Managed Service Network for Neurosurgery

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MANAGED SERVICE NETWORK
NEUROSURGERY

Paediatric Neurosurgery in Scotland 2015

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Different cell types in the sixth and early seventh layer of the cerebral cortex (detail 1904) - Santiago Ramón y Cajal
Study of a child's head by Leonardo da Vinci

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Purkinje cell (1899) - Santiago Ramón y Cajal

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Foreword

Neurosurgery in Scotland has been the subject of a number of reviews to determine how best to deliver a highly specialised service to a geographically disparate population. In 2008 the Final Report of the Neuroscience Implementation Group[1] recommended the establishment of a novel kind of network: a managed *service* network for neurosurgery. The Managed Service Network for Neurosurgery (MSN) was established in 2009 and published the results of the first national audit of adult neurosurgical services in Scotland in 2013[2]: the focus now moves to the paediatric service.

In Scotland healthcare is a devolved power to the Scottish Government, however we must ensure that when measuring the standard of care we deliver to the Scottish population, we are cognisant of the expected standards elsewhere in the UK. To that end, I am delighted to see that the MSN has taken into account the work of the National Specialised Services *Safe and Sustainable* Team[3] for paediatric neurosurgery in NHS England, and incorporated key quality measures into a bespoke audit model that best meets the needs of our geographically diverse population.

The *Safe and Sustainable* process introduced a number of standards that were a driver for concentration of the English service into fewer, bigger units[4]. Scotland's geography and demographics mean that concentration of services here would significantly threaten equity of access to treatment. The individual units in Scotland cannot meet some of the volume-based standards set out in *Safe and Sustainable* so it was therefore necessary for the MSN to develop an alternative approach to setting meaningful, quality-based standards.

The volume of paediatric cases across Scotland is such that it was essential to develop a robust system to define which procedures could be performed safely in each of the units. This categorisation of surgical procedures has been developed and implemented by the MSN and underpins safe delivery of the service. In conjunction with this development, the Paediatric Advisory Group to the MSN developed a national audit programme to examine whether the Scottish units individually meet the qualitative standards set out by UK national bodies, and whether together as a whole they can meet the quantitative standards.

This report provides a description of the neurosurgical service for children in Scotland and a baseline for future assessment of the service. Multidisciplinary review panels

visited the four units to assess the service provided in each centre and the outcome of these visits, and the results of an audit of the patient journey for a randomly selected cohort of children, are included in this report.

The MSN concludes in this report that the model of service delivery for paediatric neurosurgery in Scotland is safe.

There are exciting developments in healthcare in Scotland including major investment in two new, purpose-built paediatric hospitals: the recently opened Royal Hospital for Children in Glasgow and the new Royal Hospital for Sick Children in Edinburgh which is scheduled to open in 2017. The delivery of a safe paediatric neurosurgery service can only be enhanced by these developments which provide an ideal environment in which to look after our patients and their families.

Dr Catherine Calderwood

Chief Medical Officer

Executive Summary

The Managed Service Network for Neurosurgery (MSN) was established in 2009 with a remit to develop a single neurosurgical service delivered on multiple sites, designed to best meet the needs of the people of Scotland. This is the first of two reports of a national audit of the paediatric neurosurgical service. The national paediatric audit programme was designed by the Paediatric Advisory Group to the MSN. We have worked with patient representatives, partners in the third sector and the multidisciplinary teams and specialties involved in delivering the neurosurgical service for children in Scotland to ensure that the audit programme focuses on what matters most to patients and their families.

The national audit programme comprises eleven national standards, two quality performance indicators (traumatic brain injury and neuro-oncology) and a patient and parent experience survey.

The national report describes the systems, scope and facilities for paediatric neurosurgery in the four units: Glasgow, Edinburgh, Dundee and Aberdeen and focuses primarily on descriptive components of the national standards as they relate to the patient journey.

The key points of the report are:

- The model of delivery of paediatric neurosurgery in Scotland is safe. The model uses different strategies and solutions than those adopted in areas of the UK with greater population density but shares the national goals of safety, long term stability, support for excellence and accessibility especially for acute life threatening cases.
- Each of the four units plays an important role in the national service which the audit process has helped to define. In 2014 a total of 299 children accounted for 513 procedures undertaken in Scotland.
- A system has been developed to categorise paediatric neurosurgery according to level of complexity and associated support needs. The three categories of surgical complexity form the basis for delivering a safe paediatric neurosurgical service in Scotland by determining which procedures can safely be undertaken in each unit.
- An audit was undertaken of the patient journey of a subset of the 299 children who presented to neurosurgery in 2014. A total of 104 children who accounted for 122 admissions were included in the audit. This detailed review of the national paediatric standards as they applied to the individual components of the patient journey showed that although there is room for improvement in certain areas in certain units, there was no evidence giving cause for concern about the care provided to children undergoing neurosurgery in the four units in Scotland.
- The two larger units in Glasgow and Edinburgh have a good balance across all three levels of complexity defined by the audit process.

- The two smaller units in Aberdeen and Dundee are performing surgery of an appropriate level of complexity that does not depend upon access to paediatric intensive care or a 24/7 paediatric neurosurgery subspecialty on call rota.
- Paediatric cases are not rare and uncomfortable events in the two smaller units which treat about two operative cases per month and assess and treat as many more non-operative cases.
- All units had areas of strength and good practice and areas for improvement.
- It was intended that wide participation in the audit process and in particular the Audit Review Panel visits to each centre would play a role in building relationships between units and disseminating examples of good practice throughout the service. Evidence of this was observed during the visits and bodes well for the national service.

National clinical audit is an essential foundation of the Managed Service Network. It is our belief that the model of service delivery for paediatric neurosurgery is safe, it has structures to support excellence and that this can be maintained in the medium and longer term.

Introduction

In 2009 the Managed Service Network for Neurosurgery (MSN) was established with a remit to improve services for patients by incorporating the four neurosurgical units into a single service. The units continue to provide services locally but are managed nationally by the MSN which in turn reports to the Cabinet Secretary for Health and Wellbeing.

Central aims for the network were the establishment of a common data set, prospective national audit and development of agreed clinical standards to support patient safety, quality of services and equity of access to treatment. The MSN published Clinical Standards for Neurosurgical Services in Scotland[5] in September 2010 and an audit of all four adult units against the standards was undertaken, reporting in 2013[2].

Neurosurgery is a specialist tertiary receiving service. The specialty treats around 7,500 patients a year in four cities: Glasgow, Edinburgh, Dundee and Aberdeen. In 2014 a total of 513 neurosurgical procedures were undertaken in children and young people under 16 years of age. This report provides a description of how the paediatric service is delivered in the four centres and levels of activity in each of the units.

The Clinical Standards for Neurosurgical Services in Scotland[5] included paediatric standards, however the Paediatric Advisory Group of the MSN thought that a more detailed audit of paediatric neurosurgery was merited for several reasons:

- The subspecialty was in a period of transition at UK, Scottish and local levels;
- No neuroscience unit in Scotland had co-location of Neurosciences and tertiary paediatrics to the level of Paediatric Intensive Care at this time – the central recommendation of the Youngson report of 2001[6]; and
- New UK standards were published in 2011[7] as part of the *Safe and Sustainable* process. These standard were a component of a commissioning process by the Department of Health in England and were informed by our national professional body, the British Paediatric Neurosurgical Group, a subgroup of the Society of British Neurosurgical Surgeons.

Many of the UK standards are quantitative or volume-based. Scotland's geography, population and service configuration make many of the UK standards difficult or impossible to achieve in some units. This posed a challenge for the Paediatric Advisory Group: how to ensure the national paediatric service could be delivered safely in four centres functioning as a national network, and how to assure patients and their families, colleagues, referring physicians, and professional bodies that the Network meets the UK *qualitative* standards and that current configuration of the service can be maintained in the longer term.

Reporting on the paediatric neurosurgery service is challenging. The service is provided in two larger units in Glasgow and Edinburgh and two smaller units in Aberdeen and Dundee. The fundamental differences between the larger and smaller units are the availability of 24/7 paediatric neurosurgeons and paediatric critical care facilities. These two factors determine the level of complexity of surgery that can be offered in the centres and necessitate the transfer of children requiring more complex surgery to the larger units in the central belt. Defining the levels of complexity of surgery was therefore the first stage in the audit process. The MSN has defined three categories of surgery based on both the urgency and the complexity of the procedure (see page 14). We have also defined appropriate levels of subspecialisation, access to subspecialty consultation in paediatric neurosurgery as well as paediatric critical care support for procedures in each category. The goal is to define the remit and role of each unit within the single networked service and to open pathways for discussion of cases.

A further challenge is reporting on a service where one of the units is relocating *during* the audit process. In March 2012 the paediatric neurosurgery service in Glasgow moved out of the Institute of Neurological Sciences into the Royal Hospital for Sick Children at Yorkhill. In June 2015 the service returned to the south Glasgow site to the new Queen Elizabeth University Hospital and is once more co-located with the adult neurosurgical service. This report reflects paediatric service as it was delivered at Yorkhill in 2014 prior to the move so the service in the new Royal Hospital for Children will be audited again in 2016.

The paediatric service in Edinburgh will move to a purpose-built facility at the Royal Infirmary of Edinburgh in 2017 and this will result in co-location of adult Neurosciences and tertiary paediatrics in Lothian. The two smaller neurosurgical units in Aberdeen and Dundee are already housed in modern hospitals where the paediatric service is co-located with neurosurgery and though they lack paediatric intensive care provision, they have systems in place for the management of children who require high dependency care or who may need transfer to paediatric intensive care in Edinburgh or Glasgow. They also provide excellent family facilities; an essential consideration for our patient group.

Finally, there was also a concern that our target-driven healthcare culture tends to place the greatest value on things that are easiest to measure. We wanted to ensure that our standards were clinically relevant. This report is a descriptive account of the service as it is delivered in the four units and includes an audit of the patient journey of a representative sample of patients from each unit.

Jennifer Brown

National Lead for Paediatric Neurosurgery
Managed Service Network for Neurosurgery

Paediatric neurosurgery in Scotland

There are four neurosurgical units in Scotland. The unit-specific information provided in this report is presented in the order in which the Audit Review Panel visited the units in 2015:

- Glasgow
- Edinburgh
- Dundee
- Aberdeen

The Managed Service Network for Neurosurgery was established in 2009. Addressing the needs of the paediatric population was considered by the MSN Board to be a priority for the network. The Paediatric Advisory Group (PAG) was formed to consider the specific needs of the paediatric age group (birth to 16th birthday) and to advise the MSN on how best to meet these needs. Scotland has a population of just over 900,000 children in this age group[8].

The PAG has representation from all four units and is a multidisciplinary group that includes patient and third sector members (Appendix I). Though various models have been considered over the years prior to and since the inception of the MSN, an over-riding concern for equity of access has been the rationale for maintaining an ability to treat children in all four centres. It was considered that the main advantages of concentrating the service in fewer centres could equally be achieved by good communication and good referral practice for complex cases and that this model would preserve better access for the most common and perhaps most treatable cases but crucially, also for the most acutely life-threatening cases.

A proliferation of guidance from various professional and regulatory bodies can be seen to be in conflict. For example, to develop 24/7 paediatric subspecialty cover and for each subspecialist to maintain an operative caseload of 50 cases per year would require concentration of services into fewer units. To maintain immediate access for our sickest children throughout the country and maintain access to neurosurgical care within two hours by road requires retention of all four units. This is the reason that we need to learn to function as a single service on four sites. Auditing paediatric neurosurgical provision as a single service in which each site has a defined role to play is an important step in 'squaring the circle'.

The Society of British Neurological Surgeons (SBNS) recommends that no child should be more than two hours by road from neurosurgical care[9]. In England, the *Safe and Sustainable* process gave serious consideration to concentrating services in fewer, bigger units[4]. With a population density of 68/km^2 in Scotland[8] compared to 413/km^2 in England, this strategy is less practical. Population densities are even

lower for the 30% of the population outside the Central Belt of Scotland. At the same time the four units have different resources and different roles within the Scottish service and together can meet the two hour recommendation for about 92% of the population. These resources have changed over time and continue to evolve but may be summarised briefly:

- Paediatric neurosurgery in Glasgow was in transition during the audit period and has moved to the new Royal Hospital for Children co-located with the adult neurosurgical unit at the Queen Elizabeth University Hospital (at the Southern General site) since the audit visit. This is a tertiary paediatric hospital with a 24-bedded Paediatric Critical Care Unit (PCCU) with Level 2 and Level 3 provision. There are four consultant paediatric neurosurgeons. This unit is large enough and consistently staffed to a level that can support other units during crises in staffing or other resource challenges. It is home to the UK's oldest craniofacial service and offers complex craniofacial surgery for the population of Scotland. It also hosts the National Vein of Galen service.
- Paediatric neurosurgery in Edinburgh will undergo a similar transition in 2017 when the Royal Hospital for Sick Children in Edinburgh relocates to same site as the Royal Infirmary of Edinburgh. The adult neurosurgical service will also relocate at the same time. Currently the paediatric service is provided in the existing children's hospital. This is also a tertiary paediatric hospital which has an 8-bedded PCCU (Level 3), and an additional 6 HDU (Level 2) beds. There are three consultant paediatric neurosurgeons and a consultant neurosurgeon with paediatric training and an ongoing interest in paediatrics. This unit is also large enough to support other units when the need arises. It hosts the National Paediatric Epilepsy Surgery service.
- Paediatric neurosurgery in Dundee is provided at Tayside Children's Hospital which is co-located with the adult neurosurgical service at Ninewells Hospital. There is a neurosurgeon with paediatric training and an ongoing interest in paediatrics, a paediatric high dependency unit (supported by the adult intensive care unit) and paediatric anaesthesia provision.
- Paediatric neurosurgery in Aberdeen is provided at the Royal Aberdeen Children's Hospital which is co-located with the adult neurosurgical service at Aberdeen Royal Infirmary. There is a neurosurgeon with paediatric training and an ongoing interest in paediatrics, now supported by a new consultant who also has an interest in paediatrics. There is a paediatric high dependency unit, an adult intensive care unit and paediatric anaesthesia provision.

  The PCCUs in Glasgow and Edinburgh share responsibility for paediatric retrieval in Scotland.

Glasgow is the only unit that has a sufficient caseload to meet the recommendation of the British Paediatric Neurosurgical Group (BPNG) that paediatric neurosurgeons manage 50 operative cases per year[10]. Even in this unit, there is sufficient variation that not every consultant achieves the recommended number of cases every year.

Throughout the Scottish service, two strategies to maintain skills and judgement in the face of smaller numbers are: (1) joint operating between two consultants, and (2) concentration on a pathology-based subspecialty across paediatric and adult practice to develop transferable skills and experience. This has the added benefit of beginning to offer children a degree of pathology-based subspecialisation that has come to be expected in adult neurosurgery.

While it is recognised that planned paediatric neurosurgery in NHS Grampian and NHS Tayside is primarily provided in each unit by a single surgeon with an interest in paediatric neurosurgery, and the service is therefore dependent on these individuals, their practice and expertise as well as a regular throughput of paediatric neurosurgical cases helps to maintain institutional experience across disciplines. Though these units do not have Level 3 PCCU provision on site, both have high dependency capability and have anaesthesia facilities for children, including facilities for short-term ventilation of children pending retrieval to the larger units in Glasgow and Edinburgh.

