



**PAEDIATRICS**

**A NATIONAL MODEL  
OF CARE FOR PAEDIATRIC  
HEALTHCARE SERVICES  
IN IRELAND  
CHAPTER 35:  
PAEDIATRIC  
NEUROSURGERY**



Féidhmeannacht na Seirbhíse Sláinte  
Health Service Executive

Clinical Strategy and Programmes Division



**ROYAL  
COLLEGE OF  
PHYSICIANS  
OF IRELAND**

## TABLE OF CONTENTS

35.0	Introduction	2
35.1	Current Service Provision	3
35.2	Proposed Model of Care	5
35.4	Requirements for Successful Implementation of Model of Care	26
35.4.1	Staffing Requirements	26
35.4.2	Interdependencies with Other Programmes	27
35.4.3	Education and Training	29
35.4.4	Child and Parent Involvement	29
35.4.5	Transition to Adult Services	30
35.5	Governance	31
35.6	Key Recommendations	31
35.7	Abbreviations and Acronyms	32
35.8	References	33

## 35.0 INTRODUCTION

In 1998, a document entitled *Safe Paediatric Neurosurgery* set out the minimum requirements for paediatric neurosurgery. At about the same time, the Paediatric Forum of the Royal College of Surgeons of England published its vision in *Children's Surgery – A First Class Service* which also contained a number of recommendations. These two publications demanded a review of the guidance on safe paediatric neurosurgery and, following the convening of an 'ad hoc' working group, a revised version was published – *Safe Paediatric Neurosurgery* (2001). Drawing from this and other guidelines, *Standards for Patients Requiring Neurosurgical Care* (2002) sets out ten objectives required to assure that neurosurgical care of children is of the highest quality, delivered by recognised paediatric neurosurgeons, supported by appropriate staff and facilities, in an appropriate paediatric environment.

There are mutual benefits of close working between adult neurosurgical specialists and paediatric specialists. Examples include treatment of pituitary tumours in children which need the expertise of adult surgeons, where there is significantly greater prevalence and therefore expertise, while the treatment of hydrocephalus in adults which benefits from the greater experience of paediatric neurosurgeons.

### Paediatric neurosurgical conditions include:

- Hydrocephalus – it is estimated that 50% of paediatric neurosurgical treatment is related to the management of hydrocephalus, where mortality risk is quoted as low as 1% for each episode of shunt malfunction
  - Head injuries
  - Brain tumours
  - Craniofacial services (team includes plastic surgeon, maxillofacial surgeon, genetics, ENT, speech and language therapy)
  - Spinal conditions (team also includes specialists in paediatric urology, urodynamics and orthopaedics)
  - Epilepsy;
- along with miscellaneous others.

In 2007, the Health Service Executive (HSE) commissioned an external review of paediatric neurosurgery. This followed the publication of the McKinsey Report *Children's Health First*, which set out that the national paediatric hospital would be linked to both regional and local hospitals, as well as to primary and community care services.

### The main objectives of this review were to:

1. Explore the benefits and risks of current paediatric neurosurgery delivery and configuration
2. Explore the impact of a paediatric neurosurgery unit on other services (such as surgery and anaesthetics) and to consider how the relationships with these partnering services should best be structured in accordance with best practice and local structures
3. Identify gaps in current tertiary paediatric neurosurgery service provision, and propose the most appropriate solution to address the gaps
4. Identify the workforce requirements needed for optimal service delivery

These objectives were set with a view to providing detailed evidence-based recommendations to the HSE in the final report. All observations were required to be made in light of what is needed to provide a sustainable, cost-effective service with the best possible clinical outcomes. The forty six recommendations were prioritised for implementation with the recruitment of two additional paediatric neurosurgeons was recognised as crucial to the development of the service. Children under six years of age now have all of their neurosurgical care provided in Temple Street Children's University Hospital (Temple Street), and children over six years of age that have surgery in Beaumont Hospital now have all outpatient follow up care in either Our Lady's Children's Hospital

Crumlin (Crumlin) or Temple Street. A fundamental component of the implementation has been the fostering of an integrated service that now functions across three sites (Crumlin, Temple Street and Beaumont Hospital). This has been made possible by way of strong clinical leadership and a positive and constructive attitude of all the multidisciplinary team.

Children's Neuroscience Networks: A Framework for Services in England (2012) sets out a strategic view of how paediatric neurosurgical services should develop in the United Kingdom (UK). A high quality multidisciplinary team (MDT) is a critical success factor and rehabilitation services emerge as a future priority. A children's neuroscience network provides the infrastructure to bring the component parts of the service together.

In developing a model of care a number of pathways were used to describe elements of the service:

- Head trauma
- Oncology
- Hydrocephalus
- Epilepsy surgery
- Spinal neural tube defects

A designated paediatric neurosurgeon should have at least 50% of his/her role allocated to paediatric neurosurgery and this should equate to at least 80 operative cases per year.

In a children's neurosurgery centre the overarching principles for care are:

- 24/7 care by paediatric neurosurgeons
- All new admissions seen by a paediatric neurosurgeon within 24 hours
- Trauma and shunt revisions should be core activities for all paediatric neurosurgeons
- Specialist paediatric neuroradiologists are integral part of the MDT
- Rehabilitation should be an integral part of the managed care process

## 35.1 CURRENT SERVICE PROVISION

An integrated service now functions across three sites (Crumlin, Temple Street and Beaumont Hospital). This service is in keeping with the recommendations of the Report of the Committee to Review Neurosurgical Services in Ireland (2005).

### Inpatient Services

There are eighteen beds on St. Gabriel's Ward in Temple Street, an additional three high dependency beds and access to paediatric intensive care. However, these beds are not dedicated to neurosurgery and will usually be occupied by several children with non-neurosurgical conditions, some of which are infectious. Fifteen beds are available in Beaumont Hospital. The service receives approximately 404 referrals each year (excluding craniofacial, epilepsy and neuro-oncology). There are approximately 50-60 oncology cases per year shared with Crumlin. Beaumont and Temple Street have approximately 900 admissions combined per year and this has been rising year on year with a projected 1100 admissions in 2020. The average length of stay is five days. There are approximately 4000 bed days occupied per year.

There are approximately 550 procedures performed each year (Beaumont and Temple Street). There is an excellent MDT with three clinical nurse specialists, 0.5WTE physiotherapist, 0.6WTE occupational therapist, 0.5WTE speech and language therapist, 0.3WTE dietitian, 0.5WTE social worker, 1.0WTE neuropsychologist and

an experienced nursing team in both Beaumont and Temple Street. The initial allocation for MDT staffing was either insufficient or absent therefore health and social care professions (HSCPs) including Occupational Therapy, Physiotherapy, Speech and Language Therapy, Dietetics, Neuropsychology, Social Work and Play Therapy, have developed clinical services in the context of restricted capacity.

Prioritisation, pathways and protocols are in place to strive for international best practice and audits and research including the Spina Bifida Research Project (Governey et al., 2014) was completed to highlight needs. The emergency referral pathway for children with a neurosurgical problem is through the registrar on call in Temple Street. Elective referrals are by fax/letter/email to office with clinic appointment. CT scanning is available in Temple Street, Crumlin and Beaumont 24 hours per day. MRI scanning is available in Temple Street and Beaumont at all times. PET scans are currently referred to the private sector.

#### Outpatient Services:

There are approximately 1,493 outpatient attendances annually (excluding attendances), with new to return ratio is 1:4. No new referral waits over two weeks. Urgent cases are seen on the same day. The top six conditions seen are hydrocephalus, brain tumours, craniosynostosis, spinal dysraphism, traumatic brain injury and lesional epilepsy. Outpatient clinics are held in Temple Street, Crumlin, the maternity hospitals, the Central Remedial Clinic (CRC) and Cork University Hospital as follows:

Temple Street	8-10 general paediatric neurosurgery clinics per month (average attendance 21 patients) 2 spina bifida clinics per month 4 craniofacial clinics per month
Crumlin	3 neuro-oncology clinics per month (average attendance 20 patients) 3 'general' clinics /month (average attendance 15 patients)
CRC	1 spasticity clinic per month (average attendance 3 patients)
Cork University Hospital	1 clinic per month
NMH Holles Street	2 foetal neurosurgical clinics per month
Beaumont	No paediatric clinics but facility for teenagers and young adults to be seen in 'adult' clinics

The National Clinical Programme for Paediatrics and Neonatology visited the Neurosurgical Unit in Temple Street in January 2013. At this time the self-assessed strengths and weaknesses of the service were:

