysraphism will require urgent transfer. There must be an agreed transfer plan for each child depending on their clinical condition and this needs to be agreed in consultation with the Consultant Paediatric Neurosurgeon, the local paediatrician and anaesthetist and the PICU consultant where appropriate.
I&P3	Definitive surgery must be undertaken by a Consultant Paediatric Neurosurgeon experienced in spinal dysraphism.

Rehabilitation, ongoing care and support	
R1	The children's neurosurgical specialist nurse within the network provides an important role in supporting children and their families; they will also provide information advice and reassurance. Providing information about any ongoing involvement advice and support of therapy staff.
R2	A care package must be identified prior to discharge following surgery which identifies ongoing care rehabilitation and support this will include clinical care at home, information and training for the family, the needs for supporting education, and strategies for learning and support as necessary for the needs of the child.
R3	The local Children's Neurological Centre will provide a key network role for specialist neuro-disability rehabilitation and support.
R4	Neurodevelopmental paediatricians, specialist paediatric physiotherapists and other therapies must also be provided more locally within the CNN to monitor the child's development and ongoing functional capabilities, supporting the family in providing a management plan for movement and development in the home.

APPENDIX B

Anaesthetic Competency Requirements

All neonates, infants and children requiring elective or emergency neurosurgery, should receive the highest standard of anaesthetic and peri-operative care, delivered (or supervised by) Consultant Anaesthetists demonstrating training, continuing clinical experience and professional development in this specialised area of practice. Every child should have care delivered by an anaesthetist or anaesthetists who possess the relevant competencies as demanded by the patient's age, disease and co-morbidities.

In Children's Neurosurgical Centres, the necessary competencies will be held by a Consultant Anaesthetist with a regular commitment to elective paediatric neuroanaesthesia and who have trained to the equivalent level identified in the CCT in Anaesthesia. Consultant anaesthetists who provide emergency neuroanaesthesia in these centres should possess the necessary competencies required to provide high quality and safe anaesthesia for such surgery. New appointees to consultant posts with a significant or whole time interest in paediatric neuroanaesthesia should have successfully completed 'Advanced Level' training in paediatric anaesthesia as defined in the CCT in Anaesthesia (August 2010), or equivalent, and an additional six months training in adult and paediatric neuroanaesthesia in a recognised neurosurgical centre. It is recognised that this training will need to be individually tailored after discussion with the RCoA Training Department and local School of Anaesthesia. For highly specialised or complex procedures, joint working of two Consultant Anaesthetists bringing together their individual expertise may be in the best interests of the patient.

In adult neurosurgical services admitting less complex elective and emergency paediatric cases, relevant anaesthetic competencies may be provided by neuroanaesthetists who can demonstrate that they undertake regular paediatric anaesthetic practice and CPD in paediatric anaesthesia, resuscitation and perioperative care. Emergency cases may require the combined efforts of an adult neuroanaesthetist working with a paediatric anaesthetist to ensure that the required competencies are assembled for any particular patient.

The RCoA will define the competencies required for revalidation in conjunction with the relevant Specialist Societies.

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

APPENDIX C

Joint Statement from the Society of British Neurological Surgeons (SBNS) and the Royal College of Anaesthetists (RCoA) Regarding the Provision of Emergency Paediatric Neurosurgical Services

(2010, Extract from main document, <http://www.rcoa.ac.uk/docs/paed-nsurgery-statement.pdf>)