All of the units have close relationships with other specialties that care for the same patient groups such as oncology, neurology and other surgical specialties or have specific skills needed to support paediatric neurosurgery such as emergency medicine, neonatology, paediatric intensive care and anaesthesia and the various paediatric subspecialties. There are a variety of multidisciplinary teams that meet either locally, regionally or nationally to afford opportunities for discussion, consultation and audit.

The national audit programme – how to ensure the service is safe?

The national audit programme for paediatric neurosurgery comprises four main components, the first two of which are contained within this report and the latter two will be reported in 2016.

1. An external review of the service provided in each centre by a multidisciplinary Audit Review Panel using a descriptive report based on the standards as an audit tool;
2. Measuring compliance with eleven national standards:
   - qualitative aspects in a description of the service
   - quantitative aspects in an audit of the patient journey;
3. Reporting on quality performance indicators relating to the management of children with traumatic brain injury and those requiring the services of neuro-oncology; and
4. A patient and parent experience survey

The PAG started work on developing the national paediatric standards in 2013. The complexity of generating meaningful audit tools to enable the collection of baseline data to measure compliance with the standards was such that data collection did not begin until 2014. Lessons learned from the audit of compliance with the adult standards informed the process: it was important to make an informal visit to each unit in advance of starting data collection, a detailed description of the service in each centre was required to answer the qualitative aspects of the national standards, and formal visits to the units were undertaken by a multi-disciplinary review panel reflecting the mix of disciplines involved in providing the service as well as parent and third sector representation. Additionally, reporting to the units was prompt: immediate feedback on the day and written feedback within two weeks of the visit, with the units asked to respond to the interim reports within 2 weeks of receipt.

Visits to the four centres

The formal visits to the four centres took place over a nine week period:

- Glasgow, NHS Greater Glasgow and Clyde on February 27th 2015
- Edinburgh, NHS Lothian on April 1st 2015
- Dundee, NHS Tayside on April 17th 2015
- Aberdeen, NHS Grampian on May 1st 2015

The PAG was keen that as many members as possible should have the opportunity to participate in at least one visit as a member of the multi-disciplinary Audit Review Panel (see Appendix 2). The national lead for paediatric neurosurgery and the national network manager were present at all the informal and formal visits.

The descriptive report was circulated to the host centre and the Audit Review Panel in advance of each visit and the senior management team of the host centre was invited to provide an introductory presentation about their service at the start of the visit. The panel members then toured the clinical areas to meet with staff and ask any questions arising from the descriptive report. Additional role-specific meetings were arranged when it was practical to do so. Panel members then met up at the end of the day to discuss their findings and the Chair of the Panel presented the outcome of the visit to the senior management team of the host centre.

The outcome of this component of the national paediatric audit programme is presented in this report. The summary findings of each visit, as they were presented to the local senior management teams on the day of the visit, are provided in the results section of the report. The interim reports of the visits submitted to each centre contained requests from the Audit Review Panel for more detailed information about the specific findings, following which each centre submitted their responses. Areas for improvement have been identified and the MSN will work with centres to achieve these aims.

This report provides a baseline for the paediatric neurosurgery service in Scotland and return visits will be made towards the end of 2015 and beginning of 2016 to review progress against the action and improvement plans submitted by the centres.

This report also presents quantitative evidence of how the national standards apply to individual patient journeys. All paediatric patients in Aberdeen and Dundee and a randomly selected sample of 40 patients in both Glasgow and Edinburgh (10 for each surgeon) have been included in a patient journey audit.

The first of the national standards is also the most difficult to audit: communication. We have worked with patients and their families or carers, the third sector and our *Neurosurgical Voices* groups to design a patient experience survey. The wide diversity of age ranges in the audit (from birth to their 16th birthday) has made this exercise particularly challenging. The survey will be reported in 2016.

Diana Beard

National Network Manager
Managed Service Network for Neurosurgery

Paediatric Neurosurgical Procedures – providing a safe service

In March 2009 Professor Sir Bruce Keogh (NHS Medical Director) asked the National Specialised Commissioning Group (NSCG) to review the delivery of paediatric neurosurgical services in England and develop robust proposals that would secure safe and sustainable world class services for children and their families[4]. These goals are shared by paediatric neurosurgical services in Scotland though the systems and strategies to achieve them differ in accordance with Scotland's geography and population as well as the configuration of neurosurgical provision.

Advice from the National Specialised Commissioning Group Review

The review of the paediatric neurosurgical service in England reported in 2010[4] and highlighted concerns about the neurosurgical management of some children requiring emergency surgery. In response the Royal College of Anaesthetists and the Society of British Neurological Surgeons issued a joint statement[11] which is cited in part below:

There are three main concerns:

- *Some surgeons and anaesthetists at neurosurgical centres that provide routine services to adults only, have indicated that they do not feel confident to care for a child with a life-threatening condition; the end result could be that some children in this situation will be refused emergency surgery at such centres.*
- *The ability of non-specialist hospital teams to take responsibility for resuscitating and stabilising children with life-threatening neurosurgical conditions.*
- *The perceived competence of staff at non-specialist hospitals to be responsible for transferring children with life-threatening neurosurgical conditions to tertiary paediatric neurosurgical services.*

Whilst the need for unscheduled admission of children to neurosurgery is relatively frequent, the need for immediate life-saving neurosurgery is rare.

Children requiring immediate life-saving care may present to hospitals without neurosurgical services however and require urgent stabilisation and transfer to a neurosciences centre. Such children may also present to Emergency Departments (ED) in hospitals with an 'adult only' neurosurgical service. Both situations necessitate emergency management of children by clinicians who may not treat children requiring neurosurgical care on a regular basis.

Clinicians called upon to provide this very occasional life-saving surgery or emergency transfer of a sick child, should be fully supported by their senior hospital management, paediatric neurosciences centre and professional associations.

The NSCG review concluded that:

> *Most children with life-threatening neurosurgical conditions will come to more harm from the delay related to the time waiting for a paediatric intensive care (PIC) retrieval team to travel to the referring hospital than from the relative risks of a direct transfer by the non-specialist hospital transfer team, or from emergency neurosurgical care by the adult neurosurgical team prior to transfer for definitive care.*

To apply this advice in a Scottish context the PAG considered the configuration of the four units in Scotland and the training of the consultant body providing out of hours neurosurgical services.

There is clearly a requirement to provide some paediatric neurosurgical procedures in all four of the centres in Scotland to address the first of the three concerns identified in the joint statement. The joint statement however acknowledges the rarity of the need for immediately life-saving neurosurgery and the PAG feared that despite this document's assurance of support, a unit required to treat only rare immediately life threatening cases would likely fail at the point of need if that unit had no regular experience of paediatric neurosurgical cases. At the same time, the Scottish units are currently well placed to comply with the guidance and the PAG is concerned to maintain this capacity. One of the strategies to maintain capacity is to lower the threshold for treating children locally. Essentially, Scotland does not have 'neurosurgical centres that provide routine services to adults only'. Criteria for category I and 2 surgery (see overleaf) take the risks (real or perceived) of this strategy into consideration.

Paediatric Content of General Neurosurgical Training

The Joint Committee on Intercollegiate Examinations[12] sets out the requirements for training in paediatrics for completion of general neurosurgical training:

> *Before completing their training, all neurosurgical trainees will undertake a six month placement in a paediatric neurosurgery service under the direct supervision of paediatric neurosurgeons with a full-time or major commitment to paediatric surgery.*
>
> *The service must provide a comprehensive range of paediatric neurosurgical care (with the exception of supra-regional services) and have a minimum annual operative workload of 250 cases.*
>
> *On completion of general paediatric training trainees will be competent to assess and undertake the emergency neurosurgical management of the critically ill child with raised intracranial pressure.*

All neurosurgeons are therefore trained and able to treat acute life-threatening neurosurgical emergencies in children. All Scottish neurosurgical units either have a

subspecialised paediatric section within a children's hospital or the adult neurosurgical unit is co–located with a children's hospital. There is therefore no reason for a child with a life-threatening neurosurgical condition to be refused care in any of the Scottish neurosurgical units.

Categories of surgery – which procedures where?

In order to ensure the national paediatric neurosurgery service is provided safely, the PAG determined which types of paediatric neurosurgical procedure could be provided in each unit. The categorisation was ratified by the MSN Board in October 2014. This process was not only fundamental to the delivery of a safe service in Scotland but also helped to define each unit's role within the Scottish service.

The PAG determined three categories of surgery that form the basis of a service that can be safely delivered within the restrictions of the wider service provision, namely the availability of paediatric intensive care and availability of a paediatric neurosurgeon on a 24/7 basis.

Category 1 Surgery

All four units should be able to provide care for paediatric patients requiring emergent neurosurgical intervention. This should be provided by any on call neurosurgical consultant with or without an interest in paediatric neurosurgery and would include any case where there is significant risk of deterioration such that transfer to a dedicated paediatric neurosurgical unit would be unsafe. This is in keeping with the joint statement of the Royal College of Anaesthetists and the SBNS[11] and with defined neurosurgical competencies of the Intercollegiate Surgical Curriculum Project[13].

Patients requiring paediatric intensive care following emergency surgery will be referred to the neurosurgical and critical care teams in either Glasgow or Edinburgh.

Interventions in Category 1 include:

Immediate surgical management of acutely raised intracranial pressure (ICP) from an expanding haematoma or acute hydrocephalus from shunt malfunction e.g.

- craniotomy for trauma and evacuation of intracranial haematoma
- decompressive craniectomy
- placement of an ICP monitor
- placement of an external ventricular drain (EVD)
- revision or new placement of a ventriculoperitoneal shunt

These procedures should generally be performed at the unit where the child initially presents even if the threat to life is not thought to be immediate.

Category 2 Surgery

Some element of elective paediatric operating enables maintenance of skills of both operating surgeons and theatre teams. The neurosurgeons with a paediatric interest in Dundee and Aberdeen should provide elective or urgent surgery which is an extension of established adult practice and where the paediatric element is analogous to and informed by the knowledge/skills gained from adult practice, or is established paediatric practice open to external audit.

Consideration should be given to the benefits of discussion with colleagues in Glasgow or Edinburgh.

The conditions treated and surgery itself cannot rely on the availability of 24/7 paediatric neurosurgery or ventilation in a Level 3 PCCU but may involve observation in the local HDU.

Interventions could include:

- management of myelomeningocele
- insertion of *Baclofen* pumps
- intraventricular haemorrhage management
- 'simple' cases of Chiari malformation in teenage patients
- resection of surface lesions
- vagal nerve stimulation
- management of acute hydrocephalus with endoscopic third ventriculostomy (ETV)

The crucial emergency treatment in acute obstructive hydrocephalus is insertion of EVD but for surgeons with endoscopic skills a natural extension is to introduce an endoscope at the same anaesthetic and inspect the floor of the third ventricle for ETV to proceed if possible. Not all adult neurosurgeons have this skill nor is there a sufficient volume for all to maintain this skill so it cannot be included in category 1 (i.e. we require all consultants to be able to perform this).

Category 3 Surgery

There are cases that should always be referred to specialist services in Glasgow or Edinburgh. These are cases that would benefit from availability of a Level 3 PCCU and 24/7 subspecialty paediatric neurosurgery cover.

Interventions include:

- malignant neuro-oncology cases particularly if there is a drive for "super-resection" of medulloblastoma or ependymoma that may require post-operative ventilation for brainstem dysfunction
- pilocytic astrocytoma in children aged over 5 years may or may not fall into this group

- posterior fossa and deep-seated tumours
- vascular cases
- craniosynostosis surgery
- epilepsy surgery
- selective dorsal rhizotomy
- complex dysraphic syndromes with tethering
- rare complex patients such as Morquio syndrome, neurofibromatosis type II, etc.
- very complex hydrocephalus patients with slit or isolated ventricles may fit between categories 1, 2 and 3 depending on their presentation
- complex anomalies at the craniocervical junction

Consideration must also be given to patient comorbidities which of themselves may require highly specialised perioperative assessment, preparation and management in Glasgow or Edinburgh, or even further afield.

The levels of activity in all three categories in 2014 are provided in table 1. A relatively even balance of cases in the three categories in Glasgow and Edinburgh and the absence of category 3 cases in Tayside and Grampian suggest that the categorisation is working well.

Table 1 Categories of surgery performed in 2014

	Category 1	Category 2	Category 3	Total
RHSC Glasgow (Yorkhill)	88 (34.2%)	83 (32.3%)	86 (33.5%)	257
RHSC Edinburgh	63 (36.6%)	44 (25.6%)	65 (37.8%)	172
Tayside Children's Hospital	7	15	0	22
Royal Aberdeen Children's Hospital	23	8	0	31
Scotland	**181**	**150**	**151**	**482**

* Excludes 30 procedures in under 16s performed at the INS, Glasgow and one procedure undertaken on a 14 year old child in the adult unit in Aberdeen Royal Infirmary.

How the service is delivered

The four units

The four neurosurgical units in Scotland provide adult and paediatric services. In this section of the report we provide a description of the various components of the service in the order of a patient journey. A descriptive report of each unit was written in conjunction with the local teams in each centre and these reports formed the basis of the audit tool that the multidisciplinary Audit Review Panels used during the visits to the children's hospitals. The descriptive reports addressed qualitative aspects of the national standards and enabled each unit to provide the MSN with an action plan in response to the findings of the Audit Review Panel.

In Glasgow and Edinburgh neurosurgical care is managed and delivered in neuroscience wards by a specialist medical and nursing team who are dedicated to this specialty and are supported by a larger staff group with responsibilities for neuroscience or general paediatrics. In Dundee children are looked after in a mixed medical and surgical ward and in Aberdeen they are looked after in either the surgical or medical ward while under the care of a neurosurgeon.

The information in this section of the report is provided in the order in which the visits to the units took place.

The Royal Hospital for Sick Children, Glasgow

The new Royal Hospital for Children at the Queen Elizabeth University Hospital is a 256 bedded facility that provides a specialist paediatric service to the population of the west coast of Scotland up to their 16th birthday. It opened on 10th June 2015. Much of the information in this report was collected in the year before the opening and reflects an interim model: in 2012 the West of Scotland paediatric neurosurgery service for children less than 13 years of age re-located from the Institute of Neurological Sciences (INS) at the Southern General Hospital to the RHSC at Yorkhill following prolonged discussions and a review process that was externally guided. The interim model was a compromise because of the lack of middle grade cover out of hours and children aged 13 years or older continued to be accommodated in the INS at the Southern General Hospital. Information relating to 30 procedures undertaken on children aged between 13 and 16 who were managed at the INS is not included in this report.

Following the opening of the new Royal Hospital for Children, paediatric and adult neurosurgical services are once again located on a single site, and paediatric neurosurgical patients will now have access to both specialist neurosurgical facilities and specialist paediatric facilities including Level 3 paediatric critical care. Co-location of neurosurgical services for children and adults and tertiary paediatrics to the level of PICU was the chief recommendation of the Youngson report report in 2001[6].

The Paediatric Neurosurgery Team

The four consultant neurosurgeons who provide the paediatric service are based within the Department of Neurosurgery at the INS, each spending one week in every four as the duty consultant at the children's hospital. During this week all commitments to the adult service at the INS are suspended.