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>• Efficient and effective service with excellent MDT team approach</li> <li>• Strong commitment to audit with quarterly morbidity and mortality meetings</li> <li>• Cohesive consultant group with agreed sub-specialisation</li> <li>• Large volume of cases (second highest in British Isles)</li> <li>• Close links to British Paediatric Neurosurgery Group with Darach Crimmins leading the UK audit group</li> <li>• Developing research arm to the department</li> <li>• Excellent PICU and radiology support</li> </ul>	<ul style="list-style-type: none"> <li>• Split site service</li> <li>• Overcrowded and unsuitable office facilities preventing ability to complete admin, research and audit</li> <li>• Lack of electronic patient records (greater IT support required)</li> <li>• No access to neuropsychology support</li> <li>• Understaffed HSCP provision allocated to Neurosurgery particularly for outpatients</li> <li>• Delays in access to a rehabilitation service in the National Rehabilitation Hospital results in the increased demand for acute inpatient rehab delivered by the HSCPs in the tertiary units, this places additional pressure on already stretched tertiary services</li> <li>• Lack of timely access to community services (predominantly children's disability teams) which can further increase length of stay in the tertiary unit</li> <li>• No paediatric palliative care consultant in Temple Street or Beaumont where all inpatient neurosurgery occurs</li> </ul>

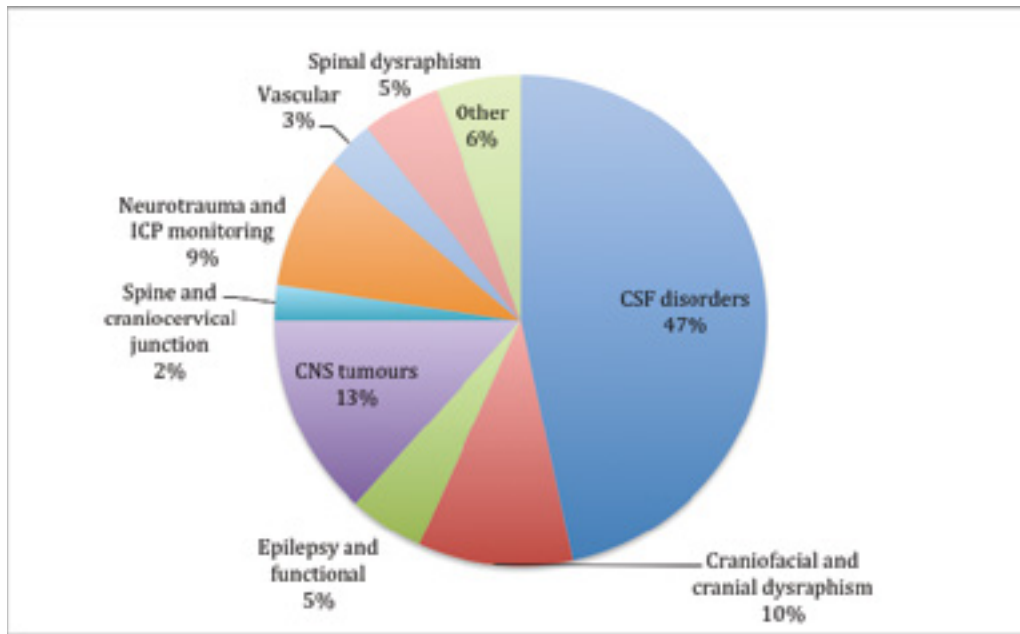
There is strong leadership within the department with Darach Crimmins as lead neurosurgeon, a lead neurosurgical nurse and an excellent MDT. The four paediatric neurosurgeons provide 24/7 cover across the network. Anaesthetic cover is excellent at the Temple Street site, with access to paediatric and neonatal intensive care as well as high dependency units. There is 24/7 availability of CT and MRI, as well as paediatric radiology opinion, in Beaumont and Temple Street. Outreach clinics to Cork, (with planned clinics in Limerick and Sligo) reduce patient journey times to access the service.

## 35.2 PROPOSED MODEL OF CARE

- There will be a single national unit for all inpatient neurosurgical care for children under 16 years of age; this will be at Temple Street until the new children's hospital opens. For the purposes of this document, Temple Street or the new children's hospital will be referred to as the Children's Neurosurgical Centre (CNC). This will be led by the consultant lead for paediatric neurosurgery.
- The CNC will carry out all inpatient treatment and surgery for children in the Republic of Ireland. Based on 2008 to 2014 figures, this will be an average of 500 surgical procedures per year. The CNC will be the busiest neurosurgical centre outside Great Ormond Street in these islands (audit figures for the UK 2008-2014).

- The CNC will have the busiest neonatal surgical practice in the UK and Ireland on account of the high incidence of spina bifida and other congenital central nervous system anomalies.
- The two dedicated 'tumour' surgeons (see below) have the largest individual practice in the UK and Ireland.

The surgical practice in the CNC can be broken down into operations for:



Therefore, if adequately resourced the CNC could be a world leader for paediatric neurosurgical care if appropriately resourced.

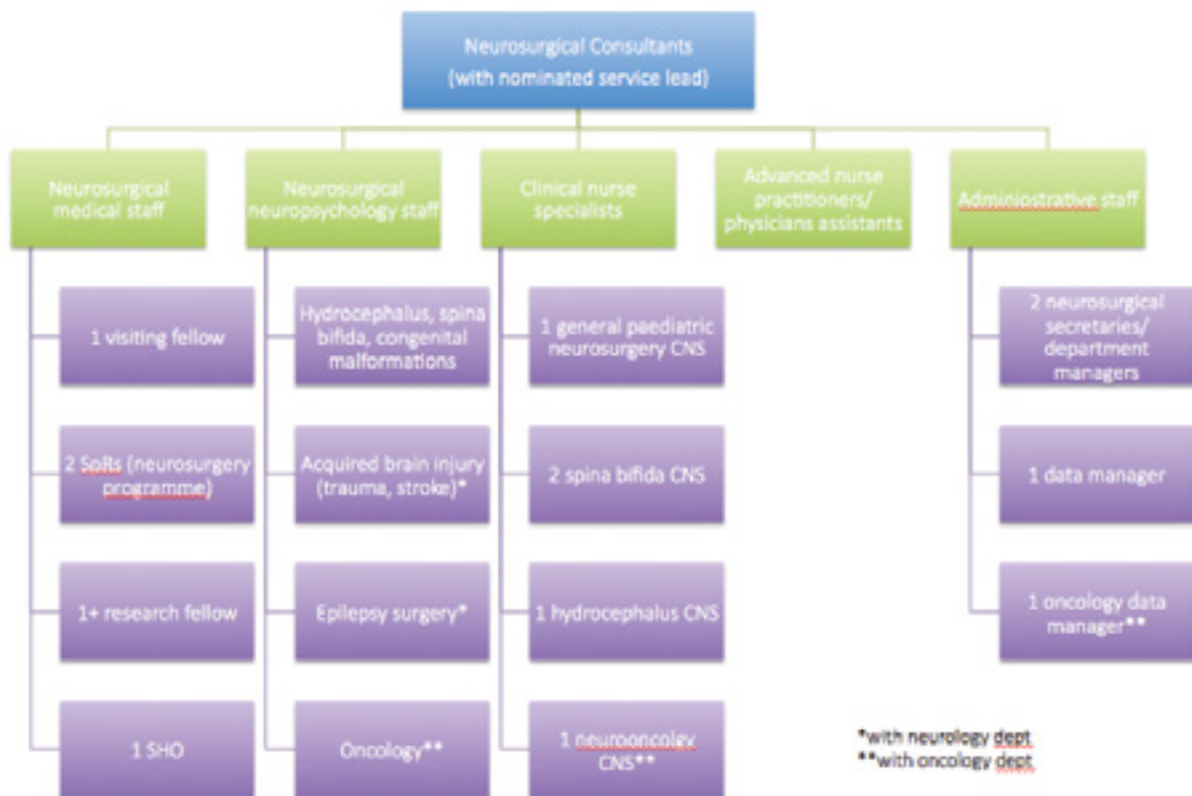
- The CNC will have direct control over its medical staff and will have clinical responsibility for activity of nursing staff, clinical nurse specialists (CNS), advanced nurse practitioners (ANP)/physicians' assistants, neuropsychologists and dedicated HSCPs.
- As most paediatric neurosurgical activity is inpatient-based, CNC staff will be based in and around the neurosurgical ward. It is therefore essential that adequate space is provided for clinical and administrative functions. This will include dedicated office space for consultants, junior doctors, research and international fellows, CNSs, ANPs/physicians' assistants and neuropsychology.

The neurosurgery department will form strong links with neurology department:

- o Shared ward with close collaboration between nursing and HSCPs
- o Combined MDTs in particular
  - Radiology
  - Epilepsy surgery
  - Cerebral palsy and movement disorders
- All nursing staff should achieve at least foundation training in neurosurgery
- Develop ANPs or physicians' assistants in the department. ANPs would require training in the UK as there are no neurosurgical ANP programmes in Ireland. In the absence of the development of ANPs, physicians' assistants could be developed with the Royal College of Surgeons of Ireland (RCSI) to work in tandem with junior medical staff.