- 1.** Hospitals accepting acute paediatric admissions should be co-located with Emergency Departments, Anaesthesia and ICU services and should have on-site CT scanners. It should also be possible to perform a CT scan on a child within one hour of admission. Ambulance services should be briefed on which hospitals are suitable for such emergency paediatric admissions.
- 2.** All children with urgent or emergency neurosurgical conditions should be discussed with the closest service providing paediatric neurosurgical care except those children admitted to hospitals with on-site “adult” neurosurgical services. In these cases, discussion should initially be with the resident team.
- 3.** In a true emergency situation involving a child requiring urgent neurosurgery for a deteriorating condition admitted to an ‘adult-only’ neurosurgical service, the most appropriate surgeon, anaesthetist and intensivist available would be expected to provide life-saving care including emergency resuscitation and surgery. This should be undertaken following full consultation with clinicians at the paediatric neurosurgical centre and be supported by senior hospital management. This action would be fully supported by both the RCoA and SBNS.
- 4.** Transfers of children for emergency neurosurgery should normally be undertaken by the referring hospital. Children deteriorating from acute neurosurgical conditions will be transferred directly by the referring hospital following primary resuscitation / CT scanning in consultation with the lead centre consultant paediatric neurosurgeon and PIC on call consultant. This transfer should be undertaken by the most appropriate and senior team possible. Very rarely, the use of retrieval teams may be appropriate (very early referral, short distances, complex associated injuries); such a decision will only be made by the Paediatric Neurosurgeon in consultation with local clinicians and the PIC/Retrieval Consultant. In patients with no indication for immediate neurosurgery, the balance of risks between retrieval and local team transfer should be agreed between the paediatric neurosurgical the PIC/Retrieval teams and local clinicians.
- 5.** Referring Hospitals should have policies and protocols in place for such situations. These should detail the personnel who should be called upon to secure the airway, stabilise and transfer the child, together with the necessary equipment (2). Ambulance services should be informed in advance of the need for systems to expedite these transfers promptly.

APPENDIX D - SERVICE INTER-DEPENDENCIES FRAMEWORK

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

This is a summary of some of the key elements from the full document. The framework of Critical Inter-dependencies was produced in order to provide a clear clinically agreed statement of relationships for specialised paediatric services. Children often need access to a number of different specialised paediatric services at any one time and these needs to be considered together. In developing the standards for safe and sustainable paediatric neurosurgery, this inter-dependencies framework remains the standard for describing these relationships.

Co-location in this context is defined as either:

- Location on the same hospital site; or
- Location in other neighbouring hospitals if specialist opinion and intervention were available within the same parameters as if services were on the same site. These would be reinforced through formal links such as consultant job plans and consultant on call rotas.

Relationships coding: The relationships between services are colour coded as follows:

RED	Absolute dependency requiring co-location	AMBER 3	Co-location is desirable but may not be practical in all configurations: <ul style="list-style-type: none"> • An integrated clinical service • Visit by consultant paediatric specialist or transfer of care • Timescale available within 4 hours
AMBER 1	Relationships under some circumstances requiring varying levels of access and contact between specialists, but not necessarily co-location: <ul style="list-style-type: none"> • Planned intervention • Timescale - as required 	AMBER 3*	Co-location is essential to provide a full specialised services, but a decision not to co-locate made be made to ensure optimum access to service centres. If an Amber 3* relationship is not co-located, the full medical specialty would not be able to provide a full specialised service and a very close clinical network with the relevant surgical specialty would be essential.
AMBER 2	<ul style="list-style-type: none"> • Visit by consultant or transfer of care • Timescale - next working day 	GREEN	Indirect no relationship

An integrated clinical service would be demonstrated by reference to consultant job plans and on-call arrangements, agreed clinical guidelines and pathways of care. Transfer of care would be direct to the optimum site of treatment, requiring an effective transfer support system to and from the specialist service.