The duty consultant neurosurgeon is supported by a specialty trainee in neurosurgery. Although the specialty trainee is based at the RHC they remain on the adult service on call rota to ensure compliance with the European Working Time Directive[14]. When the service was based at Yorkhill, this arrangement resulted in a lack of middle-grade neurosurgical input to the paediatric service out of hours and sometimes within hours. In addition, a senior clinical fellow has been appointed to augment the middle-grade cover during the hours of 9 am to 5 pm. A newly created neuroscience staff grade post was appointed and commenced duties in April 2015. The team also comprises a paediatric neurosurgery advanced nurse practitioner and a neurosurgery specialist outreach nurse.

Paediatric neuroscience nurses and administrative staff are central to the delivery of the neurosurgery service. General paediatric radiology, critical care, theatre staff and allied health professionals are also essential service providers of the neuroscience service but are not dedicated exclusively to the specialty.

Out of hours cover

Out of hours cover on the Yorkhill site was provided by a paediatric or adult consultant neurosurgeon as there was no dedicated middle-grade neurosurgical cover. Eight consultant neurosurgeons from the adult service at the Southern General Hospital contributed to this rota, which also included the Senior Clinical Fellow. In addition, a named consultant paediatric neurosurgeon was always available for advice and assistance out of hours and this 24/7 subspecialist cover will continue in the new hospital.

Return to single site working with opening of the new children's hospital is expected to improve frequency of on call for adult colleagues and intensity of on call for the paediatric neurosurgeons as resident neurosurgical middle-grade cover will once again be available on a 24/7 basis. Out of hours general paediatric medical care is provided by a paediatric middle-grade doctor. Weekend ward rounds are conducted by the paediatric neurosurgeons.

The Royal Hospital for Sick Children, Edinburgh

The RHSC has a complement of 97 beds in summer and 108 in winter. The hospital provides specialist care for children and young people from Lothian and surrounding areas and is one of two hospitals providing the National Paediatric Intensive Care Service. The inpatient specialties at the children's hospital treat young people until the age of 13, however older children with long-term conditions can be kept under the care of their specialist team in RHSC and can still be looked after in the children's hospital if it is considered in their best interest to do so. The paediatric neurosurgical service looks after patients up to (and occasionally beyond) the age of 17.

In 2017 the RHSC will be replaced by a new children's hospital at the Royal Infirmary of Edinburgh, Little France. The adult Department of Clinical Neurosciences (DCN), currently based at the Western General Hospital (WGH) in Edinburgh, will relocate at the same time so the neuroscience service for both adults and children will benefit from single site provision with access to both specialist neurosurgical and specialist paediatric facilities. Children up to the age of 16 will be looked after in the new children's hospital.

The paediatric neurosurgery service in the RHSC Edinburgh provides a comprehensive service and, together with colleagues in Glasgow, supports the paediatric neurosurgical service provided in the two smaller units in Dundee and Aberdeen.

The Paediatric Neurosurgery Team

There are three substantive paediatric neurosurgery posts and a fourth neurosurgeon with paediatric training and a focus on epilepsy in both paediatric and adult practice. The four consultant neurosurgeons work between the RHSC and the adult neurosurgical unit based at the WGH. Each of these consultants works two weeks in the paediatric service and two weeks in the adult service. Two surgeons are allocated to the paediatric service each week.

The duty consultants at the RHSC have no commitment to the adult service while providing the paediatric service. There is a neurosurgery specialty trainee on rotation from adult neurosurgery for a six month period. A team of five full-time and one part-time paediatric neurologists provide medical cover in the unit. In addition, a neurorehabilitation/neurodisability consultant contributes three weeks a year to this rota. Emergency and elective patients are admitted under the joint care of the neuroscience team.

There are a total of five specialist nurses in the unit: an epilepsy nurse consultant, an epilepsy surgery nurse (national appointment), two specialist nurses who support patients with vagal nerve stimulator implants and a neurology nurse specialist whose role includes an outreach service for children who have sustained a traumatic brain injury.

Administrative support to the neurosurgical team is provided by one full-time medical secretary.

Out of Hours Cover

All children admitted to the neuroscience unit are admitted under joint care with neurology. Middle-grade neurosurgeons support the out of hours on call service but are also on call for the DCN. All inpatients receive 24/7 paediatric neuroscience consultant cover.

In addition to the four consultant neurosurgeons who form the paediatric service, support (advice) is available from six of the consultant adult neurosurgeons, two of whom have extensive paediatric neurosurgical experience. Paediatric neurology consultants conduct the ward rounds at the weekend and will contact the on call neurosurgeon for adults if there is a requirement to do so. If necessary, the on call neurosurgeon for adults will then contact the on call paediatric neurosurgeon.

Tayside Children's Hospital, Dundee

Tayside Children's Hospital (TCH) is a 61 bedded facility adjacent to the adult and maternity facilities of Ninewells Hospital. It benefits from being co-located with the adult service with use of shared facilities.

The paediatric neurosurgery service for children in Tayside and north Fife provides an emergency service with some elective work but does not cater for the full range of complex neurosurgical conditions in children. Those children needing more complex neurosurgical intervention have their care delivered in either Edinburgh or Glasgow.

The neurosurgical care of children under the age of 14 in TCH is delivered using a shared care model by consultant paediatricians, paediatric neurologists and consultant neurosurgeons. Young people aged 14 and older are managed by the adult neurosurgery unit in the adjacent Ninewells Hospital.

The Neurosurgical Team

There are four consultant neurosurgeons in Ninewells Hospital. All four consultants are expected to manage paediatric neurosurgical emergency cases when they are on call. Although there are no specialist paediatric neurosurgeons in the unit, one consultant neurosurgeon has training in paediatric neurosurgery and a special interest in paediatric cases; this surgeon undertakes the majority of elective procedures as well as the neurosurgical follow up for paediatric cases. There is no neurosurgery specialty trainee dedicated to the paediatric service, however, all specialty trainees within the adult service gain experience of paediatric emergency and elective care whilst on call or working for the consultant with a paediatric subspecialty interest.

Out of hours cover

Consultant medical cover on the ward is provided from 8am to 6pm by the 'attending' consultant paediatrician and a paediatric consultant neurologist. The paediatric

specialty trainee provides 24/7 cover, however if no specialty trainee is available for on call duties overnight, the consultant paediatrician will remain on site. There is 24 hour access to neurology advice from a consultant paediatric neurologist.

Neurosurgery out of hours cover is provided by the adult unit with 24 hour access to a neurosurgery specialty trainee and consultant neurosurgeon. The neurosurgery specialty trainees are not resident in the hospital but live nearby.

Royal Aberdeen Children's Hospital, Aberdeen

The Royal Aberdeen Children's Hospital (RACH) has a complement of 103 inpatient beds and 13 day beds. It is co-located with Aberdeen Royal Infirmary, Aberdeen Maternity Hospital and the Medical School of the University of Aberdeen on the Foresterhill campus. It provides a comprehensive range of paediatric services, including the regional paediatric neurosurgery service for children and young people up to age sixteen in the North-East of Scotland.

Paediatric neurosurgical intervention in Aberdeen is an infrequent occurrence and is usually undertaken as an emergency or urgent procedure. Children requiring specialist paediatric neurosurgery, or who are likely to need paediatric intensive care, are referred to the paediatric neuroscience units in Edinburgh and Glasgow.

The Neurosurgical Team

There are five consultant neurosurgeons based in the adult Neurosciences Unit at Aberdeen Royal Infirmary (ARI). One consultant neurosurgeon is trained in paediatric neurosurgery and provides most of the planned paediatric neurosurgical care. A recent consultant appointment (June 2015) now provides additional support to the paediatric service.

Junior and middle-grade neuroscience doctors based in the adult Neurosciences Unit support the paediatric neurosurgery service. There are no specialist paediatric neuroscience nurses in the RACH. General paediatric nurses, allied health professionals and administrative staff are central to the delivery of the neurosurgery service in Grampian and are shared with other paediatric specialties.

Out of hours cover

Out of hours neurosurgical cover is provided by all five consultant neurosurgeons. Middle-grade out of hours cover is provided by the Neuroscience Unit as the first point of contact at evenings and weekends for the paediatric neurosurgery cases.

The general medical paediatric cover for neurosurgery patients is provided by the Surgical Ward team.

Consultant paediatricians are available on site from 8.30am to 5pm during Monday to Friday and a resident on call consultant is available outwith these times. Paediatric

specialty trainees and surgical specialty trainees are always present in the hospitals (RACH and ARI respectively). In addition, two junior doctors (FY1 and FY2) provide out-of-hours cover from 20:30 to 08:00 (RACH Medical, Surgical Wards, and HDU). A consultant paediatric surgeon is available on call from home out of hours.

Table 2 The capacity of the children's hospitals

	Total Beds	PICU/Level 3 beds	HDU /Level 2 beds
RHSC Glasgow (Yorkhill)	256	20	2
RHSC Edinburgh	108	8	6
Tayside Children's Hospital	61	0	6
Royal Aberdeen Children's Hospital	103	0	4

Acute presentations to the service

The majority of children present to the service as planned admissions however those who present via the Emergency Departments (ED) may either require emergency or urgent surgery which can involve transfer by air or land to one of the neurosurgical units. The ability of the emergency department teams to recognise a child with an acute neurosurgical emergency and organise appropriate investigations as a matter of urgency is the first step in the prompt and safe management of this patient group.

Children can present to any ED in Scotland and there are guidelines for their management available in all units. In this report, the focus is on the EDs of the children's hospitals in the four centres where paediatric neurosurgery is provided. Table 3 shows the ED activity levels in the four centres and table 4 provides information about on site ED consultant presence.

The Emergency Departments – the first point of access

In Glasgow the Emergency Department is staffed by eight consultants, two of whom are present from 9am to 5pm from Monday to Friday. Out of hours cover is provided by the on call consultant who is present until 11pm, and who will stay in the ED if there is a requirement to do so. Outwith these hours, care is provided by an Emergency Medicine Specialty Trainee CT3, an ST1 paediatric trainee or an ST2 GP trainee. At weekends, a consultant is present in the ED from midday to 6pm and outwith these hours is on call from home. Children up to the age of 16 are managed in the paediatric ED.

In Edinburgh the Emergency Department is staffed by seven consultants who are on site during the hours of 8am to 10.30pm Monday to Friday and for 9 hours a day (worked flexibly) on Saturday and Sunday. Outwith these hours, care is provided by a Specialty Trainee with an ED Consultant on call from home. Children up to the age of 13 are seen in the ED. Older children who present will be seen. In the event of a seriously ill or injured child aged between 13 and 15 presenting to the adult ED at the Royal Infirmary of Edinburgh and requiring intensive care, the child would typically be stabilised and transferred to the Paediatric Critical Care Unit (PCCU) at the RHSC.

In Dundee the Emergency Department in Ninewells Hospital looks after both adults and children and is staffed by 17 consultants. There is always an ED Consultant present until 1am Monday to Friday and until midnight at weekends, and 70% of the time there is a consultant present overnight. The team are also responsible for the ED at Perth Royal Infirmary. There are four middle-grade doctors who support the service.

Paediatric emergencies present to the ED at Ninewells Hospital but children who are referred by their General Practitioner are looked after in an Assessment Unit adjacent to Ward 29 of TCH. The Paediatric Assessment Unit sees approximately 5,500 cases a year, of which 35% were admitted in 2014. This service is available on a 24/7 basis and also provides an 'open access' service for some children e.g. children with a suspected malfunction of a shunt or *Baclofen* pump.

The Emergency Department in the RACH is co-located with the adult ED and is staffed by 10 consultants who are on site during the hours of 8 am to midnight and an on call consultant is available from home outwith these times. The ED consultants work between the RACH and ARI Emergency Departments, with a named consultant present for the RACH. There are approximately 7 to 8 middle grade doctors (Specialty Trainees years 3 - 4) who work on a rota basis between RACH and ARI. Out of hours cover is provided by the consultant on call.

Table 3 Emergency Department activity and admissions in 2014

	New Patient Attendances	Admissions	Neuroscience Admissions
RHSC Glasgow (Yorkhill)	48,508	14,021	93
RHSC Edinburgh	45,659	6,308	84
Ninewells Hospital (TCH)	9,048*	1,410	10
Royal Aberdeen Children's Hospital	18,350	3,977	7

* A further 4,864 children presented to Perth Royal Infirmary.

Table 4 Consultant presence in the Emergency Departments in 2014

	ED Consultant Mon - Fri	ED Consultant Sat - Sun	Number of ED Consultants
RHSC Glasgow (Yorkhill)	09.00 – 23.00	12.00 – 18.00	8
RHSC Edinburgh	08.00 – 22.30	9 hours	7
Dundee (adult and paediatric)	08.00 – 01.00*	08.00 – 24.00	17
Aberdeen (adult and paediatic)	08.00 – 24.00	08.00 – 24.00	10

* There is a 24/7 consultant presence in the ED at Ninewells Hospital around 70% of the time.

Imaging

The key investigations for children (and adults) who are referred to neurosurgery are CT and MRI scanning. These are essential for the accurate diagnosis and subsequent management of patients because they can identify structural pathology requiring neurosurgical intervention and differentiate these cases from other conditions with similar clinical presentations but requiring non-surgical management, often by a different team.

In the RHC Glasgow there is access to CT and MRI scanning. Both scanners are adjacent to theatre and the angiography suite. Neuro-imaging protocols were harmonised prior to the transfer of the paediatric neurosurgical service to the RHC and this appears to have worked well with no technical problems identified. Dedicated anaesthetic facilities for the imaging suite are located adjacent to the MRI scanner and the CT scanner in the new RHC. Functional MRI was available on the Yorkhill site and is to be developed in the RHC. 3T MRI scanning (including anaesthetic facilities) is available in the co-located INS building.

Neurosurgery patients must be booked into the general paediatric radiology service. This may be problematic in some cases in need of urgent imaging prior to emergency surgery. There are no dedicated neurosurgical lists and with a single MRI scanner for all patients, some access issues have been encountered.

A neuroradiologist from the INS had a single allocated session at the RHSC at Yorkhill but within this time was unable to review all neuro-imaging undertaken there. This session is used for review and reporting of neurology and neurosurgery imaging and was in place prior to the transfer of the paediatric service. Paediatric neurosurgical imaging was previously undertaken at the Institute of Neurological Sciences and reported by neuroradiologists. No new resource was made available for reporting neuro-imaging at the RHSC following the transfer of neurosurgery patients to this setting

Neuroradiologists participate in multi-disciplinary meetings for children with cancer and those having epilepsy surgery, reviewing all paediatric imaging in this setting.

Paediatric radiologists are unable to participate in the multi-disciplinary meetings. Paediatric neurologists and paediatric radiologists hold a weekly clinical radiology meeting to review and discuss cases. Although the neurosurgeons are welcome to join this meeting and bring cases for review, the timing of the meeting partly coincides with a paediatric neurosurgery outpatient clinic.

In the RHSC in Edinburgh there is a CT scanner and an MRI scanner. If an MRI scan is required out of hours, four of the ten radiographers on this rota can undertake MRI scans. In the event the radiographer on call cannot undertake an MRI scan, the child can be transferred to the adult DCN at the WGH and the paediatric anaesthetist and nurse who staff the CEPOD theatre accompany the patient.