- Build further capacity to engage in rehabilitation. A pathway must be developed for patients with physical or cognitive disability as a result of their condition or surgery:
  - Inpatient access to acute rehabilitation under the auspices of the rehabilitation medicine consultant
  - Timely access to suitable inpatient rehabilitation facilities where the child's medical condition is deemed stable but where there are significant on-going nursing needs
  - Comprehensive care plans to deliver effective rehabilitation in the home as soon as possible when fit for discharge from hospital
- Develop outreach clinics in larger regional centres (Cork, Limerick, and Sligo).
- Implement an electronic patient record (EPR) with a database of all activity and outcomes. This will require a dedicated data manager.
- The CNC must have CT, MRI (with or without general anaesthetic), and ultrasound available for children 24/7 in an appropriate timeframe dictated by clinical need.
- The CNC must have 24 hour access to operating theatres and paediatric intensive care unit (PICU).
- The CNC will promote a network approach to managing patients across the country. Close ties with local paediatricians and emergency departments through education, audit and research will encourage efficiency in referral, transfer and subsequent local rehabilitation of these patients. HSCPs will likewise promote this through education of their colleagues in secondary care and the community.

## Neurosurgical Team





#### The neurosurgical ward will:

- Have 14 beds, including high dependency and one bed suitable for invasive telemetry when needed
- Will be adjacent to the neurology inpatient area
- For patients unable to leave ward for long periods (e.g. external ventricular drains) there will be
  - o Adjacent assessment/therapy/rehabilitation space
  - o Adjacent school facilities and playroom
- Have a suitable interview/counselling room for in depth discussion with patients/carers and 'bad news'
- Have adequate storage room for equipment specific to paediatric neurosurgical practice
  - o Lumbar puncture needles, lumbar drains and CSF manometers
  - o EVD drainage apparatus
  - o Shunt tap and suture packs
  - o ICP monitoring apparatus
  - o Portable ultrasound and EEG
- Some neurosurgical patients will be still be managed in the neonatal or paediatric intensive care units where appropriate.

#### Procedure for admission to the neurosurgical ward:

1. Elective admissions
  - Generally through the outpatient clinic for assessment or surgery
  - Where possible patients will be admitted on the day of surgery with pre-operative assessment and investigations performed prior to admission
  - Where possible day case surgery will be performed (e.g. VNS insertion/revision, removal of skin tags, minor skull procedures)
  - Elective surgery will be planned where possible to cause minimal disruption to child's school and other activities
2. Urgent scheduled admissions
  - Often by direct referral from other hospital or clinic (e.g. oncology) where there is deteriorating clinical condition or imminent threat of death or disability
  - Patient scheduled for next available neurosurgical operating list if possible
3. Emergency admissions
  - Usually through emergency department or referring hospitals (including maternity hospitals)
  - admission to:
    - o ward for observation/further investigation
    - o operating theatre for surgery
    - o PICU

#### Procedure for discharge from the neurosurgical ward:

1. Home/palliative care
  - All patients discharged home will have a comprehensive discharge letter with details of admission and management, discharge medication with copies for carers, general practitioner (GP) and referring paediatricians
  - Comprehensive care plan to include on-going therapy in the community with close collaboration with community health professionals prior to discharge
  - Family will have documentation describing child's condition, information on support groups and contact information for both routine and emergency advice
  - Firm follow up plan for outpatient consultation, HSCP visits, imaging and referral to other specialties if indicated

- Where palliative care is required, there will be close liaison with hospital and community palliative care teams. Actions in the event of clinical deterioration must be clearly understood by the family palliative care team, local hospital and GP. In particular, the need for resuscitation or other active treatments must be established in a clear manner. This is to avoid inappropriate aggressive, life extending treatment with a potential for prolonged suffering.
2. Other hospital or rehabilitation facility
- All patients will have a comprehensive transfer letter with details of admission and management, discharge medication with copies for carers and GP.
  - There should be continuity of care between HSCPs in the CNC and referring hospital/rehabilitation facility, ideally with reciprocal visits between them to examine and compare practice.
  - Firm follow up plan for outpatient consultation, HSCP visits, imaging and referral to other specialties if indicated.
  - Family will have documentation describing child's condition, information on support groups and contact information for both routine and emergency advice.
  - There will be image link facilities between the CNC and the transfer hospital. Failing this, copies of imaging and reports will accompany the patient.

## Referral Pathways

### Non-urgent referrals (outpatient):

- Usually by letter or fax to the neurosurgical office or by email to [referrals@brainchild.ie](mailto:referrals@brainchild.ie)
- Ideally accompanied by copies of scans (on CD) if done
- If no appointment necessary (e.g. just imaging opinion sought, or not appropriate for neurosurgery review) return letter or email to referrer within 48 hours
- If appointment appropriate appointment offered for next available outpatient clinic (maximum two weeks)
- Referrals can be from other hospital departments, GPs or even external HSCPs (e.g. community physiotherapist)

### Urgent referrals (inpatient care):

- These can be made to the registrar on call through the CNC switchboard or directly to the consultant (most paediatricians have mobile numbers of individual consultants)
- All transfers to be accompanied by transfer letter, results of investigations and copies of imaging on CD
- If the child is for surgery or intensive care, advice is given regarding:
  - o Immediate management, stabilisation
  - o Direct transfer to the operating theatre or PICU, in consultation with consultant anaesthetist/intensivist on call
  - o Child must not be transferred to emergency department unless
    - further immediate imaging is required
    - additional secondary survey required
- If the child is for transfer to the neurosurgery ward (e.g. mild/moderate head injury or brain tumour with stable neurology):
  - o Transfer is directly to the ward
  - o Child must not be transferred to emergency department

### Self-referrals:

- On occasion, children known to the department will be admitted directly to the CNC after contact from carers directly.
- This will most commonly occur in patients:
  - With CSF shunts where parents concerned about shunt function and child is not deteriorating
  - In children who have had recent surgery and there is concern about secondary complications (e.g. wound issues or persistent symptoms)
- In cases where child is sick or deteriorating, carers will be advised to take their child to their nearest hospital so that transfer over distances is safe.
- Parents must have been allowed to have contact with the neurosurgery CNS during 8 to 5 on weekdays and the neurosurgery registrar on call or ward out of hours.

### Outpatient Services

Site	Clinic type	Frequency	Lead	Other staff
CNC	General paediatric neurosurgery	3 x daily (15/week)	Paediatric Neurosurgeon	Neurosurgical registrar Neurosurgical CNS Physiotherapy & OT
CNC	Spina bifida (SB)	1 x weekly	Paediatrician	Neurosurgeon Urologist SB CNS Physiotherapy & OT
CNC	Craniofacial clinic	1 x weekly	Neurosurgeon Plastic surgeon	Craniofacial CNS Clinical geneticist Physiotherapy & OT
CNC	Epilepsy surgery	2 x monthly	Neurosurgeon Epileptologist	Epilepsy CNS
CNC	Metabolic (craniocervical junction)	6 monthly (2/year)	Metabolic team	Neurosurgeon Orthopaedic Surgeon Physiotherapy & OT
Crumlin (later new children's hospital)	Neuro-oncology*	1 x weekly	Oncologist	Neurosurgeon Neuro-oncology CNS Clinical oncologist
Crumlin (later new children's hospital)	Neurofibromatosis clinic*	1 x monthly	Geneticist	Neurosurgeon Neurologist Oncologist Physiotherapy & OT
At NMH (Holles street)	Foetal neurosurgery clinic	2 x monthly	Neurosurgeon Foetal medicine specialist	Sonographer Neurosurgical CNS/SB CNS
Cork University Hospital	General paediatric neurosurgery	1 x monthly	Paediatric Neurosurgeon	Neurosurgical CNS Physiotherapy & OT
Limerick University Hospital	General paediatric neurosurgery	1 x monthly	Paediatric Neurosurgeon	Neurosurgical CNS Physiotherapy & OT
Sligo General Hospital**	General paediatric neurosurgery	1 x monthly	Paediatric Neurosurgeon	Neurosurgical CNS Physiotherapy & OT

\* preferably in parallel with and adjacent to ophthalmology and endocrine clinics

\*\* chosen over Galway to cater for patients in the North West region

### Education, Training and Public Awareness

- The CNC will have a comprehensive interactive website for information and access for patients, carers and health professionals. The website ([www.brainchild.ie](http://www.brainchild.ie)) will have:
  - o Information on the department including staff, contact details, geography, clinic times
  - o Information on specific conditions including,
    - hydrocephalus, myelomeningocele, occult dysraphism and other congenital malformations
    - CSF shunts
    - pathways for neurotrauma
    - CNS tumours
    - Craniosynostosis
    - Epilepsy surgery pathway
  - o Email access for referrals to the outpatient clinics
  - o Up to date audit figures for activity and outcome to be published online. (as it is for congenital heart disease surgery)
  - o Patient, carer and family information pages to highlight health and service issues
- The neurosurgery department will lead a strong education programme:
  - o Annual paediatric neurosurgery study day for health professionals to be updated on
    - Hydrocephalus and spinal dysraphism
    - Craniosynostosis
    - Paediatric epilepsy surgery
    - Paediatric brain tumours
  - o Biennial study day highlighting issues related to neurotrauma in children. This would be done in conjunction with colleagues in ED, PICU, neurorehabilitation and basic science workers in the universities
  - o Local lecture events where consultant paediatric neurosurgeon will give talks on common problems in regional paediatric departments where local health care providers and patient support groups can attend. Such a tour was done in 2010/11 and was very well received.
- A national education and publicity programme for primary care providers and carers highlighting:
  - o Earlier diagnosis of brain tumours, in collaboration with the Headsmart group in the UK with local champions. Every effort should be made to ensure parents and primary care providers are aware of red flags pointing to concern regarding a possible diagnosis of a brain tumour.
  - o Folic acid supplementation pre-conception re prevention of neural tube defects.