Specialised Paediatric Service	A BMT	B Clinical haemo	C Immun	D Met Med	E Onc	F Burns	G Infect Dis	H Resp Med	I Cardio	J Card Surg	K Neuro	L Neuro Surg	M Major Trauma	N Spec Ortho & Spinal	O Neph	P Uro	Q Endo	R Gastro	S ENT Airway	T Neonato	U Spec Paed Surg	V Paed Crit Care	W Spec Paed Anaesth
1 Blood and Marrow Transplant					3		2	3	1		1				3			2			3		1
2 Clinical Haematology (Non-malignant)			1						1													2	1
3 Immunological Disorder	2	1					3	2							1			3			1	1	1
4 Metabolic Medicine		2						1	2		2				1								1
5 Oncology (inc Haemato-oncology)	1						1	3	1	1	3	3*	1	1	3	2	1	2	1				
6 Burns											1		3		1								
7 Infectious Diseases			2					1	1		1							1				2	1
8 Respiratory Medicine			1				2		3		1						1	3	3		3*	3	1
9 Cardiology								1		3*	1										1		1
10 Cardiothoracic Surgery		1						2			2				1				2	1	3		
11 Neurology		1	1	2			1	2	1			3*		1	1		1	1	2		1		1
12 Neurosurgery					3								3*	2	1	1	2		2	1	2		
13 Major Trauma (inc Maxfax and Plastics)		1							2	2	1			1	1	2							
14 Spec Ortho and Spinal Surgery					1			2	1		2	1				1					1	3*	
15 Nephrology		2	2	1	1		1	2	3		2			2		3*	2	2	2	3			
16 Urology					2										3*						3		1
17 Endocrinology												1										1	1
18 Gastroenterology			2	1			2														3	1	1
19 ENT (Airway)								3	2	2	1		1								2		
20 Neonatology									2												3		1
21 Specialised Paediatric Surgery		3			1			3	1	1	2	3	1	3		3	3	3	1	3			
22 Paediatric Critical Care		3	1	2			1	3	3		2	3	2		2	1		1					
23 Specialised Paediatric Anaesthesia		1						1	1								1		1	1	1		

The common core of any specialist paediatric centre or network is Paediatric Critical Care; Specialist Paediatric Anaesthesia; ENT (Airway) and specialised Paediatric Surgery.

Major Trauma (including Maxillofacial and plastic surgery) requires co-location with the common core above plus Neurology and Neurosurgery.

Specialised Paediatric Service	A BMT	B Clinical haemo	C Immun	D Met Med	E Onc	F Burns	G Infect Dis	H Resp Med	I Cardio	J Card Surg	K Neuro	L Neuro Surg	M Major Trauma	N Spec Ortho & Spinal	O Neph	P Uro	Q Endo	R Gastro	S ENT Airway	T Neonato	U Spec Paed Surg	V Paed Crit Care	W Spec Paed Anaesth	
1 Blood and Marrow Transplant	Black	Orange	Orange																Orange		Orange	Orange	Orange	
2 Clinical Haematology (Non-malignant)		Black																						
3 Immunological Disorder			Black																	Orange		Orange	Orange	Orange
4 Metabolic Medicine				Black																Orange		Orange	Orange	Orange
5 Oncology (inc Haemato-oncology)		Orange			Black															Orange		Orange	Orange	Orange
6 Burns						Black																		
7 Infectious Diseases							Black																	
8 Respiratory Medicine								Black												Orange		Orange	Orange	Orange
9 Cardiology									Black											Orange		Orange	Orange	Orange
10 Cardiothoracic Surgery										Orange	Black									Orange		Orange	Orange	Orange
11 Neurology											Black									Orange		Orange	Orange	Orange
12 Neurosurgery												Orange	Black							Orange		Orange	Orange	Orange
13 Major Trauma (inc Maxfax and Plastics)													Orange	Black						Orange		Orange	Orange	Orange
14 Spec Ortho and Spinal Surgery														Black						Orange		Orange	Orange	Orange
15 Nephrology															Black					Orange		Orange	Orange	Orange
16 Urology																Black				Orange		Orange	Orange	Orange
17 Endocrinology																	Black			Orange		Orange	Orange	Orange
18 Gastroenterology																		Black		Orange		Orange	Orange	Orange
19 ENT (Airway)																			Black		Orange	Orange	Orange	Orange
20 Neonatology																				Black		Orange	Orange	Orange
21 Specialised Paediatric Surgery																				Orange	Black	Orange	Orange	Orange
22 Paediatric Critical Care																				Orange		Black	Orange	Orange
23 Specialised Paediatric Anaesthesia																				Orange		Orange	Orange	Black



Specialised Services

Comments

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