The anaesthetic facilities for scanning purposes are located within the MRI/CT suite. There is flexibility to request further investigation while the child is anaesthetised and the radiologist will review and report on the scan before the GA is reversed. There are two and a half GA lists a week on average for planned investigations and emergencies are slotted in as soon as possible, with re-scheduling of the planned list. While CT is always available, MRI activity is such that availability is limited.

There is a weekly clinical neuroradiology meeting with the Consultant Neurologists, Consultant Neurosurgeon and Consultant adult neuro-radiologist. There is a supra-regional weekly neuro-oncology meeting which includes (via video conferencing) colleagues from NHS Grampian and NHS Tayside.

Functional MRI is not available at the RHSC in Edinburgh and is currently performed in the adult service at the WGH. The service will be available in the new hospital within the adult patient facilities and paediatric patients will be able to access the service.

In Dundee radiological imaging for children in TCH is incorporated into the main radiology suite in Ninewells Hospital which is also in close proximity to the adult neuroscience unit. There are two multi-slice CT scanners and two MRI scanners, one with spectroscopy available. Functional MRI is not available.

There is a dedicated paediatric MRI list each Monday where three to four children with a variety of conditions are scanned, the majority of whom require general anaesthesia. This is provided by a paediatric anaesthetist who is also accredited for MRI imaging. There are facilities for the administration of and recovery from general anaesthesia immediately adjacent to the scanner. Paediatric neuroscience elective cases are included in the planned paediatric list. There is sufficient flexibility in the structure of the list to undertake additional procedures while the child is anaesthetised. In the event of an emergency, paediatric cases are prioritised if there is a clinical indication to do so.

Within the general radiology service there is one specialist consultant neuro-radiologist and two consultant radiologists with a specialist interest in this field. Reporting on paediatric neuro-imaging is undertaken by two consultants with an interest in paediatric radiology. The radiologists work in collaboration with colleagues in Lothian and contribute to the supra-regional multidisciplinary team meeting.

In Aberdeen, the RACH shares the CT and MRI facilities with the adult service in ARI. The Radiology Department at the RACH performs cranial ultrasound. There are three CT scanners in the adult hospital: one in the Emergency Care Centre (ECC) which is adjacent to the RACH and two scanners in the Radiology Department in the main hospital. There is access to three MRI scanners in total: there is one MRI scanner in the adult hospital and this facility includes an area for the administration of general anaesthesia. This area is used for much of the paediatric work and also provides the emergency service but not on a 24/7 basis. The adult and children's hospitals are joined by a short corridor so scans can be performed quickly. CT and MRI paediatric neurosurgery requests are prioritised alongside but not ahead of adults, and urgent and emergency imaging is performed as required. There is access to CT scanning on a 24/7 basis, but limited out of hours MRI provision.

Inpatient MRI scanning is available Monday to Friday, between 9 am and 5 pm with additional outpatient availability between 8 am to 9 am and between 5 pm to 8 pm. On Saturdays, there is a slot available for acute spinal cord compression, but there is no MRI service on Sundays.

Both CT and MRI can be performed under general anaesthesia if required. There is a planned weekly list for elective MRI investigations under GA and emergency investigations are arranged as required.

All CT and MRI scans are reviewed by a paediatric radiologist at the RACH and neuroradiologists at ARI. The radiologists work in collaboration with colleagues in Lothian and contribute to the supra-regional multidisciplinary team meeting.

Theatre

Theatre provision

None of the children's hospitals has a dedicated full-time neurosurgical theatre. Arrangements vary across the centres and systems have developed to best meet the needs of their respective populations. The arrangements for unscheduled surgery are generally managed by the duty paediatric neurosurgeon whether this requires re-arranging an elective procedure or negotiating an additional theatre slot with other specialties on a day when there is no neurosurgery session.

In the RHC in Glasgow, Theatre 9 is a purpose-built theatre for neurosurgery, craniofacial surgery and cleft surgery. There are three neurosurgery and two

craniofacial sessions available per week in Theatre 9. The theatre is adjacent to CT and MRI scanners and to the angiography suite. It is in close proximity to the PCCU, ED and ward.

When there is no neurosurgical theatre list, emergency and scheduled surgery is undertaken in either the general emergency theatre or Theatre 9 as appropriate. Theatre 9 is set up for neurosurgery emergencies at the end of every day irrespective of the specialty using it on the following day. This allows for some emergency out of hours procedures to be performed in the neurosurgery theatre rather than the general theatre.

Paediatric neurosurgeons may operate alone, with another consultant or with the support of a neurosurgery specialty trainee or senior clinical fellow. Although not neurosurgically trained, the Theatre 9 paediatric theatre nursing and anaesthesia team are experienced in neurosurgical procedures. There is no out of hours neurosurgery scrub team rota. If it becomes evident during theatre session that an operating list is likely to run beyond the scheduled time, the Senior Charge Nurse staffs the theatre with neurosurgery experienced scrub nurses where possible.

In the RHSC in Edinburgh Theatre 2 is fully resourced with specialist neurosurgery equipment and is allocated to neurosurgery for an average of 1.5 sessions per week.

Emergency cases can be undertaken in Theatre 2 out of hours or in the CEPOD theatre. The arrangements for unscheduled surgery are managed by the consultant paediatric neurosurgeon on call in conjunction with the anaesthesia and theatre teams at the daily morning meeting. There is no out of hours neurosurgical scrub team so emergency neurosurgery cases are undertaken by the team covering the CEPOD theatre.

The paediatric neurosurgeons operate alone, with another consultant surgeon or with the neurosurgery specialty trainee. The theatre suite is on the second floor with the paediatric neuroscience ward directly below on the first floor.

In Dundee there is a dedicated neurosurgery theatre in Ninewells Hospital adjacent to the adult neurosurgery unit on Level 6. There are no fixed paediatric sessions but paediatric procedures are undertaken in the neurosurgery theatre with paediatric surgical equipment. Specialist neurosurgical theatre nurses are on call at all times. Paediatric theatre and recovery nurses are not utilised in the neurosurgery theatre area. The surgeon with an interest in paediatrics who undertakes elective work typically operates with a trainee.

There is one theatre in TCH to support the paediatric surgical service and a business case to build two new paediatric theatres is being submitted as part of the Tayside theatre services review.

The distance between the neurosurgical theatre on Level 6 and the paediatric ward on Level 4 is 200 metres. Paediatric patients are recovered in the neurosurgery Recovery Area and the transfer of post-operative patients from the Recovery Area to the paediatric ward is undertaken by a paediatric nurse.

In Aberdeen there are three paediatric theatres. Paediatric neurosurgery is undertaken infrequently so there are no scheduled paediatric neurosurgery theatre sessions.

There is no dedicated paediatric neurosurgery scrub team, however there are two lead paediatric scrub nurse in RACH theatres who are the link nurses for neurosurgery. Currently, theatre staff are on site during the hours of 8 am to 10 pm, and on call from home between 10 pm to 8 am.

Specialist neurosurgery equipment is available in the RACH theatres. A fully equipped adult neurosurgery theatre is located in the adjacent adult hospital and both equipment and staff can be accessed if required. If necessary, children can have surgery in the adult facility supported by a team of paediatric anaesthetic consultants and paediatric theatre staff. There were no issues or delays reported in relation to the neurosurgical scrub team being required concurrently in both the adult and paediatric theatres.

Unscheduled neurosurgical cases are allocated to the theatres according to the degree of urgency. There have been no cases when there was a delay to gain access to theatre for a neurosurgical case.

Consultant neurosurgeons operate alone or with support from a neurosurgery specialty trainee.

Theatre activity in 2014

Neurosurgical procedures are classified as planned or emergency cases on the theatre data system. Emergency cases are those which must be undertaken at the first opportunity. Planned procedures include scheduled routine elective operations and also cases which may follow an unplanned admission but can safely be delayed and scheduled for an elective list. A proportion of the planned procedures may have followed an unplanned admission and as such may not be routine elective cases.

In Glasgow a total of 136 children accounted for 257 neurosurgical procedures undertaken in the RHSC Yorkhill theatre suite. The majority of procedures (62%, 160/257) were undertaken in Theatre 7 (neurosurgery), and 94 procedures (36.5%) were undertaken in Theatre 2 (general/emergency). Three procedures were carried out in other theatres. The hospital hosts the National Vein of Galen Service. Twelve vascular procedures were undertaken in the Catheter Lab.

The table in this section of the report relates to the activity at the RHSC in Glasgow but does not include the 30 procedures undertaken on 17 children aged between 13 and 15 who were managed at the INS.

The majority of operations (63.8%, 164/257) were scheduled as planned procedures with the remaining cases undertaken as emergency or urgent operations.

NHS Greater Glasgow and Clyde provides the national craniofacial service. In 2014 there were 20 procedures undertaken. An application for national service designation has been submitted to the National Services Division of NHS National Services Scotland and a response is expected in the autumn of 2015.

In Edinburgh a total of 115 children accounted for 172 neurosurgical procedures undertaken at the RHSC. Of the 127 surgical procedures documented in the theatre system 'ORSOS', fewer than half (45%, 57/127) were undertaken in Theatre 2. Thirty-one procedures (24%) were undertaken in Theatre 1, 35 procedures (28%) in Theatre 3, and four procedures (3%) in Theatre 4. Fewer than half of operations (45.3%, 78/172) were scheduled as planned neurosurgical procedures with the remaining cases undertaken (54.7%, 94/172) as emergency or urgent procedures.

NHS Lothian provides the National Epilepsy Surgery Service. All cases are discussed at the national multidisciplinary meetings; the service is supported by a nurse consultant specialising in epilepsy and a nurse specialist for epilepsy surgery. The national service designation for paediatric epilepsy will be reviewed in 2015/16 as part of the three year cycle of reviews undertaken by National Services Division of NHS National Services Scotland.

In 2014 there were seven surgical procedures undertaken by the epilepsy surgery team.

In Dundee a total of 10 children had 22 neurosurgical procedures undertaken in the adult theatre and none in the paediatric theatre in the children's hospital. Of these 22 neurosurgical procedures undertaken in 2014, 11 were categorised as emergency or urgent operations and 11 were planned procedures.

In Aberdeen 21 children under age 16 accounted for a total of 32 neurosurgical procedures. Of these, 31 procedures were undertaken in the RACH theatres with 29 of the 31 procedures taking place in the emergency theatre. In addition, one elective procedure was undertaken in Theatre 8 in ARI (the dedicated neurosurgical theatre) on a 14 year old child. Almost two thirds of neurosurgical procedures (20/31, 64.5%) were categorised as emergency operations. The remaining 11 were scheduled as planned procedures.

Table 5 Number of patients and percentage of procedures performed as emergencies

	Children	Procedures	Emergency %
RHSC Glasgow (Yorkhill)	136*	257	36.2%
RHSC Edinburgh	115	172	54.7%
Tayside Children's Hospital	10	22	50.0%
Royal Aberdeen Children's Hospital	20*	31	64.5%

* A further 17 children aged between 13 and 15 years who had surgery (30 procedures) at the Institute of Neurological Sciences at the Southern General Hospital in Glasgow are not included in this table because no breakdown of elective vs emergency was available. The single case who had surgery in the adult theatre in Aberdeen Royal Infirmary is also not included.

The classification of 'emergency' procedures varies between hospitals. Although a standard definition was agreed in advance of starting the audit, the clinical databases from which the data was extracted did not reflect the standard definition in all cases. This will be addressed to facilitate future audits.

Anaesthesia and Critical Care

Anaesthesia

Ideally anaesthesia for children requiring neurosurgery should be provided by anaesthetists who are trained in paediatric neuroanaesthesia[3]. This degree of subspecialisation cannot be achieved in all four centres however the categorisation of surgery ensures that the more complex cases are undertaken in the larger centres where expertise in paediatric neuroanaesthesia is available.

In Glasgow the service comprises 17 paediatric anaesthetists and one neuroanaesthetist with paediatric training and a part-time commitment to the RHC. All 17 consultant paediatric anaesthetists have had three to six months of intermediate training in neuroanaesthesia and support the emergency service. There are three paediatric anaesthetists who support the elective neuroanaesthesia practice along with their neuroanaesthesia colleague.

In Edinburgh the service comprises 18 paediatric anaesthetists, three of whom have specialist training in neuroanaesthesia and support the elective caseload. All paediatric anaesthetists have had some training in paediatric neuroanaesthesia and anaesthetise children for neurosurgical procedures out of hours.

In Dundee a paediatric anaesthetist joins the neuroanaesthetist during elective operations on children under the age of five. Neuroanaesthetists maintain continuing professional development in paediatric anaesthesia by attending paediatric neuroscience meetings, working in paediatric theatre and working with colleagues in

the children's hospital. There are eight paediatric anaesthetists in TCH, all of whom have neuroanaesthesia training and are available for emergency or out of hours neurosurgery. All elective and urgent cases are discussed prior to surgery with the paediatric anaesthesia team and a decision is made as to whether a neuroanaesthetist is needed as well.

In Aberdeen both paediatric and neuroanaesthetists can be available in theatre. There is a team of six paediatric anaesthetists on site during the hours of 8 am to 6 pm and they are on call from home out of hours. Each paediatric neurosurgery case is discussed by the consultant neurosurgeons, neuroanaesthetists and paediatric anaesthetists. The discussion includes the location of the operation (RACH or ARI), equipment, anaesthetist, recovery, and post-operative care. Movement of equipment between the adult and paediatric theatres is also considered. In the case of children likely to require critical care post-operatively, the discussions are guided by the paediatric anaesthetist and the appropriate arrangements are put in place for retrieval team transfer to a PICU in Glasgow or Edinburgh.

Critical Care

The Paediatric Intensive Care Society (PICS) publishes standards of care and all paediatric intensive care units in the UK are expected to be compliant with the standards[15]. There are no specialist neurosurgery or neuroscience high dependency facilities and no dedicated beds for the specialty within either the Glasgow or Edinburgh Paediatric Critical Care Units (PCCU). Children who require Level 2 or Level 3 care are managed jointly by paediatric neurosurgeons and paediatric intensivists.

In Glasgow and Edinburgh the critical care units have intensive care beds (Level 3) and high dependency beds (Level 2) co-located within a single unit. Patients can move between intensive care and high dependency beds or may be admitted directly to high dependency beds depending on their clinical needs.

There is no Level 3 PCCU in either Dundee or Aberdeen. Patients who are likely to require admission to Level 3 PCCU after elective surgery are discussed with a paediatric neurosurgeon in Glasgow or Edinburgh and pre-operative or, in the case of emergency surgery, post-operative transfer is arranged. The paediatric retrieval team can transport patients by road or by air.

The two designated PCCUs work in collaboration to provide the National Paediatric Intensive Care Service for children from throughout Scotland. The paediatric high dependency units in the four units also work collaboratively and, in conjunction with the two intensive care units, participate in a national audit process that reviews the activity in all units.

In Glasgow the paediatric critical care unit in the RCH is located on the first floor of the hospital, immediately adjacent to the theatre suite, providing access to 24 critical care (both Levels 2 and 3). It is envisaged that much high dependency care will occur in ward areas but none of the wards currently provide a 1:2 nurse-to-patient ratio. The PCCU is adjacent to theatres and the imaging suite. There is currently a team of twelve intensivists with a further two to be appointed. The HDU and PICU at the Yorkhill site had a total of 22 beds staffed flexibly depending on the staffing ratio and level of care required. It has always been possible to arrange a PICU or HDU bed when required and no child has required transfer to an alternative unit because of a lack of bed space.