## 35.3 MANAGEMENT OF SPECIFIC CONDITIONS

### Hydrocephalus

All hydrocephalus management must be coordinated 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 literature, the infection rate after primary shunt insertion is 5% to 10%. This varies with the age of the patient and the condition. Endoscopic Third Ventriculostomy (ETV) is an alternative treatment option in some patients with obstructive hydrocephalus.

The commonest causes of hydrocephalus (requiring treatment) in Ireland are:

- Prematurity related intraventricular haemorrhage
- Tumours
- Congenital aqueduct stenosis
- Congenital cysts
- Myelomeningocele

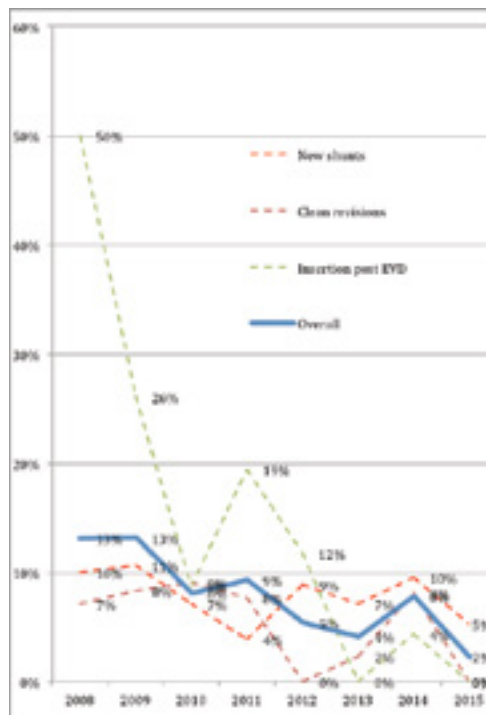
Local pathways for hydrocephalus care must be developed and there needs to be a clear referral pathway for urgent and emergency care.

- An “open door” policy needs to be available with all contacts (direct and telephone) recorded and audited.
- Children/families unable to access the “open door” policy at the centre, with a suspected shunt blockage must go directly to their local paediatric department in the first instance. These hospitals must:
  - o be part of a network of care where consultant paediatric neurosurgical advice and care is available 24/7
  - o Have 24/7 availability to perform cranial imaging and have facilities for transmission of scans to the neurosurgical centre
  - o Have facilities for urgent transfer of children requiring emergency surgery without depending on retrieval teams
  - o 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.
- Shunt surgery must be a consultant-led service, i.e. whenever possible this must be performed or directly supervised by a consultant paediatric neurosurgeon
- 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 paediatric neurosurgeon at the children’s neurosurgical centre. This only applies to Cork University Hospital.
- Where hydrocephalus is caused by tumour then the on-going management plan will be agreed in consultation with the neuro-oncology MDT.
- 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 outpatient clinic attended by both a paediatric and ‘adult’ neurosurgeon. All four paediatric neurosurgeons have an adult practice and this is likely to remain the case.
- The child should arrive in the neurosurgical centre within four hours of initial referral. Children in coma or with a deteriorating conscious level should be transferred within one hour and be transferred directly to the operating theatre.
- 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 one hour of arrival in the neurosurgical centre. Any child with a suspected shunt problem must be seen and assessed by a consultant paediatric neurosurgeon within 24 hours of hospital admission.
- A full time nurse specialist(s) in paediatric hydrocephalus providing advice and support must be available in hours to:
  - o help co-ordinate the care of children with hydrocephalus in their network
  - o educate other health professionals about hydrocephalus, shunts and ETV
  - o coordinate baseline imaging and provide carers with information booklets, alert cards and CDs of baseline scans
  - o collect data on children treated for hydrocephalus and other CSF disorders for national audit looking at incidence, treatment and outcomes. This will be carried out in collaboration with neurosurgical data manager.

- All children with a shunt or an ETV must have a 'baseline' CT scan when they are well (typically done in the asymptomatic child two weeks following their shunt insertion). The child's carers must have a copy of the baseline scan on CD that they can bring with them to hospitals outside the CNC in cases of suspected shunt malfunction.
- All children with hydrocephalus and other CSF circulation disorders (e.g. Dandy Walker malformation, arachnoid cysts) must have formal neuropsychological evaluation at five years of age (prior to attending school) and 12 years of age (pre-secondary school) where appropriate.
- Where hydrocephalus is diagnosed antenatally, all mothers should be offered a referral to the twice monthly foetal neurosurgery clinic at the National Maternity Hospital, Holles Street.
- Children with hydrocephalus and other congenital brain anomalies should be assessed by HSCPs (including physiotherapy, occupational therapy, speech and language therapy) while they are inpatients if indicated.

**Audit in hydrocephalus/CSF disorders will examine:**

- Incidence, aetiology and comorbidity associated with hydrocephalus
- Frequency of antenatal diagnosis in cases of congenital hydrocephalus
- Need for CSF diversion surgery
- Shunt complication rates
  - o Revision rates at 30 days, 6 months, 1 year, 10 years
  - o Shunt infection rates (see below)
  - o Surgical complication rates (e.g. haemorrhage, epilepsy)
- ETV complication rates
  - o Failure rates at 30 days, 6 months, 1 year, 10 years
  - o Infection rates
  - o Surgical complication rates (e.g. vascular injury, hypothalamic injury)



## Brain Trauma

Traumatic brain injury (TBI) is the most common cause of morbidity, mortality and disability in children over 1 year of age. Severe TBI is defined as a Glasgow Coma Scale (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. The key elements for the care of these children are:

### 1. At first contact hospital (referring hospital if not CNC)

- High-quality trauma resuscitation including thorough secondary survey to rule out/identify life threatening non-central nervous system injuries
- 24 hour access to:
  - o rapid medical resuscitation including intubation (where appropriate) within 10 minutes of arrival/deterioration
  - o CT brain and cervical spine
  - o Advice from consultant paediatric neurosurgeon
  - o Safe and rapid transfer to the CNC where appropriate
  - o Where urgent decompressive surgery required (e.g. haematoma evacuation, ventricular drainage)
- Transfer plan must be determined by paediatric neurosurgeon in consultation with referring emergency staff and anaesthetics/intensivists at CNC
- Referring hospital must have patient sedated, ventilated and in ambulance for transfer within 30 minutes of CT being performed
- Where the child has a GCS of between 9 and 13, and a normal CT scan, a management plan must be agreed between local clinicians and the paediatric neurosurgeon.
- 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.

### 2. At CNC:

- The CNC must have consultant radiology support available 24/7 for neuro-radiological imaging including CT, MRI, ultrasound and general radiology available for children 24/7.
- Immediate access to paediatric anaesthesia, operating theatre and intensive care.
- A management plan must be created for children with severe brain injury by the paediatric neurosurgeon and PICU consultant immediately. This must address surgical treatment, intracranial pressure (ICP) monitoring and paediatric intensive care.
- Where urgent decompressive surgery required, e.g. haematoma evacuation, ventricular drainage:
  - o Transfer must be to the operating theatre, pre-prepared based on images transferred from referring hospital
  - o Secondary survey repeated by surgeons/orthopaedics at CNC when possible
- In severe traumatic brain injuries, where prolonged sedation is required, intracranial pressure will be monitored and managed according to locally established protocols. These have already been developed by anaesthesia/neurosurgery and are updated regularly.
- The CNC will have 24 hour expertise in the assessment and management of spinal injuries
- When medically stable and intracranial pressure is normalised the patient will be transferred to the neurosurgical ward for:
  - o intensive inpatient rehabilitation
  - o management of specific needs (e.g. tracheostomy/parenteral feeding)
  - o nutritional support
  - o surveillance for secondary complications

- hydrocephalus
- endocrine disturbances
- seizures
- late infections
- consequences of spasticity
  - Consultation with other specialties
    - o Other surgical disciplines (plastics, MaxFac, orthopaedics, general surgery)
    - o Endocrinology
    - o Neurology/neurodisability
    - o Physiotherapy/occupational therapy
    - o Speech and language therapy/dietetics
    - o Nurse specialists (head injury, PEG/tracheostomy, epilepsy)
    - o Rehabilitation
    - o Social workers
    - o Neuropsychology

### 3. Rehabilitation

- Rehabilitation starts in the acute phase of the management of the severe head injury. This may require visits by the relevant health professionals to the PICU (e.g. physiotherapy, occupational therapy, speech and language therapy) to begin rehabilitation and to prevent secondary complications such as contractures.
- There will be a lead consultant neurologist in children's neurodisability responsible for the rehabilitation management plan. They will provide specialised rehabilitation services and act as a source of expertise and advice to the network.
- The MDT for neuro-rehabilitation must be included at relevant discussions for developing the plan. Each relevant member of the MDT must complete an appropriate assessment to determine the child/family's needs.
- A key worker/children's neurosurgical specialist nurse must be identified to provide an important role in supporting children and families; they will also provide information advice and reassurance. This will usually be the neurosurgery CNS.
- Early contact/referrals must be made with local paediatricians, multidisciplinary teams, and GPs and children's community nursing team so that they can be involved in planning in the long-term care.
- The CNC will provide a key network role for specialist rehabilitation and support. As soon as a child is medically fit for discharge from acute neurosurgical inpatient care there should be ready access to:
  - o Inpatient rehabilitation unit
  - o Adequate community delivered rehabilitation
- The CNC will have access to adequate dedicated inpatient HSCP support including neuropsychology.
  - o Physiotherapy, OT, SLT and neuropsychology deliver inpatient rehabilitation and liaison with community services or the rehabilitation unit.

#### The CNC will be involved in relevant audit for neurotrauma.

- Epidemiological data collection
  - o including type of trauma, age, circumstances of injury, geography, socio-economic status
  - o this will direct public health and prevention strategies



- Service delivery status
  - Access to and timeliness of immediate medical care and resuscitation
  - Access to imaging and other investigations
  - Access to neurosurgical opinion and acceptance for transfer
  - Transfer times from diagnosis (scan), ambulance times/distances and transfer within the CNC
  - Times from diagnosis to definitive neurosurgical management (e.g. surgery)
  - This will highlight shortfalls and possible areas if improvement in communication and resource allocation
- Management outcomes including
  - Morbidity and mortality at 30 days, six months and one year
  - Complication rates from surgery
  - Physical and cognitive disability at six months and two years (Extended Glasgow Outcome Scale, Disability Rating Scale, Vineland Adaptive Behaviour Scale, other neuropsychological measures that are standardised across the patient population)
  - Length of stay
  - Outcome will be compared to predictive outcome models (CRASH and IMPACT - see below) and data submitted to national (NOCA) and international (TARN-UK) trauma audits

## Brain Tumours

Brain tumours are the second most common of cancer in children and are the primary cause of cancer deaths and disability. The degree of urgency is largely dependent on clinical presentation, namely the severity of neurological symptoms and signs and the rate of progression of these clinical features. Imaging features including severe hydrocephalus and tumour mass effect are also factors determining need for urgent surgery. 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 central nervous system tumours and difficulties in prioritising access to brain scanning combine to explain this delay. A national campaign to raise awareness of symptoms in the UK is the HEADSMART project (Diagnosis of Brain Tumours in Children, a Guideline for Health Professionals).

- The management of brain tumours must be managed by a robust and cohesive MDT led by paediatric neurosurgeons and paediatric oncologists. The larger group will comprise of:
  - o Neurosurgeons (2)
  - o Oncologists (3) – medical and clinical
  - o Radiologist
  - o Neuropathologist
  - o Endocrinologist
  - o Ophthalmologist
  - o Palliative care consultant
  - o Neuropsychologist
  - o HSCPs
    - Physiotherapy
    - Occupational therapy
    - Speech and language therapy
    - Dietetics
    - Social worker
  - o Neuro-oncology CNS
- There will be an identified key worker for each patient to coordinate care and ensure good communication.
- Children diagnosed with a central nervous system tumour must have immediate access to the neurosurgeon and the oncologist.
- 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 central nervous system tumour.
- All referring hospitals must have imaging facilities and links, which allow for immediate transfer of images to the CNC.
- Emergency life-saving surgery, such as for associated hydrocephalus, must be provided without delay by an appropriately skilled neurosurgeon.
- All definitive surgery for paediatric CNS tumours must be carried out by two specific neurosurgeons. This will ensure that the individual ‘tumour’ surgeons remain competent by maintaining skills through experience. Occasionally, in tumours at specific anatomical sites an appropriately experienced ‘adult neurosurgeon’ might be needed for surgery (e.g. skull base, transphenoidal).
- Definitive tumour imaging will be conducted pre and post operatively at the CNC, with appropriate anaesthetic support, according to nationally agreed protocols, and will be reported by radiologists with expertise in children’s CNS central nervous system tumours. These paediatric radiologists will attend all MDT meetings. Intraoperative imaging will be possible with the installation of intraoperative MRI. Intraoperative ultrasound is already available.
- There must be a 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. These meetings will occur weekly in line with standard practice in the UK and Europe.
- 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.
- CNCs will have rapid reliable access to intra-operative smear reports. Reporting will be undertaken by the neuropathologist with expertise in children’s CNS tumours, with peer review and central standardisation of reporting. The neuropathologist or their cover will attend the MDT meetings.
- The CNC must have sufficient endocrinology expertise available for the initial MDT assessment and on-going management for midline tumours and good access to advice for the per-operative management of these children.

- Appropriately sited and resourced services with all of the required facilities, personnel and anaesthetic support will deliver paediatric radiotherapy.
- 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.
- 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.
- As soon as the child is medically stable, the CNC 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 on-going needs and provide support in reintegrating to the community, local services and education.
- Within the CNC there must be available pathways for the transition into supportive end of life services for the child and their family in appropriate cases.
- The CNC will have on-going 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.
- CNCs 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. There should be a network wide school re-integration policy for children with CNS tumours.
- The CNC must be involved in national audits of activity and outcomes from surgery and following adjuvant treatments:
  - Epidemiological data to inform public health campaigns and allocate resources
  - Tumour data including site, stage, grade, histological group and biological types
  - Treatment data including surgical and adjuvant therapy morbidity and mortality, neurocognitive outcomes and late effects
  - 30 day intervention mortality and reoperation
  - surgical resection rates on MRI
  - Service performance indicators looking at times from symptom onset to diagnosis, imaging and treatment. This will identify service gaps and key areas of resourcing
  - Audit will be done in collaboration with the CCLG in the UK
  - Registration of all children with CCLG
  - Survival rates will be compared with units in the UK, Europe and North America divided into age and tumour type
    - Five year survival rate
    - Performance status at five years (e.g. mobility, tracheostomy)
- All children with a central nervous system tumour (even if benign, asymptomatic or associated with another condition) must be referred to the CNC and registered on the CNC tumour database (DENDRITE)
- All children will have tissue storage and cytogenetic analysis
- The CNC will endeavour to enrol 90% patients in to international trials in line with similar units in the UK

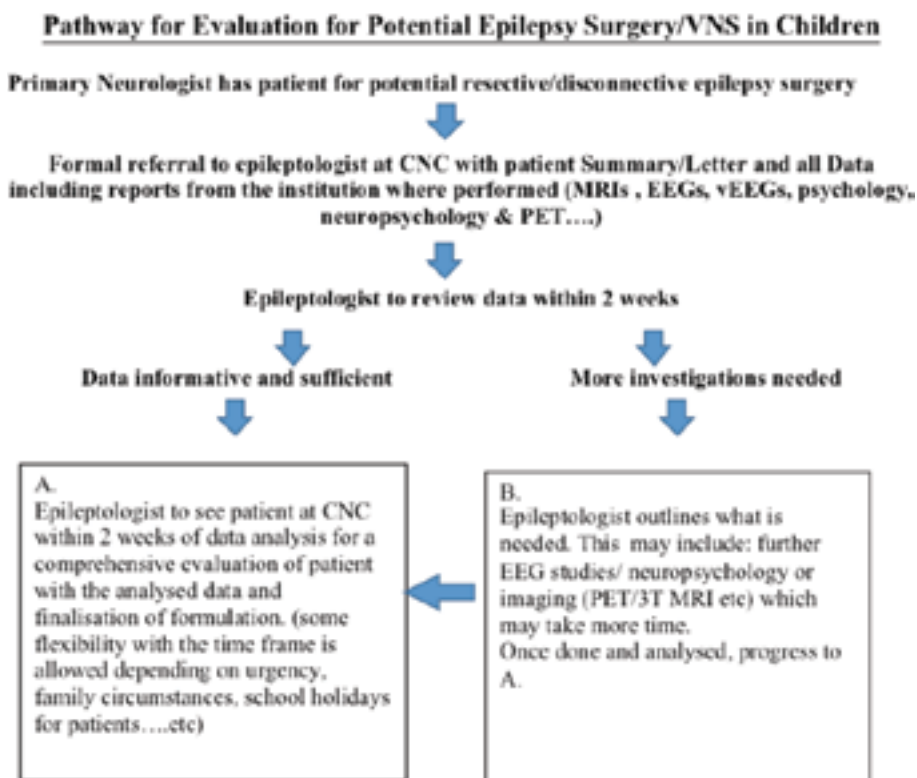
### Epilepsy Surgery

Epilepsy surgery is increasingly recognised as beneficial in selected children. Local review and epilepsy surgery referral pathways need to be developed supported by the CNC designated as an epilepsy surgery centre and disseminated widely to referring clinicians. It is widely accepted that earlier treatment of surgically remediable epilepsy improves developmental outcome and long-term quality of life.