Critical care nursing in the RHC in Glasgow is provided by nursing staff with specialist paediatric critical care training. Prior to the transfer of the paediatric neurosurgical service to Yorkhill, a mandatory neurosurgery core competencies package was developed by the PICU/HDU lecturer-practitioner and senior charge nurse. All nursing staff complete the competencies as a core component of their in-house PICU education with sign off of neurosurgical competencies at an early stage in the induction timetable.

In Edinburgh the PICU and HDU facilities are co-located on the first floor in close proximity to the theatre suite. The Critical Care area comprises an eight bedded intensive care unit and a six bedded high dependency unit offering flexibility in how the beds are deployed.

The critical care capacity will increase in the new children's hospital to 10 ICU beds and 6 HDU beds. There is currently a team of six intensivists and a further three will be appointed for the move to the new hospital. There is a separate medical and nursing rota for the retrieval service.

Critical Care has a comprehensive Education Framework that covers all aspects of Critical Care and is supported by two practice educators. There are specific Learning Contracts for care of the neurologically compromised child or young person, including ICP monitoring and there are specific guidelines in place e.g. sampling from EVDs.

In Dundee the paediatric HDU is a six bedded unit with telemetry based in Ward 29 (a mixed medical and surgical ward). Children are not ventilated in this unit unless they are on home ventilation. The unit works collaboratively with the adult ICU in Ninewells Hospital, the PCCUs in Edinburgh and Glasgow and the paediatric Northern Network. There is an unannounced emergency simulation each week to enable staff to respond to emergency situations.

Children with serious head injuries may require an intensive care unit admission. In the event of a child requiring ventilation, they are looked after by the consultant neurosurgeon and the Intensive Care consultants in the adult ICU with input from

paediatric medical and nursing staff while awaiting transfer to Glasgow or Edinburgh.

The management of children is discussed with the PCCU in Edinburgh or Glasgow and all critical care admissions, whether to the paediatric HDU or the adult ICU and those transferred to the Edinburgh or Glasgow units, are reviewed at an annual audit meeting with attendance from Dundee, Edinburgh and Glasgow Intensive Care consultants. There have been no adult ICU to PICU transfers in the last 10 years.

High dependency nursing care is provided by nursing staff with specialist paediatric training but not neuroscience training. Staffing levels in paediatric HDU are maintained at 1:2 or 1:3 ratio depending upon the level of dependency in the unit.

In Aberdeen children requiring Level 2 care are managed jointly by the consultant neurosurgeon and consultant paediatrician in the paediatric HDU. The HDU is located on the first floor close to the RACH theatre facilities. It has four staffed beds, admitting children from birth to 16 years from all paediatric specialties. There are two cubicles available for Level 3 care while awaiting retrieval to either Glasgow or Edinburgh. All children up to 16 years who require retrieval are managed in the paediatric HDU.

Although there are no dedicated neuroscience beds within the paediatric HDU, it has always been possible to arrange a HDU bed when required and no child has been transferred to an alternative unit because of lack of HDU bed space.

High dependency nursing care is provided by paediatric nursing staff with specialist high dependency nurse training but not neuroscience training.

Table 6 Admissions to Critical Care in 2014

	PICU admissions	HDU admissions	Total
RHSC Glasgow (Yorkhill)	31	71	102
RHSC Edinburgh	33	5	38
Tayside Children's Hospital	0	1	1
Royal Aberdeen Children's Hospital	0	19	19

The children's wards

In Glasgow and Edinburgh there are dedicated neuroscience wards in which children with neurological and neurosurgical conditions are looked after. In Dundee and Aberdeen children under the care of a neurosurgeon are looked after in surgical, medical or mixed children's wards.

In Glasgow's new RHC the neuroscience service is housed on a 24 bedded ward with other specialties including long term ventilation patients. The ward comprises a four

bedded observation bay and 20 single rooms. There are no ring-fenced neuroscience beds within the ward. There is access to a sensory room which is shared with other specialties. Video telemetry facilities are available in the new neuroscience ward.

On the Yorkhill site in Glasgow children under the care of a consultant neurosurgeon were admitted to Ward 7A, a 12 bedded neuroscience ward comprising one four bedded bay and eight single rooms for neurology and neurosurgical patients. A specialist neuroscience team was developing well on 7A but there are concerns that a loss of neuroscience nurses as well as the change in case mix at the time of relocation has adversely affected the neuroscience specialist environment. These will be areas for attention at the time of the review visit in 2016.

Neuroscience Nursing

Some nursing staff specialising in paediatric neurosurgery at the INS moved with the service to Ward 7A at Yorkhill, however many of the most experienced neurosurgical staff were lost to the service during this transition. A paediatric neurosurgery competencies package was developed by staff at the INS prior to the transfer and implemented by the paediatric neurosurgery advanced nurse practitioner and the neurosurgery specialist outreach nurse. The competencies package has been shared with colleagues in Dundee and Aberdeen.

Unfortunately there has been a further loss of neuroscience nurses with the move to the new RHC and the implementation of paediatric neuroscience competencies is therefore ongoing. There are six specialist nurses in the neuroscience unit: a neurosurgery specialist outreach nurse, an advanced nurse practitioner for neurosurgery, a nurse consultant in epilepsy, two epilepsy nurse specialists and a neuromuscular nurse specialist.

In 2014, approximately 283 children were admitted to the paediatric neuroscience ward under the care of a neurosurgeon. Of these, 136 required surgery and accounted for 257 procedures undertaken in the children's hospital.

In Edinburgh children admitted to the neuroscience ward are not admitted under the care of a named consultant neurosurgeon but instead are admitted under a 'joint care' model. Ward 7 is a 12 bedded neuroscience ward comprising a two bedded video telemetry room, a four bedded bay and six beds in the main ward area. There is a treatment room within the ward area and a playroom next to the reception area. There are outpatient facilities as well as offices for administrative staff and clinical staff immediately adjacent to the ward. Neurophysiology is located in the ward area.

Neuroscience nursing

Nursing staff in Ward 7 in the RHSC in Edinburgh are all paediatric trained, complete neuroscience competencies and participate in CPD courses in relation to

neurosciences. The number of specialist nurses on the ward has increased to five: a nurse consultant for epilepsy services, a nurse specialist for epilepsy surgery, two nurse specialists who support children with vagal nerve stimulator implants, and a nurse specialist whose role incorporates the co-ordination of care for children with motor disorders, traumatic brain injury, general neurosurgery and support to the ante-natal clinic.

As a result of the joint care admissions practice, it is not possible to identify of the number of children admitted in 2014 to the neuroscience ward under the care of a neurosurgeon however 115 children accounted for 172 procedures.

In Dundee children under the age of 14 requiring neurosurgical care are admitted to Ward 29 of Tayside Children's Hospital. Ward 29 is a 40 bedded medical and surgical unit incorporating a paediatric HDU and a short stay Assessment Unit. Children with neurosurgical conditions are admitted to the ward under the care of a paediatric neurologist and care is jointly managed by a consultant paediatric neurologist, a consultant neurosurgeon and a consultant paediatrician.

Although in a separate wing of Ninewells Hospital, the children's hospital is within the same building as the adult neurosurgery unit and has ready access to associated specialties and the neurosurgery unit. Consultant neurosurgeons visit the children's hospital regularly to facilitate the joint management of paediatric care.

In 2014, 3,626 children were admitted to Ward 29. Of the 12 children who were looked after by the neurosurgical team, five required surgery and seven did not. An additional three children who had surgery were managed in the neonatal unit and a further two older children who had surgery were managed in the adult ward.

In Aberdeen the service is provided mainly in the Surgical Ward within the RACH. There are 19 staffed beds located in 7 cubicles and two 6-bedded bays.

The general medical paediatric cover of the neurosurgery patients in the Surgical Ward is led by the consultant neurosurgeon who may delegate the daily ward review to another member of the neuroscience team; usually the neurosurgery middle-grade doctor. Some children with neurosurgical conditions (particularly those requiring neuro-oncology services or with neurological comorbidities) are admitted to the Medical Ward under the care of Paediatric Oncology, Paediatric Neurology or General Paediatric Medicine. These patients are referred to the neurosurgeons if there is a clinical indication to do so.

In 2014, neurosurgery patients accounted for approximately 1.2% (28/2,377) of all admissions to the paediatric Surgical Ward. In addition, in 2014, neurosurgery patients accounted for approximately 0.8% (12/1,539) of all admissions to the paediatric Medical Ward.

Table 7 Type and capacity of wards and number of cases and procedures in 2014

	Ward	Beds	Neurosurgery cases (procedures)	
RHSC Glasgow (Yorkhill)	Neuroscience	12	136	(257)
RHSC Edinburgh	Neuroscience	12	115	(172)
Tayside Children's Hospital	Mixed general	40*	10	(22)
Royal Aberdeen Children's Hospital	Surgical	25*	21	(30)

* No dedicated neuroscience beds.

Neonatal patients may be looked after in the Special Baby Care Unit or Neonatal Intensive Care Unit and these cots are not included in the number of beds in each unit.

The paediatric wards in Dundee and Aberdeen are staffed by paediatric trained nurses but have no specialist neurosurgical training. The caseload does not warrant the development of such a specialised staff in either unit but the recent links made with neuroscience nurses in the other paediatric units as part of the MSN joint paediatric nurse and allied health professionals group and sharing of paediatric neurosurgical competency materials are helping to build neuroscience competencies. There are no paediatric neurosurgery specialist nurses in either unit.

Type of admission and length of stay

Neither of the Neuroscience Units in Glasgow or Edinburgh accurately assigns admissions to neurology or neurosurgery. Information on type of admission and length of stay in the retrospective data set for the neurosurgical cohort cannot be interpreted accurately. Prospective data may help to avoid this but poor definition and inaccurate consultant allocation of 'episodes of care' are characteristic of the patient administration systems in current use.

Residential facilities

In Glasgow residential facilities in the new hospital are available to allow one parent or carer to stay at the child's bedside in a pull down bed. All rooms have en-suite facilities and have disabled access. The ward also has a fully equipped family room where families can have a break, a coffee or eat a meal. There are also rooms that can be used for private meetings with parents as well as a quiet room. The new Ronald MacDonald House opened at the same time as the new hospital.

In Edinburgh there are no beds available for families in the ward area however parents can stay with their child or have a bed set up in the playroom. Within the hospital there is a variety of well-equipped accommodation and facilities that families can access via the Family Support Team. There will be a Ronald MacDonald house available at the new hospital in 2017.

In Dundee each bed-space in the children's ward has facilities for a parent or carer to stay with the child. There is a fully equipped relatives' lounge within the ward area. In addition, there is a self-contained suite of rooms that sleeps four with an open plan kitchen/living area and access to a private garden for families of seriously ill children or those who need support to continue care at home. The Audit Review Panel were particularly impressed with the sensitivity and thoughtfulness of the design of this facility which combines privacy with immediate access to clinical staff should the need arise. There is also accommodation in Ronald MacDonald House for families of children in the High Dependency Unit.

In Aberdeen the RACH provides residential facilities to allow one parent or carer to stay at the child's bedside and where possible, long stay patients are cared for in single cubicles. Some single rooms have fold-down beds and the Parents Accommodation Suite has four double and 16 single rooms on the first floor.

The patient journey

The Audit Review Panel visited each centre in 2015 to ascertain how the paediatric neurosurgical service is delivered in Scotland. Having gained an understanding of *the process* of care in each of the centres, the Paediatric Advisory Group were keen to audit specific aspects of the delivery of care for a selected group of children admitted to the four units in 2014. A total of 104 children were included in the Patient Journey Audit. These children accounted for 122 admissions:

- All admissions to the RACH (24)
- All admissions to the TCH (18)
- A randomly selected group of 80 admissions comprising 10 cases for each paediatric neurosurgeon (5 planned and 5 emergent) were identified in NHS Lothian and NHS GG&C.

In Scotland as a whole, and in each centre, there were more males than females (66 (63.5%) v 38 (36.5%). Ages were grouped into categories: ≤ 4 weeks (11, 10.6%)); >4 weeks to 23 months: (21, (20.2%); 24 months to 4 years: (16; 15.4%); 5 to 12 years: 42, 40.4%); and 13 to 16 years: (14, 13.4%). Just under half of the children (51/104) had a long term neurological condition.

There were differences in classification of emergency and elective cases between the units so the definition of emergency/urgent was any admission that was not scheduled in advance of admission.

Table 8 Patient Journey Audit: Type of admission

	RACH	TCH	RHSC Edinburgh	RHSC Glasgow (Yorkhill)	Scotland
Emergency	14 (58.3%)	6 (33.3%)	17 (42.5%)	19 (47.5%)	56 (45.9%)
Elective	10 (41.7%)	12 (66.6%)	23 (57.5%)	21 (52.5%)	66 (54.1%)
Total Admissions	24	18	40	40	122

Note: the proportions of emergency and elective admissions changed following random substitution of duplicate cases.

Emergency admissions were likelier to present out of hours (18.00hrs to 08.00hrs) in Glasgow 13/26 (50.0%) than in Edinburgh 5/17 (29.4%) and inter-hospital transfers were more common in Glasgow (17, 42.5%) than in Edinburgh (8, 20.0%). The difference in inter-hospital transfer rate is a reflection on the location of the four centres: one in the West coast and three in the East coast.

Seniority of clinician making the referral to neurosurgery was highlighted as an issue in Glasgow during the course of the Audit Review Panel visits and this is reflected in the number of referrals made by consultants for both intra and inter-hospital transfers respectively: 3/11 (27.3%) and 7/17 (41.2%). This was not an issue in the other three centres.

The provision of detailed clinical information at the time of referral is essential, regardless of whether or not the child is an internal referral (within the provider unit) or an inter-hospital referral. The Glasgow Coma Scale (GCS) score at the point of referral was documented in all emergency admissions with the exception of Glasgow where in 10 of 26 cases (38.5%) the Glasgow Coma Scale score was not recorded in referral documentation. Whilst it is acknowledged that all referrals to neurosurgery are initially made by telephone, the documentation accompanying the child should also include this essential observation.

Children should be scanned prior to referral to neurosurgery and in the majority of cases this had been undertaken although it is not documented if scans were undertaken spontaneously by the referring clinician or at the request of the receiving neurosurgeon.

For the most part, information relating to physiological observations, examination, history, duration of symptoms and a management plan was available for the majority of emergency referrals. In the 113 cases where a provisional diagnosis was documented at the point of referral, it matched the discharge diagnosis in 109 cases (96.5%).

Of the 34 emergency admissions involving a suspected shunt malfunction where times were available, only six were scanned within two hours of arrival at hospital. Current guidance[4] recommends the scans should be conducted within two hours of arrival at hospital so this aspect of care requires collaborative effort to improve compliance in all hospitals throughout Scotland where children may present.

The three categories of surgery described on page 14 provide guidance on which procedures should only be undertaken in the two specialist centres in Edinburgh and Glasgow and the table on page 18 indicates that this guidance is being followed. Within the cohort of randomly selected admissions for the Patient Journey audit, Edinburgh has 50% of cases in category 3 and Glasgow has 25% of category 3 cases selected. Caution should therefore be applied when interpreting the theatre data.

The national standards recommend that children requiring neurosurgical intervention should be looked after by an anaesthetist with paediatric and neurosurgical training. This was achieved nationally in 13.9% (17/122) of cases and most frequently in Edinburgh (12/40 cases).

Across Scotland there were four instances of delay to theatre (4/122, 3.3%) involving category 1 or 2 procedures. The mean duration of delay was 25 minutes.

The critical care service in the four children's units comprises high dependency units (HDU) in Aberdeen and Dundee and paediatric intensive care units (PICU) co-located with high dependency units in Edinburgh and Glasgow. Children in Aberdeen and Dundee were more frequently looked after in their respective HDUs in the immediate post-operative phase: 14/26 (53.28%) and 9/18 (50.0%) respectively. In Edinburgh the proportion of children whose destination from theatre was PICU was lower at 25% (10/40) and in Glasgow it was 45% (18/40).

In 2014 there were 11 cases admitted to PICU in Edinburgh (27.5%) and 15 cases in Glasgow (37.5%) and of these 26 cases, 50% involved children who were planned admissions. There was variation in mean length of stay in PICU for children undergoing category 3 procedures: in Edinburgh 8 cases generated a mean length of stay of 2 days and in Glasgow five cases generated a mean length of stay of 13 days. The number of cases in both units is small and the flexibility in PICU or HDU classification of bed occupancy makes comparison difficult. During this time period there were 37 cases admitted to HDU: Aberdeen 14/24 (58.3%); Dundee 6/18 (33.3%); Edinburgh 2/40 (5.0%) and in Glasgow 15/40 (37.5%). Children who were admitted as emergencies to Aberdeen had the longest HDU stay with 12 cases generating a mean length of stay of 10.92 days.

Paediatric neurosurgery involves a multidisciplinary approach if the children are to achieve the best outcome possible. As described previously in this report, children who require neurosurgical intervention in Aberdeen and Dundee are looked after in general paediatric wards (surgical, medical or mixed) and those who present to the units in Edinburgh and Glasgow are looked after in specialist neuroscience areas. Table 9 shows the *documented* involvement of the multidisciplinary teams in each centre.

Although there was documented evidence of children being reviewed on daily ward rounds, in a number of cases neither the medical nor nursing documentation stated that a consultant neurosurgeon was present. Further investigation confirms that this

appears to be a failure of documentation in some centres, which is not unusual in an audit undertaken retrospectively. The Audit Review Panel visits confirmed normal practice in relation to ward rounds (see pages 18 to 22).

Table 9 Patient Journey Audit: multidisciplinary team involvement

	RACH n=24	TCH n=18	RHSC Edinburgh n=40	RHSC Glasgow (Yorkhill) n=40	Scotland n=122
Consultant Neurosurgeon Ward Review	19 (79.2%)	13 (72.2%)	37 (92.5%)	33 (82.5%)	102 (83.6%)
Consultant Paediatrician Ward Review	19 (79.2%)	11 (61.1%)	37 (92.5%)	13 (32.5%)	98 (80.3%)
Allied Health Professionals	6 (25.0%	13 (72.2%)	31 (77.5%)	20 (50.0%)	70 (57.4%)
Other specialty	22 (91.7%)	13 (72.2%	38 (95%)	31 (77.5%)	104 (85.2%)
Specialist MDT meeting	11 (45.8%)	8 (44.4%)	30 (75%)	13 (32.5%)	62 (50.8%)

Of particular note in Glasgow is the low incidence of documented review of these children by the paediatricians and the involvement of the Allied Health Professionals (AHPs). It is noted on page 42 of this report that there was no additional AHP resource allocated to neurosurgery at the time of transfer of the paediatric service from the INS to the RHSC at Yorkhill; the data appears to confirm this shortfall.

The involvement of AHPs in only 25% of cases in Aberdeen warrants further investigation.

The median length of stay in hospital for these children is shown in table 10.

Table 10 Patient Journey Audit: median length of stay by category of surgery

	RACH n=24	TCH n=18	RHSC Edinburgh n=40	RHSC Glasgow (Yorkhill) n=40
Category 1	5.0	6.0	7.0	11.5
Category 2	5.5	6.0	9.0	17.5
Category 3	-	-	8.0	11.0

Neuroscience specialties

Neurosurgery is one of a range of neuroscience specialties. These specialties work together to provide a collaborative service to meet the needs of individual patients. The specialties participate in their respective regional or national clinical networks and are dependent on effective communication whether formally in the setting of a multidisciplinary team meeting or in less formal discussion of individual patient plans.

In Dundee and Aberdeen paediatric neurologists join the Paediatric Neuro-Oncology Group (PNOG) weekly meeting by video-conference with colleagues in Edinburgh. The PNOG is a supra-regional MDT, covering NHS Lothian, Grampian, Tayside and Highland and includes oncology, neurosurgery, radiology, pathology, neurology, ophthalmology, radiotherapy, shared care, and nursing input.

Children being considered for epilepsy surgery are discussed within a national MDT meeting and surgery is currently undertaken in Edinburgh or at Great Ormond Street Hospital, London.

Neuro-pathology (including frozen section) is available in Edinburgh via video-conference from the DCN.

Table 11 Availability of neuroscience specialties

	Neurology	Neuro radiology	Neuro pathology	Neuro oncology	Neuro Physiology	Neuro psychology	Endocrinology	Maxillofacial
RHSC Glasgow (Yorkhill)	Y	Y	Y	Y	Y	Y	Y	Y
RHSC Edinburgh	Y	Y	N	Y	Y	Y	Y	N
Tayside Children's Hospital	Y	Y*	N	Y	Y	Y	Y	Y
Royal Aberdeen Children's Hospital	Y	Y*	N	Y	Y	Y	Y	N

* Neuroradiology available in the adjacent adult hospitals.

Neurorehabilitation and therapy services

Patients requiring neurosurgical care for their illness or injury frequently have new disabilities following their diagnosis and inpatient treatment. A team that can assess and support these needs is crucial to the successful return to home, school and recreation.

Allied Health Professionals

In Glasgow inpatient neurorehabilitation services are co-ordinated by a consultant neurologist. Whilst traumatic brain injury has always been within the remit of the neurorehabilitation service, neurosurgical patients are now on the ward from the early acute phase. The increasing neurosurgical patient population has resulted in the scope of the service being expanded without additional resource to meet this demand. This service is not designated for neurosurgery.

Therapy services for inpatients are delivered by a team of five specialist paediatric therapists. Members of the team attend the neurosurgical ward rounds. Therapists deliver inpatient care and also neurology outpatient services in the Fraser of Allander unit. A weekly neurorehabilitation meeting is chaired by the consultant neurologist with responsibility for this service. The meeting is attended by allied health professionals (AHP), a psychiatric nurse, the inpatient liaison nurse, a consultant in neurodisability and representation from the Social Work service.

Concerns have been expressed about the amount of AHP time available for neurology and neurorehabilitation patients. The acute needs and intensive support required for some neurosurgical patients were highlighted as critical issues in changing the profile of the therapy service. Priority is given to acutely unwell children, reducing the capacity to work with those who are no longer acutely unwell but require more intensive rehabilitation.

In Edinburgh the neurorehabilitation service is led by a paediatric consultant specialising in neurodisability and is closely linked with community services, education and social work departments. Unlike Glasgow, the paediatric neurosurgery service has long been embedded within the paediatric Neuroscience Unit and as such has an appropriately resourced team of AHPs sufficient to meet the complex needs of the neurosurgery patients.

A team of seven AHPs work with children and families in the neuroscience unit. They liaise with colleagues in the community for those children who require continuing therapy. There is a weekly MDT meeting which is attended by the on call consultant, the charge nurse, the neurosurgical registrar, the clinical nurse specialist, allied health professionals and representation from the Social Work service.

In Dundee the inpatient component of paediatric neurorehabilitation is led by a consultant paediatric neurologist and consultant paediatrician. Inpatient acute brain injury rehabilitation facilities are limited, there is a lack of storage space for equipment and adult facilities are sometimes used for physiotherapy and occupational therapy. The number of such children in any year is very small and ad hoc arrangements can be made through the multidisciplinary team meetings. There is good support from

community-based rehabilitation for children with complex neurodisability. This service is led by a consultant paediatrician in Community Child Health. A team of four WTE paediatric AHPs work with children and families in Ward 29. The team provide a service to both the inpatient and outpatient areas and also support other paediatric specialties including oncology, rheumatology and neonates.

In Aberdeen paediatric neurorehabilitation is co-ordinated by the neurology team. The paediatric neurology team and the neurology network team are available for neurodevelopmental assessment and care. These cases are jointly managed with the child development teams in Combined Child Health. All allied health professionals work within the multidisciplinary teams such as neurology, oncology, and surgery.

Neuropsychology

Neuropsychology services in Scotland have been expanded over the course of 2014, however limitations in this resource remain a challenge for neurosurgical services overall. There is no specific funding for paediatric neuropsychology to provide a service to neurosurgery with the exception of patients being assessed for epilepsy surgery in Lothian.

In Glasgow the neuropsychology service is provided by a consultant neuropsychologist, clinical psychologist and a part-time assistant psychologist. Access to neuropsychology after discharge is obtained by referral to board of residence. The neuropsychology team works with other agencies including education and social work as well as participating in matters relating to child protection.

In Edinburgh the neuropsychology service has a strict referral pathway as a result of limited resources. A full neuropsychological assessment takes 25 hours per child (this includes the liaison work with families, schools and the community) so services are limited to the children with the most complex needs.

In Dundee the neuropsychology service is led by a clinical psychologist specialising in paediatric neuropsychology. The service covers both hospital and community. Referrals are currently made to the neuropsychology service by the paediatric neurology team. Referrals are accepted from Child and Adolescent Psychiatrists if the child has a diagnosed CNS disorder. Neuropsychology clinics are usually held in the paediatric outpatient department or in Child and Adolescent Mental Health Services (CAMHS) departments in Dundee and Perth. There are also a small number of assessments performed in schools.

In Aberdeen the neuropsychology service offers an inpatient and outpatient neuropsychology service to NHS Grampian, NHS Shetland and NHS Orkney. There is one clinical paediatric neuropsychologist based at the RACH. Referrals are accepted from all personnel within the medical specialities based at the RACH, as well as paediatricians based in Community Child Health, community Allied Health Professionals, Primary Care, and Educational Psychology. The service in Grampian is provided to children from the age of four years to the end of full-time education. Given the current population covered and the service configuration, the paediatric neuropsychology service at RACH does not meet minimum staffing guidelines as set out by the British Psychological Society.

Play Specialists

In Glasgow the play specialist service is provided by a team of 20 staff. The neuroscience ward has a play assistant who is available 25 hours per week over four days and there is a dedicated play area within the ward. Older children are served by the youth services team and can also access Zone 12 which is an area specifically for children aged 12 and over. The ward in the new hospital has access to a children's roof garden.

In Edinburgh the play team comprises nine play specialists and five play assistants who work across the hospital. Older children can also access a games area.

In Dundee a team of five play specialists and three play leaders provide a service based in a purpose-built play area that is divided into age-appropriate sections and has access to a children's garden and picnic area. Within the play area of the ward there is a specific room with separate access for the use of young people.

In Aberdeen a team of eight play specialists are based in the wards. The play facilities include activity areas and a teen room.

Outpatient and outreach services

Our patient groups have emphasised the importance of good communication through all aspects of the patient journey and in particular at the interface between hospitals and the community. The two larger units in Glasgow and Edinburgh both provide a nurse outreach service but neither of the units in Dundee or Aberdeen have sufficient cases to warrant specialist neurosurgical outreach nurses.

Communication at the interface between the acute sector and care in the community is an issue that has been raised by our patient and family groups. Audit of the documented evidence relating to this specific component of the patient journey:

communication with outreach or specialist nurses, the patient's General Practitioner, and the community team showed variation between units and indicates there is room for improvement in communication or documentation of said communication. It is worth noting that in Glasgow all children are visited by the neurosurgical outreach nurse unless they are under the care of the neuro-oncology specialist nurse, however there was documented evidence of referral to either the neurosurgical or neuro-oncology outreach nurses in only 26 cases (see table 12).

Table 12 Patient Journey Audit: Communication at the interface

	RACH n=24	TCH n=18	RHSC Edinburgh n=40	RHSC Glasgow (Yorkhill) n=40	Scotland n=122
Outreach/specialist nurse	11 (45.8%)	0	30 (75.0%)	26 (65.0%)	67 (54.9%)
General Practitioner	23 (95.8%)	18 (100%)	40 (100%)	40 (100%)	121 (99.2%)
Community Team	22 (91.7%)	15 (83.3%)	36 (0.0%)	10 (25.0%)	83 (68.0%)
Neuro-rehabilitation	6	1	4	2	13

Outpatient services

In Glasgow, two consultant sessions each week are allocated to running general paediatric neurosurgery clinics; on Monday and Friday afternoons. Each clinic has appointments for three new and five return patients with an extra slot left unallocated to accommodate any urgent appointments. Training grade doctors can also attend. There are seven general paediatric neurosurgery clinics per four week block. In addition, there is a dedicated weekly craniofacial clinic with multidisciplinary input from neurosurgery, oromaxillofacial surgery, genetics and Speech and Language Therapy. This clinic displaces one general clinic per four week period.

New out-patient referrals are vetted by the duty consultant and allocated to the appropriate clinic. There are no problems accommodating new patients within 10 weeks of referral. In 2014 a total of 145 new patient appointments were offered and of those, 17 patients did not attend. There were 475 return appointments offered and of these 102 patients did not attend resulting in a 19% failure to attend rate.

In Edinburgh there is one fixed paediatric neurosurgical clinic per week in the outpatient department with appointments for two new patients and seven review patients. There are no slots kept free for urgent appointments however children who need to be seen urgently are reviewed in the clinic area in Ward 7. In addition, there is a specialist clinic for children with epilepsy who are being considered for, or who have had surgery. This clinic is held on an ad hoc basis in response to demand.

New outpatient referrals are reviewed by the lead consultant neurosurgeon. If the duty consultant is in theatre, the clinic patients are reviewed by a second consultant. Trainees can attend the outpatient clinics.

In 2014, 617 neurosurgery outpatient appointments were offered. The failure to attend rate is not known.

In Dundee there is a dedicated paediatric outpatient neurosurgery service provided by the consultant neurosurgeon with an interest in paediatric neurosurgery. Some children are seen jointly by the consultant neurosurgeon and a consultant paediatric neurologist in the paediatric outpatient clinic. Outpatients Clinics are held every two months but children are seen at any time between clinics. There are plans to increase the proportion of neurosurgical children seen in a paediatric clinic setting rather than in the adult outpatient facility.

In 2014, 25 outpatient appointments were offered.

In Aberdeen the outpatient clinics are held every three months in the children's Outpatient Department. The clinics are led by the consultant with a special interest in paediatric neurosurgery. The average outpatient clinic caseload is approximately between one and four new patients per session. The neurosurgery trainees can also attend the outpatient clinics.

The paediatric neurosurgery team hold a number of joint clinics with other specialties, including neurology, neuropsychology, oncology, endocrinology.

In 2014, 42 outpatient appointments were offered.