The pre-surgical evaluation will include interictal sleep EEG recording, video EEG recording of seizures, MRI with specified protocol including serial scans, access to Functional imaging, ophthalmology and age-appropriate neuropsychology assessment including neuropsychiatry. This is a complex process requiring a number of specialist staff with different essential expertise:

- Paediatric epileptologist
- Paediatric 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 surgery specialist nurse
- Therapies including occupational therapy, speech and language therapy, physiotherapy
- Paediatric neuroanaesthetist
- Neuropathologist
- Paediatric ophthalmologist

The pre-surgical evaluation will be undertaken and discussed and reviewed by the paediatric epilepsy MDT comprising the above members at scheduled meetings at the CNC.



#### **Outcome**

**In all cases, Epileptologist formulates a formal report and sends to referring colleague:**

- Prior to surgical decision all cases are discussed at the epilepsy surgery MDT with all core members present
- The case is not suitable for resective or disconnective surgery. The referring colleague/neurologist may wish to meet with epileptologist to discuss decision/formulation, including reviewing MRI and EEG data..

- The management plan needs to be agreed with the family and shared with them on an on-going basis as the needs of the child changes.
- All epilepsy surgery will take place in a single designated centre. Definitive surgery must be undertaken by a consultant paediatric neurosurgeon experienced in epilepsy surgery.
- 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.
- A care package must be identified prior to discharge, which identifies on-going 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.
- The CNC 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.
- The CNC will perform annual epilepsy surgery audit looking at:
  - Service standards
    - o Referral patterns and prevalence of epilepsy surgery resection rates (internationally recommended standard 27/1,000,000) will determine whether epilepsy surgery is adequately considered and appropriately referred. Ireland should have at least 40 such cases per year
    - o Time from referral of children with epilepsy to specialist neurology services
    - o Time from diagnosis to imaging, neurophysiology
    - o Time from referral for epilepsy surgery to evaluation and MDT discussion
    - o Time from decision to surgery
    - o Incidence of SUDEP
  - Surgery standards
    - o Perioperative morbidity and mortality
    - o Resection completeness rates of lesional epilepsy on imaging
    - o Epilepsy surgery success rates (Engel Class at 1, 2 years and 5 years)
    - o Neurodevelopmental outcomes and quality of life
    - o Reoperation rates

Standards for epilepsy surgery will be in line with Children's Epilepsy Surgery Services (CESS) centres in the UK (London, Manchester/Liverpool, Bristol and Birmingham). Outcomes will be audited and compared to UK units (see 2013/14 NHS Standard Contract for Children's Epilepsy Surgery Services).

## Spinal dysraphism

Spinal dysraphism comprises a group of developmental disorders of the brain and spinal cord and associated mesodermal tissues that have their embryological origin in the initial stages of central nervous system formation early in the first trimester of pregnancy. Broadly speaking there are two categories:

### 1. Open neural tube defects

This comprises of myelomeningocele and anencephaly, the latter a universally fatal and not relevant to this document. Myelomeningocele (otherwise known as open spina bifida or Chiari 2 malformation) is the commonest survivable congenital nervous system disorder. There are 25 to 30 new cases per year requiring closure in the CNC.

### The CNC provides:

- Antenatal counselling through the foetal neurosurgical clinic at the National Maternity Hospital, Holles Street
- Surgery to close the defect ideally within 72 hours of birth to prevent the onset of meningitis, chronic cerebrospinal fluid (CSF) leakage, and for reasons of cosmesis and ease of care
- Surgical treatment of hydrocephalus (80% of cases) and Chiari 2 malformation (<5% of cases)
- Coordination of the spina bifida MDT:
  - Led by consultant in paediatric neurodisability
  - Spina bifida CNS (2x)
  - Consultant paediatric neurosurgeon (x1 with special interest in dysraphism and hydrocephalus)
  - Consultant paediatric urologist (bladder management)
  - Consultant paediatric orthopaedic surgeon (management of talipes, hip disorders and spinal deformity)
  - Dedicated physiotherapist
  - Dedicated occupational therapist
  - Speech and language therapy
  - Dietetics
  - Social worker

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.

- The immediate management plan for the child needs to be agreed between the referring clinician and the consultant paediatric neurosurgeon at the CNC. Ideally this can be determined before delivery if the mother has attended the foetal neurosurgical clinic at the NMH.
- Transfer to the CNC should occur within 24 hours.
- 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.
- Preoperative assessment must occur on the same day as arrival comprising of:
  - Paediatric neurosurgical assessment to determine neurological deficit, degree of hydrocephalus (need for and/or timing of shunt surgery) and feasibility and likely method of repair of the defect
  - Physiotherapy assessment to provide a record of muscle function before treatment and in the course of follow up
  - Cranial ultrasound to determine baseline ventricular size and thus inform decisions regarding CSF diversion
- Closure of the defect will occur on the next available day-time theatre list. Occasionally for larger defects plastic surgery is required for rotation of skin flaps. Orthopaedic expertise is occasionally required in cases of severe kyphosis. Latex-free precautions are required because of the higher incidence of latex sensitivity in this group of patients.
- 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.
- The role of the physiotherapist should also include coordination of care between physiotherapy services at the CNC and locally.
- 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.
- Prior to discharge the child must be assessed by all members of the MDT and where appropriate ophthalmology and genetics (particularly in cases with associated anomalies)

- All children must have prior to discharge:
  - o MRI brain and spine
  - o Genetic testing for chromosomal disorders
  - o Ultrasound bladder/ureters/kidneys
  - o Ultrasound of hips
- A care package must be identified prior to discharge following surgery which identifies on-going 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.

The CNC will partake in audit with respect to myelomeningocele. Data collected will include:

- Demographic data including socioeconomic group, parental professions, health status
- Periconception folate supplementation, family history of dysraphism or CNS anomalies, maternal drug history, maternal weight
- Antenatal diagnosis and access to counselling
- Gestational age at birth, birth weight, mode of delivery, multiple births, physiological and neurological status immediately after birth
- Associated anomalies (e.g. renal/cardiac defects or palatal defects)
- Time to transfer to the CNC
- Time to closure of defect
- Complications including wound breakdown and hydrocephalus
- Data on CSF diversion (as for audit in hydrocephalus above)
- Continence and mobility at 5 years of age (prior to school) and during teenage years
- Neurocognitive outcomes at age 5, 12 and 16

Further spina bifida recommendations and standards are outlined in report entitled The Health and Therapy Needs of Children with Spina Bifida in Ireland (Governey et al., 2014).

## 2. Closed Dysraphism:

This group of conditions is commonly categorised as spina bifida occulta. They occur as a result of problems of mesodermal development and neural tube dysjunction. They are associated with other caudal problems including anatomical abnormalities of the bladder, distal bowel, bony skeleton and external genitalia. They are not folate-dependent and are less common than open neural tube defects.

These include:

Spinal cord tethering	Lipomomyelomeningocele/lipomas Fatty filum	Occasionally need surgery
Dermal spinal tracts and intraspinal dermoids		Always need surgery
Split cord anomalies	Diplomyelia Diastematomyelia	Diastems need surgery
Spinal neurenteric cysts	Can communicate with GI tract	Commonly need surgery
Terminal cystocele		Occasionally need surgery
Meningocele	Can be anterior	Commonly need surgery
Syndromes associated with occult Dysraphism and sacral agenesis	VACTERL Currarino syndrome OEIS syndrome	Occasionally need surgery

#### Closed dysraphism can present in different ways:

- Abnormalities in the skin adjacent to the spine
  - o Dimples
  - o Lumps or swellings
  - o Hairy patches
  - o Cutaneous haemangiomas
- Associated pelvic malformations
  - o Imperforate anus
  - o Bladder and urethral/cloacal anomalies
- Lower limb deformities
- Delay in walking or early bladder/bowel problems, e.g. recurrent urinary tract infections, delay in toilet training
- Incidental finding on spinal imaging
- Back pain, limb pain or spinal deformity in older children

#### All children with occult dysraphism:

- must be referred for assessment at the CNC
- must have MRI brain and spine
- must have assessment of bladder and kidney function (Ultrasound of the renal tract as a minimum, urodynamic testing if symptomatic)
- must have access to paediatric urology expertise

Surgery for occult dysraphism is complicated with high incidence of post-operative wound complications and significant risk of new neurological deficit. Children who have occult dysraphism and neurological deficit must have access to spina bifida nurse specialist, urologist, physiotherapy, orthotics and orthopaedic services.

### Functional Neurosurgery

In the Irish context this refers to the management of spasticity, largely in children with cerebral palsy.