While it is acknowledged that if a child and their parent or carer attends an outpatient clinic, there is communication between the consultant and the family, auditing this component of the patient journey showed variation between the units in the documentation of the substance of the conversation and also the provision of written communication e.g. patient information leaflets. Practice varies between the outpatient departments in the paediatric units and it is recognised that clinic nurses often provide information to families however this is not documented in the child's case notes.

Table 13 Patient Journey Audit: Communication at the outpatient clinic

	RACH n=24	TCH n=18	RHSC Edinburgh n=40	RHSC Glasgow (Yorkhill) n=40	Scotland n=122
Documentation of the substance of the conversation	24 (100%)	18 (100%)	39 (97.5%)	29 (72.5%	109 (89.3%)
Evidence of the provision of written information	19 (79.2%)	6 (33.3%)	15 (37.5%)	3 (7.5%)	43 (35.2%)

Outreach service

In Glasgow children having surgery under the management of a consultant neurosurgeon receive at least one home visit from the paediatric neurosurgery outreach nurse specialist. The outreach nurse liaises with nurseries, schools, and the Education and Social Work Departments in the child's board of residence to assist and support their re-integration back into education. Information about specific conditions and each child's needs is provided for teachers, health visitors and other key personnel. Support and teaching for parents and patients with a new diagnosis of hydrocephalus and first shunt prior to discharge is provided. The outreach nurse supports children with low grade tumours as well as craniofacial patients and their families.

In Edinburgh the neurology nurse specialist provides an outreach service for children with neurological and neurosurgical conditions whenever there is an indication to do so. Most communication is by telephone however, when required she will meet with families in their home. Support is provided to any family who needs it and involves liaison with nurseries, schools, support groups and the community team. The nurse consultant for children with epilepsy looks after patients before and after surgery and works closely with the nurse specialist for epilepsy surgery.

The neonatal neurosurgical service

All four neurosurgical centres in Scotland provide a neonatal neurosurgical service. The most common conditions treated are hydrocephalus and congenital anomalies such as myelomeningocoele (spina bifida aperta).

In Glasgow the neonatal unit in the new RHC comprises 18 neonatal ICU beds and 18 step-down beds. Neonatal neurosurgery is performed by the four paediatric neurosurgeons, often in collaboration with a plastic surgeon. In the past, much of this service was provided by the paediatric general surgeons. The main transition period took place during late 2013 and 2014 and was audited internally with external

verification. Two of the neurosurgeons lead this work, attend the foetal medicine meeting and offer antenatal counselling to parents on an ad hoc basis.

The transition has been well supported by the neonatologists but changes in ward configuration in the new RHC mean that well term babies are in the ward attached to their specialty consultant rather than in a neonatal unit. As a result of this, there is no longer a thrice weekly review by neonatologists as was the standard practice at Yorkhill prior to the move. Concerns about this arrangement have already been expressed by the MSN so this area will remain a particular focus of audit.

In 2014 eight infants accounted for 17 procedures.

In Edinburgh the special care baby unit is located in the Simpson Centre for Reproductive Health (SCRH) at Little France (adjacent to the RIE). There is a four bedded neonatal unit located in a surgical ward within the children's hospital in which there are two beds available for special care spinal patients. Neonatal neurosurgery is performed by the four paediatric neurosurgeons. The infants are transferred to Ward 7 from the neonatal unit at the SCRH at Little France by the transfer team. The majority of infants are discharged home from Ward 7. Only complex cases with other non-neurosurgical issues are transferred back to the neonatal unit at the SCRH.

There is an antenatal multidisciplinary team that meets each month and is attended by paediatricians, neonatologists, obstetricians, radiologists, neurologists and neurosurgeons.

In 2014 one neonate accounted for two procedures.

In Dundee neonatal care is provided in a 21 bedded unit that looks after infants up to three months of age. It incorporates four beds in ICU, three beds in HDU and 14 Special Care beds, four of which are transitional. The unit is staffed by consultants and the majority of care is consultant delivered with some consultants also providing cover for the middle-grade rota. The unit has neonatal nurse practitioners as part of the team. Neonatal neurosurgery is performed by the neurosurgeon with a special interest in paediatric neurosurgery.

In 2014, three neonates had a total of seven neurosurgical procedures and were looked after in the neonatal unit.

In Aberdeen newborn children with neurosurgical conditions are admitted directly to the Neonatal Ward in Aberdeen Maternity Hospital (AMH). This is a 38 bedded neonatal unit providing Level 3 care which consists of 10 ICU beds, 5 HDU beds, 16 special care rooms, one isolation cubicle and six beds in a 'pre-discharge' room.

All neurosurgical cases are referred primarily to the local neurosurgery team. Individual cases may be transferred out of Grampian based on a case-specific consideration by the attending consultant neurosurgeon. Spina bifida cases are managed jointly by a paediatric surgeon with an interest in spina bifida, the neurosurgeon with an interest in paediatric neurosurgery, and a plastic surgeon. The surgery is performed in the RACH theatre suite and infants are transported from, and returned to the neonatal unit in the adjacent Aberdeen Maternity Hospital.

In 2014, four neonates accounted for eight procedures.

Young people and transition services

The transition services of neurosurgical care for young patients who transfer to adult services are straightforward as all paediatric neurosurgeons in Scotland maintain an adolescent and adult practice.

In Glasgow inpatients aged 13 and over were looked after in the adult unit at the INS in single rooms (where possible) on Ward 64 until the new children's hospital opened. New patients aged between age 13 and 16th birthday are now treated in the new RHC. Existing INS adolescent cases will not have their care transferred to the RHC unless there is a specific indication to do so. One of the surgeons maintains a dedicated adolescent clinic to ensure that these patients are looked after separately from an established adult practice. The four paediatric neurosurgeons work in both the adult and paediatric neurosurgical units in Glasgow.

In 2014, a total of 39 neurosurgical procedures were undertaken on young people aged between 13 and 15, of these nine procedures were carried out in the RHSC and 30 procedures were performed in the INS.

In Edinburgh young people up to the age of 16 who require neurosurgery are usually cared for in the RHSC. There are some young people with long-term conditions who continue to be looked after at the RHSC into early adulthood. The needs of the young person and their family are taken into account when making the transition to the adult service.

Prior to the appointment of two additional paediatric neurosurgeons in 2013/14, the transition service for young people in Lothian was provided by the patient's consultant neurologist. Since the appointment of the additional consultant neurosurgeons, this service is provided by their consultant neurosurgeon.

In 2014, a total of 24 neurosurgical procedures were undertaken on 19 young people aged between 13 and 15.

In Dundee young people aged 14 and 15 are cared for in the adult neuroscience unit. A transition service is in place for children with brain tumours and long-term epilepsy

followed up by the Tayside Children's Hospital. Children with brain tumours are followed up by their paediatric oncologist and the neurosurgeon with a special interest in paediatric neurosurgery. Children with epilepsy are seen initially in a dedicated teenage epilepsy clinic and subsequently in a joint paediatric neurologist/adult neurologist clinic at the time of handover to adult services.

In 2014, two young people in this age group had three neurosurgical procedures undertaken.

In Aberdeen patients up to age 16 are normally cared for in the RACH. Patients with special needs can continue to receive surgery and ongoing care at the RACH until an appropriate time to transfer their care to the adult Neuroscience Unit. If there is a specific reason for a young patient to be looked after in the adult unit, single rooms can be used to provide a more appropriate environment.

In 2014, one 14 year old patient had elective surgery in the adult theatre and three young people aged 13 to 15 had surgery in the RACH theatre.

Palliative care

Unexpected deaths are rare throughout the service. Palliative care for children is provided by the individual specialties that comprise the neuroscience service working in conjunction with palliative care teams in the acute service and teams in the community. There are two children's hospices in Scotland: Rachel House Hospice in Kinross and Robin House Hospice in Balloch. These two facilities are run by the charity *Children's Hospice Association Scotland* which also provides a home care service. The hospices provide residential facilities for families to look after their child in a purpose built, supportive environment. The four neuroscience teams can refer children and their families to the hospices.

The Managed Service Network for *Children and Young People with Cancer* co-ordinates national multidisciplinary team meetings where the management of children with cancer is discussed by specialist teams from around the country.

In Glasgow in the event of a child requiring palliative care, there are a number of options available to families. If the family wishes to care for the child at home, liaison with the community team is undertaken by the palliative care team working with the consultant neurosurgeon. If the decision is taken to care for the child within the children's hospital, care is provided by the patient's consultant neurosurgeon and oncologist in conjunction with the palliative care team. Ongoing support for the family is provided by the appropriate specialist service as well as palliative care and community services.

In Edinburgh the families of children requiring palliative care have the support of the palliative care team who work closely with the neuroscience specialties and the paediatric neurosurgical nurse specialists. In the event of a terminally ill child dying, the parents and family are offered professional bereavement support and bereavement counselling. Bereaved families are offered the opportunity to meet the team to discuss the course of their child's illness and avail themselves of any support they require.

In Dundee in the event of a child requiring palliative care, if the family prefer their child to remain in Ward 29, there is a purpose-built family apartment with a private garden that can be used. Alternatively if the family wish to care for their child at home, the liaison service for palliative care comprises a consultant paediatrician, an associate specialist and palliative care nurses who work closely with teams in the community.

In Aberdeen children requiring palliative care can be looked after at home or in the children's wards. If the family is more comfortable in a hospital environment, the child can be admitted to the Palliative Care Unit in the RACH. There is not a children's hospice in Grampian, and though referral to Rachel House Hospice in Kinross or Robin House Hospice in Balloch is offered, to date this option has not been used. Palliative care is co-ordinated by the oncology team, often working with primary care, secondary/tertiary care, and the third sector, to provide individualised support to patients and their families.

Child protection services

Child protection issues arise for a few neurosurgical patients each year. Usually the context is a young child who has injuries that are not explained by the history available. Good collaborative relationships between neurosurgeons, general paediatricians and the non-medical members of the Child Protection Team are needed to ensure that other injuries, and evidence of other illness and of neglect including malnutrition are identified and managed. Tremendous care and expertise is required around decisions about returning children home, family support, the welfare of siblings and arrangements for foster care if necessary.

In Glasgow the Child Protection Team (CPT) comprises the Medical Director, a General Practitioner with a special interest, the Head of Child Protection Development, a Business Manager, 11 Child Protection Advisors and 7 administrative staff. The CPT responds to referrals on a case by case basis and provides a service for early sharing and collation of information which supports holistic multi-agency care. Training and education in child protection is provided through the use of electronic *Learn Pro* modules and bespoke sessions. There is no mandatory training for medical staff.

In Edinburgh the Child Protection Team comprises consultant community paediatricians, a team of 8 Child Protection Advisors, managerial and administrative support. The community paediatricians have a lead role in child protection and there is a lead paediatrician in the local authority area in Lothian. All referrals for child protection advice are handled by the CPT and there are inter-agency referral discussions to agree an appropriate plan of action. The CPT is available Monday to Friday 9 am to 5 pm and there is a consultant to consultant referral service out of hours. Following assessment, the CPT will document their findings in the child's case notes. Level 1 training in child protection is mandatory for all staff through *Learn Pro* (an *e*-learning module).

In Dundee the Child Protection Team comprises of a designated doctor, a lead nurse, a nurse advisor in Child Protection within Acute Services, and a further eight nurse advisors in Child Protection. A Child Protection nurse attends the children's ward on a daily basis. Referrals to the team are made by any of the nursing or medical staff. The Child Protection protocol is known to staff in both Ward 29 and 23B and training is provided to all staff through mandatory update child protection sessions provided by the hospital. The CPT document their findings in the child's case notes but other findings will be held by the CPT, the Social Work team and the police.

In Aberdeen the Child Protection Team comprises three doctors, a child protection nurse consultant, a child protection trainer and support team; they are available to give advice to anyone who has child protection concerns. There is a mandatory eLearning in Child Protection and an awareness training module is available for all NHS Grampian staff through eKSF.

Quality improvement and governance and activities

Patient safety and equity of access are at the core of paediatric neurosurgical provision in Scotland. This report is the first national audit of paediatric neurosurgery services and as such addresses the systems in place to facilitate safe practice across the four units that together comprise a service that uses a more diffuse model than other paediatric neurosurgical services in the UK.

As described previously, the development of the three categories of surgery in 2014 has provided a framework to ensure that surgical procedures of varying complexity and urgency are undertaken in an appropriate environment at an appropriate time. This section of the report provides information on each unit's participation in local, regional and national governance activities.

Morbidity and mortality meetings play a significant part in ensuring the service is safe and that the care we provide is subject to an appropriate degree of scrutiny. Although there were five deaths of children under the care of the neurosurgeons in 2014, there were no deaths in the randomly selected cohort of 104 children included in the audit of the patient journey.

There would appear however to be marked variation in the reporting of morbidity at unit morbidity and mortality meetings. One case was reviewed in Aberdeen, no cases were reviewed in Dundee, nine cases (22.5%) were reviewed in Edinburgh and 24 of 40 cases (60.0%) were reviewed in Glasgow.

In Glasgow the audit activity currently undertaken by the neurosurgical team is as follows: an audit of blood loss in craniofacial surgery, a hyponatraemia audit and an EVD infection rate audit. In addition the clinicians submit data to the following national audits/registries:

- UK Shunt Registry
- Epilepsy Audit
- Brain Tumour Audit
- Spinal Dysraphism
- BPNG

The unit in Glasgow provides the national craniofacial service but does not participate in the UK audit because this is specific to the units in England. Representatives of the Scottish service have attended the annual review meetings of the four English supra-regional services however they are not routinely invited.

Morbidity and mortality (M&M) data is collected prospectively and reviewed each month with meetings held on a quarterly basis in conjunction with the local Operational Management Group. An anaesthetic representative is invited to these meetings. Learning points are documented in the minutes and evidence of change is audited and reviewed by one of the neurosurgeons. “Near-misses” are also reported at this meeting.

In 2014, there were four deaths in the unit. These cases were reviewed at morbidity and mortality meetings.

In Edinburgh the neurosurgical team participate in a Morbidity and Mortality Audit and the clinicians submit data to the following national audits/registries:

- UK Shunt Registry
- Epilepsy Audit
- Brain Tumour Audit
- BPNG

M&M data is collected and reviewed at M&M meetings held in conjunction with the monthly adult M&M meeting. Learning points are discussed and ‘near misses’ are reported at the time of the M&M. There are also M&M meetings held at the RHSC. The death of a child is discussed at both the adult Neuroscience M&M and also the RHSC M&M meetings.

In 2014, there was one death in the unit.

In Dundee the clinicians submit data to the UK Shunt Registry. There is a monthly M&M meeting which takes place as part of the Clinical Effectiveness meetings. The Clinical Governance Lead chairs this meeting whenever possible. Paediatric cases can be discussed at this meeting and learning points are disseminated by the Clinical Governance Lead. “Near misses” are discussed at the M&M meetings.

In 2014, there were no deaths of children under the care of neurosurgeons in the unit.

In Aberdeen the audit activity currently undertaken by the neurosurgical team is as follows:

- Shunt Audit
- Audit of back closure and complications in spina bifida.

M&M meetings are held on a 4 monthly basis in conjunction with the whole RACH medical and surgical teams. Learning points are documented in a circulated review of the meeting and evidence of change is documented in Datix incidence reporting data.

'Near-misses' are reported at the M&M meeting and through Datix reporting. The Neonatal Unit at Aberdeen Maternity Hospital also runs regular 'near-miss' meetings. In the event of a child dying, the unit protocol requires that an incident reporting form is completed. Every child death in Grampian is also subsequently reviewed by the Child Death Review Group.

In 2014, there were no deaths of children under the care of neurosurgeons in the unit.

Results of the Audit Review Panel visits to the centres

This section of the report provides the summary findings of the Audit Review Panel visits to each of the four centres. This information and a list of centre-specific questions formed the basis of an Interim Report that was submitted to the senior teams in each of the hospitals. The MSN has received responses from each of the four units and will work with the teams to support change where there is an indication to do so and monitor progress against improvement plans.

The service in Glasgow

Summary comments about the visit to the RHSC at Yorkhill in Glasgow

- There were no safety concerns raised by Audit Review Panel that would have caused the audit process to be halted prematurely.
- The Panel commented positively on the very good level of open communication with the staff during the visit and the level of positivity was good.
- The views expressed by the Panel primarily related to suggestions for improvement and maintaining existing areas of strength such as High Dependency Unit care, the demarcated Neuroscience Ward and rehabilitation services.
- It was acknowledged that the visit coincided with the significant change process involved in relocating the hospital. The Panel considered the change process to be challenging but well-managed overall. They urged caution however in the commonly expressed view that “it will be better once we’ve moved”.
- Staff raised concerns that the incorporation of the Neuroscience Unit into a mixed medical ward will dilute their identity as a specialist tertiary receiving unit. Given that Cardiology is to retain its very specific identity after the move, the Panel would like to know what plans are in place to ensure the Neuroscience Unit has a similarly clear identity?
- The Panel sought reassurance that the concerns expressed by staff and their well-being prior to and after the move to the new hospital were being addressed by their respective management structures.
- The Panel will visit the new Royal Children’s Hospital at the beginning of 2016.

Specific responses were requested in relation to how the hospital's senior team planned to address the following points:

How to compensate for the loss of neuroscience trained nurses to other clinical areas e.g. oncology.

How to maintain a 'Neuroscience Unit' identity commensurate with a tertiary receiving service within a mixed medical ward.

How to demarcate nursing teams within a mixed ward to mitigate the potential risk of cross-infection arising from patients on long-term ventilation.

How to ensure appropriate assessment and investigation of children is undertaken by the ED team *prior to* referral to neurosurgery.

How to ensure the appropriate level of general medical paediatric support for neurosurgical patients.

How to improve transition services for young people with certain neurological conditions.

How to ensure continuity of care for GG&C patients when provision of the National Paediatric Epilepsy Surgery Service is currently located in NHS Lothian.

How to secure an appropriate level of AHP resource for patients who have had neurosurgery.

What arrangements have been put in place at the new hospital to compensate for the loss of dedicated neuroscience therapy areas?

The service in Edinburgh

Summary comments about the visit to the RHSC in Edinburgh

- There were no safety concerns raised by Audit Review Panel that would have caused the audit process to be halted prematurely.
- It was evident to the Panel that the paediatric neuroscience service is delivered in a long-standing, well-established unit that is well-resourced.
- The Panel commented positively on the communication systems embedded within the hospital in particular the communication between disciplines: the daily bed meeting, the CEPOD 'huddle' and the Ward 7 'huddle'. The impact of this approach on patient safety and patient flow was commended.
- The weekly multidisciplinary team meeting appears to promote good planning at the interface between the acute sector and the community with a strong focus on continuity within the child's rehabilitation programme. It was acknowledged however that continuity was easier to achieve within Lothian than in some of the referring boards.
- The Panel sought reassurance that the good practice that has evolved over the years will be recognised, protected and continue when the hospital relocates in 2017 to the campus at Little France.
- The overall impression of the Panel was that this is a cohesive neuroscience unit.

Specific responses were requested in relation to how the hospital's senior team planned to address the following points:

How to ensure the Neuroscience Unit does not lose neuroscience trained nurses when the hospital relocates in 2017.

How to ensure the 'critical care without walls' initiative of patients with increased levels of dependency on the ward is safely implemented and monitored.

How to develop a system whereby both inpatient and outpatient neurosurgical activity can be easily ascertained.

The service in Dundee

Summary comments about the visit to the Tayside Children's Hospital in Dundee

- There were no safety concerns raised by Audit Review Panel that would have caused the audit process to be halted prematurely.
- The Panel acknowledged that there are few children requiring neurosurgical intervention in Tayside: 10 children accounted for 22 procedures in 2014 and this volume of activity presents its own challenges.
- The Panel was impressed with the level of communication and collaboration between specialties that enables the provision of a safe paediatric neurosurgical service.
- The Panel commented positively on the effective utilisation of resources between the paediatric and adult service and supported the prioritisation of children when there was a clinical indication to do so.
- The level of cleanliness throughout the hospital was spontaneously described as excellent (although not within the remit of the visit).
- The Panel expressed concern that the good practice that has evolved over the years is in part personality dependent and therefore may not be sustainable in the longer term. A plan for paediatric neurosurgery in Tayside in the future is requested.
- The overall impression of the Panel was that a collaborative, child-centred system of care has been developed to provide a safe paediatric neurosurgical service that facilitates the provision of appropriately complex care at a local level while ensuring a robust system for the transfer of children requiring more complex care.

Specific responses were requested in relation to how the hospital's senior team planned to address the following concerns:

How will the long-term sustainability of the service be ensured?

How will the risk involved in the lack of a 24/7 MRI service be addressed?

How are the skills and experience of the HDU-trained nurses dispersed throughout the nursing team?

How will the lack of dedicated paediatric therapy space be addressed?

The service in Aberdeen

Summary comments about the visit to the Royal Aberdeen Children's Hospital

- There were no safety concerns raised by Audit Review Panel that would have caused the audit process to be halted prematurely.
- The Panel's initial impression was that the children's hospital provides a bright, welcoming environment for children and their families.
- The Panel commented positively on what appears to be good communication between medical and nursing staff. This should result in a service based on strong relationships with people working collaboratively.
- The overall impression of the Panel was that the service is child-centred, however the Panel were concerned that children requiring neurosurgical care may be admitted to either the medical or the surgical ward and that in the presence of a relatively low incidence of paediatric neurosurgical admissions, this risks diluting experience: twenty one children presented in 2014 but never the less require specialist skills and expertise. The Panel would see advantage in concentrating this work in a single ward.
- There appear to be differing views from paediatric medical and nursing staff about the involvement of the neurosurgical team in the daily review of children admitted to the RACH. The Panel advises that documentation of daily review by the neurosurgeons in the patient's casenotes would address this issue.

Specific responses were requested in relation to how the hospital's senior team planned to address the following points:

How to maintain skills to cope with neurosurgical emergencies e.g. consider having unannounced emergency simulation exercises in both HDU and the Surgical Ward.

How will the risk involved in the lack of a 24/7 MRI service be addressed?

How to ensure the adult ICU and paediatric HDU teams work together to care for the child who requires ventilation prior to retrieval e.g. consider a dual care model where an adult ICU nurse works alongside a paediatric HDU nurse.

How to ensure that children requiring neurosurgical intervention are looked after in the surgical ward rather than the medical ward.

How to ensure the paediatric nurses in the surgical ward and HDU can acquire/ maintain the skills required to look after children requiring neurosurgical intervention.

Conclusions

The model of service delivery for paediatric neurosurgery in Scotland is safe. The Audit Review Panel would like to commend the staff in the four centres for their co-operation with the review process and the prompt response to the panel's interim findings and requests for further information.

The service overall provided operative treatment to 299 children aged under 16 and performed 513 procedures on this group in 2014. The two specialist paediatric units had relatively even splits of patients in the three categories and no Category 3 surgery was undertaken in the units without Level 3 PCCU facilities and a 24/7 subspecialist paediatric neurosurgical on call rota. This suggests that referral pathways are working well and that children are being cared for in appropriate facilities.

The Patient Journey audit was undertaken to ascertain if the service that was described by each of the four provider units matched the service that was delivered. It did. The management of 104 children who accounted for 122 procedures in 2014 has shown that while there is variation in service provision (as indicated in the descriptions of each of the four units) there was no evidence that this variation gives cause for concern. It is clear however that there is room for improvement in documentation of a number of aspects of service delivery.

There was no evidence to suggest that further concentration of services would improve the quality of care and evidence of good practice as well as areas for improvement were observed in all four centres. Our patients and their families have made clear their desire to be treated as close to home as possible and the MSN is committed to ensuring that where the specialist skills are available, this wish is respected.

The network model of service delivery that has been developed and audited in Scotland may have a wider application for paediatric neurosurgery elsewhere and in other subspecialty areas of adult neurosurgery within Scotland.

Acknowledgements

The MSN would like to thank the staff in each of the four centres who have contributed information to the national paediatric audit programme. Writing the descriptive reports for each centre involved clinical, managerial and administrative staff taking time to work with the MSN team on the collation of information about all aspects of their service delivery and the MSN is grateful for their efforts

We would also like to thank our third sector partners and in particular the Scottish Spina Bifida Association families who provided an excellent patient and family perspective that has informed the work we are undertaking.

The membership of the Audit Review Panels is provided in Appendix 2. The willingness of clinical staff, patient representatives and third sector partners to undertake the visits to the centres in addition to their already busy schedules is very much appreciated. Their expertise was fundamental to the success of this component of the national audit programme.

The work of the MSN team in collating the information for their centres is to be commended: Miss Margaret Winters, Clinical Co-ordinator of the MSN who designed the audit tools and led the team; Dr Alena Vasianovich, Audit Facilitator in NHS Grampian; Mrs Anne Addison, Audit Facilitator in NHS Tayside and NHS Lothian; and Mrs Denise Pentland, Audit Facilitator in NHS GG&C. The excellent work undertaken by Ms Jennifer Lee, former Tayside Audit Facilitator in the early stages of developing the audit is much appreciated.

The logistical challenge of organising the visits to the centres was considerable and undertaken with great efficiency by Ms Susan Chambers, former Network Administrator.

Finally we would like to thank Dr Simon P Young and Mr Eric Ballantyne for their contribution to editing the report.

Appendix 1 The Paediatric Advisory Group

Miss Jennifer Brown	Chair, National Lead for Paediatric Neurosurgery
Mr Eric Ballantyne	MSN Clinical Director
Miss Diana Beard	MSN Network Manager
Mr Pragnesh Bhatt	Consultant Neurosurgeon, NHS Grampian
Dr Mark Brougham	Consultant Paediatric Oncologist, NHS Lothian
Miss Emer Campbell	Consultant Neurosurgeon, NHS GG&C
Ms Karen Duguid	Senior Charge Nurse, NHS Lothian
Dr Paul Eunson	Consultant Paediatric Neurologist, NHS Lothian
Dr Kirsten Forbes	Consultant Neuroradiologist, NHS GG&C
Mrs Shona Forsyth	Neuropaediatric Outreach Nurse, NHS GG&C
Mr Pasquale Gallo	Consultant Paediatric Neurosurgeon, NHS Lothian
Ms Claire Hedley	Advanced Occupational Therapist, NHS GG&C
Ms Andrena Hughes	Parent Representative, NHS GG&C
Mr Jothy Kandasamy	Consultant Paediatric Neurosurgeon, NHS Lothian
Ms Valerie Kennedy	Clinical Specialist Physiotherapist, NHS Lothian
Dr Martin Kirkpatrick	Consultant Paediatric Neurologist, NHS Tayside
Mr Roddy O'Kane	Consultant Neurosurgeon, NHS GG&C
Mr Jamie Redfern	General Manager, NHS GG&C
Ms Tracy Rendall	Parent Representative, NHS Lothian
Mr Raju Sangra	Consultant Neurosurgeon, NHS GG&C
Dr Jairam Sastry	Paediatric Oncologist, NHS GG&C
Mr Drahoslav Sokol	Consultant Paediatric Neurosurgeon, NHS Lothian
Ms Lorraine Todd	Advanced Nurse Practitioner, NHS GG&C
Ms Anissa Tonberg	Policy Development Manager, *Epilepsy Scotland*
Ms Margaret Winters	MSN Clinical Co-ordinator, NHS GG&C
Mr Andy Wynd	Chief Executive, *Scottish Spina Bifida Association*
Dr Simon P Young	Consultant Neuroanaesthetist, NHS GG&C

Appendix 2 The Audit Review Panels

RHSC Glasgow visit 27.02.15

Chair	Miss Jennifer Brown (MSN National Lead for Paediatric Neurosurgery)
Neurosurgeons	Mr Jothy Kandasamy (NHSL)
	Mr Drahus Sokol (NHSL)
Anaesthetist	Dr Mary Rose (NHSL)
Nurse	SCN Karen Duguid (NHSL)
AHP	Ms Val Kennedy (NHSL)
Patient Representative	Ms Andrena Hughes
Third Sector	Ms Lesslie Young (*Epilepsy Scotland*)
MSN	Miss Diana Beard (National Network Manager)
	Miss Margaret Winters (Clinical Co-ordinator)

RHSC Edinburgh visit 01.04.15

Chair	Miss Jennifer Brown (MSN National Lead for Paediatric Neurosurgery)
Neurosurgeons	Mr Pragnesh Bhatt (NHS Grampian)
	Mr Eric Ballantyne (NHS Tayside)
Anaesthetist	Dr Simon P Young (NHS GG&C)
Nurse	SCN Lesley Wilson (NHSL GG&C)
AHP	Ms Claire Hedley (NHS GG&C)
Patient Representative	Ms Tracy Hughes
Third Sector	Ms Candice Dillen Young (*Neurological Alliance of Scotland*)
	Mr Alan Moir (*Epilepsy Scotland*)
MSN	Miss Diana Beard (National Network Manager)
	Ms Margaret Winters (Clinical Co-ordinator)

Tayside Children's Hospital visit 17.04.15

Chair	Miss Jennifer Brown (MSN National Lead for Paediatric Neurosurgery)
Neurosurgeon	Mr Roddy O'Kane (NHS GG&C)
Anaesthetist	Dr Simon P Young (NHS GG&C)
Nurse	CNM Peter Campbell (NHS Lothian)
AHP	Ms Val Kennedy (NHS Lothian)
Third Sector	Mr Andy Wynd (Chief Executive of the *Scottish Spina Bifida Association*)
Patient Representative	None present
MSN	Miss Diana Beard (National Network Manager)
	Ms Margaret Winters (Clinical Co-ordinator)
	Mrs Anne Addison (Audit Facilitator)

Royal Aberdeen Children's Hospital visit 01.05.15

Chair	Miss Jennifer Brown (MSN National Lead for Paediatric Neurosurgery)
Neurosurgeons	Miss Emer Campbell (NHS GG&C)
	Mr Chandru Kaliaperumal (NHS Lothian)
Anaesthetist	Dr Simon P Young (NHS GG&C)
Nurses	SCN Ms Catherine Borland (NHS Tayside), Outreach Nurse Mrs Shona Forsyth (NHS GG&C), ANP Ms Lorraine Todd (NHS GG&C)
AHP	*None present*
Patient Representative	*None present*
Third Sector	Ms Stephanie Fraser (*Bobath*)
MSN	Miss Diana Beard (National Network Manager)
	Ms Margaret Winters (Clinical Co-ordinator)
	Dr Alena Vasianovich (Audit Facilitator)

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