Neurosurgical treatments include:

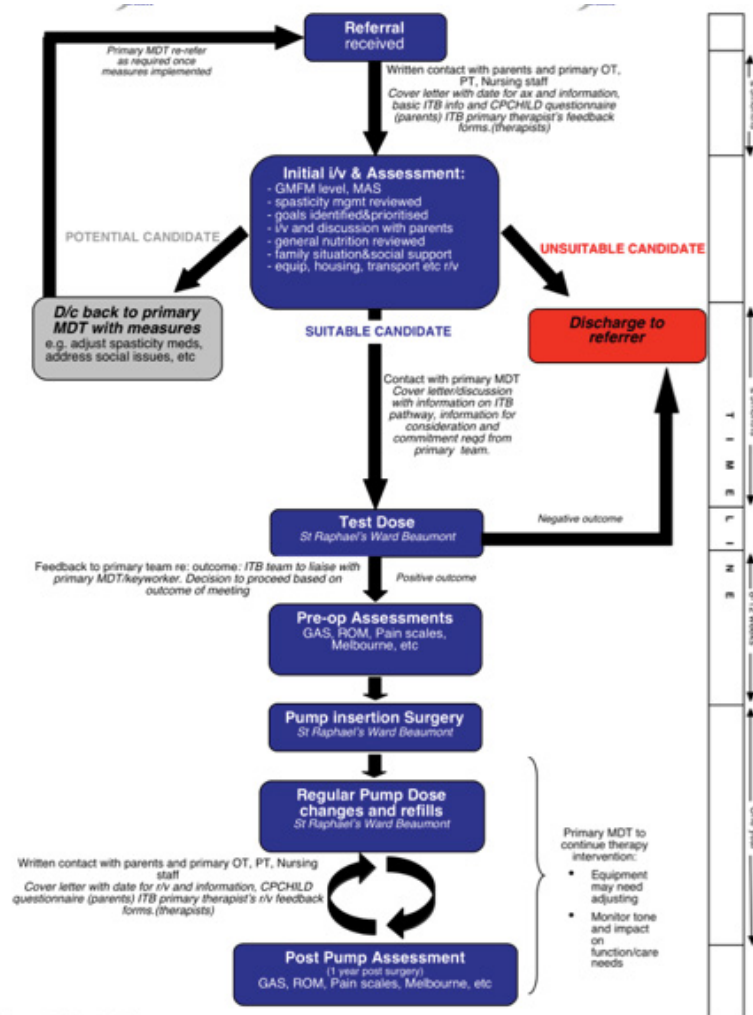
- intrathecal baclofen
- selective dorsal rhizotomy

The CNC will (in conjunction with the CRC) take referrals from community paediatricians, orthopaedic surgeons and neurologists for surgical treatment of problematic spasticity. This is through developmental paediatrician Dr. Jane Leonard. All referrals are on a standard proforma. If the patient satisfies criteria for intrathecal baclofen or selective dorsal rhizotomy, a detailed questionnaire is completed by the referring clinician, physiotherapist and carer.



### Intrathecal baclofen pathway:

Intrathecal baclofen is generally beneficial for children who have generalised spasticity and who are non-ambulant.



### Selective dorsal rhizotomy pathway:

Selective dorsal rhizotomy (SDR) is usually for ambulant children with lower limb spasticity impairing gait. It involves a 3-4 hour procedure with detailed intra-operative neurophysiology of the lumbo-sacral spinal nerves

- Initial review by paediatric disability physician, neurosurgeon, physiotherapist and occupational therapist at neurosurgical spasticity clinic after completing all questionnaires
- Discussion of the needs of the child, the expectations of the parents, the potential suitability for SDR, the requirements for SDR, consideration of alternative treatment as well as discussion on the rehabilitation commitment necessary after SDR
- Formal physiotherapy evaluation by a team of experienced paediatric physiotherapists (two hour assessment, to include Ashworth scores, MRC strength grading, isolation of movements as well as video recording of functional postures, movement and gait)
- Formal review of each patient within a multidisciplinary setting involving paediatric physiotherapy, paediatric orthopaedics, paediatric neurology and paediatric neurosurgery

- Review of brain MRI, hip and spine x-rays
- Agreement by team on appropriate course of action
- Decision on date of surgery six weeks in advance
- Booking for gait assessment, orthotics casting and pre-operative physiotherapy assessment (GMFM) minimum 3 weeks prior to surgery date;
- Booking for Gait Lab assessment at CRC
- Booking for pre-operative assessment clinic
- Quality of life questionnaire to be completed by parents/child prior to surgery
- Plan for hospital discharge at around three weeks to allow commencement of physiotherapy and rehabilitation programme;
- Structured reviews at 3, 6, 12 and 24 months;
- 3 month review – post-operative spasticity clinic review
- 6 month review – disability medicine, neurosurgery and physiotherapy
- 12 month review – neurosurgery and detailed physiotherapy review to include Ashworth scores, range of movement, GMFM scores, video recording, and QOL questionnaire
- 24 month review – neurosurgery and physiotherapy review to include Ashworth scores, range of movement, GMFM scores, video recording and QOL questionnaire
- Gait laboratory evaluation at 24 months

All functional interventions will be subject to strict audit

- Perioperative complication rates
  - o wound or implant infection
  - o neurological injury (in particular incontinence)
  - o length of stay
- Post-operative assessment at 6 months, 1 year and 2 years of:
  - o spasticity
  - o pain/discomfort
  - o quality of life
  - o mobility (where appropriate)
  - o need for orthopaedic interventions
- Late complications
  - o Spinal deformity

## 35.4 REQUIREMENTS FOR SUCCESSFUL IMPLEMENTATION OF MODEL OF CARE

### 35.4.1 Staffing Requirements

Staff Category	Current (WTE)	Proposed (WTE)
Consultant Paediatric Neurosurgeon	4	4 each with special interest
Specialist Registrar	1 – Temple Street	3 in CNC 2 research fellows (also covering out of hours call) 1 post CCT international fellow
Registrar	2 – Beaumont (with additional adult duties)	
SHO	1 – Beaumont (with additional adult duties)	1 in CNC
Nurse	Staff of St Gabriel's Ward and St Raphael's	Fully staffed neurosurgical ward (14 beds) with HDU
Advance Nurse Practitioner or physicians' assistant	0	2
Clinical Nurse Specialist		
Paediatric neurosurgery	1	1 hydrocephalus
Spina Bifida	1	1 epilepsy surgery
Neuro-oncology	1	1 craniofacial
		1 general neurosurgery
		2 spina bifida
		1 neuro-oncology
Dietitian	0.3	1
Occupational Therapy	0.6	1.4 senior occupational therapist 1 clinical specialist 0.5 staff grade (above needs of spina bifida service)
Pharmacist		Access at all times
Physiotherapy	0.6	1 senior physiotherapist 1 clinical specialist 1 staff grade (above needs of spina bifida service)
Speech and Language Therapist	0.5	2
Neuropsychologist	1 (vacant post since 2011)	0.5 principal neuropsychologist as clinical lead 1 for neuro-oncology 0.5 for epilepsy surgery (over and above need for epilepsy in general) 1 for acquired brain injury (haemorrhage/trauma/infection) 1 for congenital developmental disorders (hydrocephalus, spina bifida, encephalocele, congenital cysts)

Intra-operative neurophysiologist	0	1 for intra-operative neurophysiology for spinal cord tumours, complex dysraphism and intracranial EEG in epilepsy surgery
Social worker	0.5	1
Data collection/audit manager		1 for general neurosurgery (including spina bifida, shunts, SSIs, surgical outcomes) 1 for CNS tumours
Endocrinology		1 Consultant Endocrinologist 0.5 Endocrine CNS
Ophthalmology		1 Consultant Ophthalmologist

### 35.4.2 Interdependencies with Other Programmes

<b>Radiology</b>	<p>All services will be supported by a two tier imaging network (i.e. referring hospital and CNC).</p> <p>Within the network:</p> <ul style="list-style-type: none"> <li>• It will be clearly defined which imaging test or interventional procedure can be performed and reported at each site</li> <li>• Robust procedures will be in place for image transfer for review by a specialist radiologist, these will be supported by appropriate contractual and information governance arrangements</li> <li>• Robust arrangements will be in place for patient transfer if more complex imaging or intervention is required</li> <li>• Common standards, protocols and governance procedures will exist throughout the network</li> <li>• All radiologists, and radiographers will have appropriate training, supervision and access to continuing professional development</li> <li>• All equipment will be optimised for paediatric use and use specific paediatric software</li> </ul>
<b>Paediatric Anaesthesia and Intensive Care</b>	<p>All children undergoing neurosurgical procedures must be looked after by staff with appropriate experience and training in paediatric neuroanaesthesia, intensive care and perioperative pain and fluid management. Anaesthetists working in specialist centres must have undergone additional (specialist) training and should maintain the competencies so acquired. These competencies include the care of very young/premature babies, the care of babies and children undergoing complex surgery and/or those with major/complex co-morbidity (including those already requiring intensive care support).</p> <p>As well as providing an essential co-dependent service for surgery, specialist anaesthesia and sedation services may be required to facilitate radiological procedures and interventions (for example MRI scans) and medical interventions (for example intrathecal chemotherapy), and for assistance with vascular access in babies and children with complex needs such as</p>

	<p>intravenous feeding. Specialist acute pain services for babies and children are organised within existing departments of paediatric anaesthesia and include the provision of agreed (hospital wide) guidance for acute pain, the safe administration of complex analgesia regimes including epidural analgesia, and the daily input of specialist anaesthetists and acute pain nurses with expertise in paediatrics.</p> <p>Interventional radiology procedures for vascular malformations are likely to continue to take place outside the CNC (Beaumont Hospital) because of the complex myriad of equipment needs for these procedures. Anaesthetic staff and facilities must therefore be made available for the safe transfer to and from Beaumont of children requiring neurovascular intervention, usually under general anaesthetic and sometimes in very small babies and unstable children (e.g. babies with cardiac failure secondary to vein of galen malformations)</p>
<b>Theatre</b>	<p>The CNC carries out on average 500 operations per year (total 1400 hours anaesthetic time). 360 (900 hours) of these are elective or urgent scheduled (next available list). This amounts to 17 hours scheduled operating per week (minimum 2.5 days fixed lists) and 10 hours emergency operating requiring access 24/7 to a shared emergency theatre. There will be 70 cases per year which will benefit from intra-operative MRI (1.5 per week). There must be a specific theatre equipped for neurosurgery with appropriate MRI compatible operating table and attachments, image guidance and ultrasound operating microscope, CUSA, specialised diathermy and microinstruments. Theatre staff must be trained to assist with neurosurgical operating.</p>
<b>Child and Adolescent Mental Health Services</b>	<p>There may be a need to involve CAMHS in care and close working relationships are essential. Although there is not a huge demand on CAMHS by the CNC, input is required especially for children with behavioural problems related to epilepsy and congenital or acquired brain anomalies.</p>
<b>Neuropathology</b>	<p>Neuropathology back up on site is essential. This is particularly important for intraoperative diagnosis of tissue specimens to direct surgery.</p>
<b>Endocrinology</b>	<p>Approximately 50 paediatric neurosurgical cases per year (1 per week) will predictably affect the hypothalamic pituitary axis. These patients require considerable input from endocrinology in the perioperative period with multiple visits interventions and complex decisions (often at night). Many other neurosurgical patients (who do not have procedures involving the pituitary) have issues with electrolyte balance. This will require a minimum of a consultant endocrinologist (1WTE) to support.</p> <p>The pituitary dynamic testing and patient education will require 0.5WTE Endocrine CNS.</p>

<p><b>Ophthalmology</b></p>	<p>A significant proportion of children in the CNC will have visual impairment due to optic pathway/nerve compression (midline tumours), raised intracranial pressure (hydrocephalus) and cortical visual impairment (congenital/ABI/surgery). Cranial palsies as a result of injury, pathology or surgery can cause significant gaze disturbances. They will require pre-operative and post-operative assessment of fundi, acuity, visual fields (where possible). On-going ophthalmology follow up is essential in these patients. This will require a minimum of 1WTE consultant ophthalmologist.</p>
<p><b>Neurology and General Paediatric Medicine</b></p>	<p>Day to day management of medical issues of neurosurgical inpatients is important as many of these children have other comorbidities and their physiology is more easily compromised than adults with similar conditions. Practice is variable across the UK. In some units where neurology and neurosurgery share a ward, neurology teams manage medical issues. This is practical in that many of the issues can be neurological (seizures, tone and movement disorders). In other units, there is general paediatric cover. Given that there are over 1000 admissions per year and 4000 bed days used, at least one additional general paediatrician or neurologist is required.</p>

### 35.4.3 Education and Training

The development of a fellowship in paediatric neurosurgery, support for higher degrees, and further study in the prevention and management of spinal dysraphism are important in terms of medical education. It is recommended that all nursing staff complete at least a foundation level course in neurosurgery with possible greater links to neurology.

The presently robust MD programme for neurosurgical trainees will continue in close collaboration with the universities and the neuropathology department.

Annual study days will take place at the CNC for interested health professionals to update on:

- Hydrocephalus and its management
- Congenital neurological anomalies
- Spina bifida
- Neuro-oncology
- Craniofacial disorders including craniosynostosis and dysraphism
- Paediatric epilepsy surgery
- Paediatric neurotrauma

Nursing and HSCP staff should have access to education and training both locally and abroad (in other paediatric neurosurgical units) for purposes of benchmarking.

### 35.4.4 Child and Parent Involvement

- There must be dedicated clinical facilities that are designed around the needs of children (diagnostic, ward, theatre, staffing, support).
- 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.

- 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. This will largely be provided by the website and contact cards.
- 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 Measures (PROMs) and patient experience measures and surveys. The neurosurgical centre will make this feedback openly available (through the website). There must be formal arrangements for addressing complaints and other comments made by children, parents, and carers.
- The children's neurosurgical specialist nurse will provide children and their families/carers with information about how to get in touch with patient groups.
- 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
  - Culturally appropriate support services including faith support, social workers, interpreters, clinical psychologists benefit advice and bereavement counsellors
  - Access to general resources including toys, books, magazines, computers and other age appropriate activity coordinated by play specialist team
- 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. This will be done through the website.
- The CNC 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.

#### **35.4.5 Transition to Adult Services**

Poorly planned transition from paediatric to adult-oriented health services can be associated with increased risk of non-adherence to treatment and loss to follow-up, which can have serious consequences. There are measurable adverse consequences in terms of morbidity and mortality as well as in social and educational outcomes. When children and young people who use paediatric services are moving to access adult services (for example, during transition for those with long term conditions), these should be organised so that all those involved in the care, treatment and support cooperate with the planning and provision to ensure that the services provided continue to be appropriate to the age and needs of the person who uses services.

All paediatric neurosurgeons in Ireland also cover adult services and therefore can manage the neurosurgical issues seamlessly. Other key personnel must have a robust and coordinated process to hand patients over to adult care at 16 years of age. These personnel include:

- General paediatrics and neurology
- Endocrinology
- Ophthalmology
- HSCPs and disability medicine
- Oncology
- Neuropsychology

## 35.5 GOVERNANCE

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

An annual audit of clinical outcomes, using appropriate benchmark comparators should be compiled and an annual report should be published. 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. This is described in more detail in the sections above. Results will be monitored and compared against international outcome statistics in particular 30-day mortality figures, and 30-day readmission rates for all paediatric neurosurgical cases.

## 35.6 KEY RECOMMENDATIONS

- All children up to 16 years of age will have their inpatient neurosurgical treatment on a single site in a children's hospital.
- Children with neurosurgical conditions will have adequate and timely access to outpatient review, inpatient treatment and surgery, made possible by ample bed and theatre availability.
- There should be adequate access to neuropsychology review for all children. Neurocognitive outcomes will be audited for all conditions where psychomotor impairment is possible.
- The CNC will have intraoperative MRI to improve tumour resection rates and reduce operative morbidity.
- The CNC will have an interactive website which will have up to date publication of all audit results, information and videos for patients and health professionals and facilities for online referral.
- The CNC will have adequate HSCP staffing to maximise recovery from illness and surgery. HSCPs will report clinically to the consultant neurosurgeon and professionally to their line manager in their relevant department.
- Children recovering in the CNC will have timely access to rehabilitation beds and community rehabilitation outside the CNC.
- There will be dedicated neurosurgery ANP/physicians' assistants to work at the middle grade level for ward and outpatient management of neurosurgical patients.
- The CNC will have a dedicated data manager to spearhead data collection for audit and research.
- The CNC will have a close working relationship with services in regional hospitals and the community made possible through easy contact mechanisms, communication through the website and regular focussed teaching days.



## 35.7 ABBREVIATIONS AND ACRONYMS

ABI	Acquired Brain Injury
ANP	Advanced Nurse Practitioners
CAMHS	Child and Adolescent Mental Health Services
CESS	Children's Epilepsy Surgery Services
CNC	Children's Neurosurgery Centre
CNS	Clinical Nurse Specialist
CRC	Central Remedial Clinic
CSF	Cerebrospinal Fluid
CT	Computer-aided Tomography
EEG	Electroencephalogram
EPR	Electronic Patient Record
ETV	Endoscopic Third Ventriculostomy
GCS	Glasgow Coma Scale
GP	General Practitioner
HDU	High Dependency Unit
HSCP	Health and Social Care Professional
HSE	Health Service Executive
ICP	Intra-Cranial Pressure
MDT	Multidisciplinary Team
MRI	Magnetic Resonance Imaging
NMH	National Maternity Hospital
NTD	Neural Tube Defect
OT	Occupational Therapy
PET	Positron Emission Tomography
PICU	Paediatric Intensive Care Unit
PROM	Patient Reported Outcome Measures
RCSI	Royal College of Surgeons of Ireland
SB	Spina Bifida
SDR	Selective Dorsal Rhizotomy
SLT	Speech and Language Therapy
TBI	Traumatic Brain Injury
UK	United Kingdom
WTE	Whole Time Equivalent

## 35.8 REFERENCES

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