MANAGED SERVICE NETWORK
NEUROSURGERY

The Paediatric Neurosurgical Service in Scotland

Activity
Patient Experience
Quality Performance Indicators

June 2018

Version 1.0

Contents

Introduction

The Managed Service Network for Neurosurgery (MSN) was established in 2009 and has the responsibility of delivering a single national neurosurgical service across four neurosurgical centres in Scotland based in the cities of Aberdeen, Dundee, Edinburgh and Glasgow. The MSN has a full programme of service evaluation and audit working across both adult and paediatric neurosurgery: http://www.msn-neuro.scot.nhs.uk/.

There are significant differences in the number of paediatric neurosurgical cases performed in each of the four centres and also in the complexity of surgery that is undertaken. A national audit of the paediatric neurosurgical service was reported in 2015[1]. The report concluded that the model of delivering neurosurgery across the four centres in Scotland was safe. Using the system of categorising paediatric neurosurgery according to level of complexity and associated support needs developed through this work, it was established that each centre had an important role to play. The two larger centres (Edinburgh and Glasgow) have a good balance across all three levels of complexity, whilst the smaller centres (Dundee and Aberdeen) performed surgery at an appropriate level.

The Paediatric Advisory Group (PAG) subsequently developed a national paediatric audit programme for 2016–17. The programme comprised:

- an activity audit that documented the categories of surgery and provided a denominator database for our paediatric work;
- a patient experience survey which asked children, young people and parents/carers about their experience of paediatric neurosurgery. Three age specific surveys were developed; the children’s survey is aimed at 8 -11 year olds, the young people survey to 12 – 16 year olds, and there is also a survey for parents/carers and
- the development and implementation of two quality performance indicators (QPIs) focusing on traumatic brain injury (TBI) and central nervous system (CNS) tumours.

This report details the findings from the three components of the programme. Children and young people aged less than 16 years at the time of admission to hospital between the dates of June 1st 2016 and May 31st 2017 are included.

The QPIs for CNS tumours and traumatic brain tumour documented deaths at 30 days and one year post-admission hence the publication of this report in 2018.

Activity

The table below shows the level of activity for the four neurosurgical centres in Scotland for the period of 1st of June 2016 to 31st of May 2017. The categories of surgery were determined based on the level of complexity of the procedure and therefore the likelihood of the patient requiring paediatric critical care facilities and the availability of a paediatric neurosurgeon on a 24/7 basis[1].
There was one category 3 procedure carried out in NHS Grampian during this period. This case was discussed with the PAG and level of risk assessed. It was decided that the case should proceed following consideration of the patient's age (14 years), the nature of their presentation, and the required specialist skills being available in NHS Grampian.

The level of activity reported here is in line with previous activity levels reported by the MSN[1].

Table 1	**Operative activity**				
	Number of Children	**Category 1**	**Category 2**	**Category 3**	**Total**
NHS Grampian	18	22	4	1	**27**
NHS Tayside	14	9	8	0	**17**
NHS Lothian	112	53	44	48	**145**
NHS GG&C	198	178	36	70	**284**
Scotland	**342**	**262**	**92**	**119**	**473**

Patient Experience Survey

What did we do and how did we do it?

The survey designs were based on the recommended Picker format[2] and were developed by the MSN team in collaboration with neurosurgical *Voices* groups[3]. Each unit received copies of all three age group-specific surveys[4] to distribute to the paediatric ward within their centre. Posters informing families of the survey were also placed in the paediatric ward. The posters included the MSN website address which also hosted copies of the surveys that could be downloaded. Ward staff (nursing and administration) were recruited to ensure that all families received the age-appropriate survey prior to discharge. The respondent received the relevant survey along with a pre-paid envelope to allow them to post the completed survey back to the MSN central office.

For each question on the survey a score out of 10 was generated. This was achieved by scoring the most positive response with a 10, subsequent positive responses with a 5, and a 0 for negative responses. No score was given to responses which did not express an opinion (e.g. don't know/ can't remember). The mean score was then generated, with 10 being the most positive reflection on an experience and 0 being the most negative. Appendix 1 details the score generated for each question on the surveys.

What did we show?

The survey ran from the 1st of June 2016 to the 31st of May 2017. A total of 342 children underwent a neurosurgical procedure during this time period. The response rate was 11%.

Table 2 demonstrates a breakdown of the responses received.

Table 2	**Paediatric neurosurgery survey responses**			
	Parent/Carer	**Children** (8 - 11 yrs)	**Young People** (12 -16 yrs)	**Total**
NHS Grampian	6[1]	1	2	**9**
NHS Tayside	0	0	1	**1**
NHS Lothian	6	2	4	**12**
NHS GG&C	8	1	7	**16**
Total	**20**	**4**	**14**	**38**

The average age of the children completing the survey was 7.8 years with a range of 7-11 years. Slightly more children were female (5) compared to male (4). Slightly more females (57%) also completed the young people's survey compared to males. The average age of the young people was 14.38 years with a range of 13-16 years.

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[1] *In NHS Grampian all parents/carers were provided with a copy of the parent/carer survey, whilst in all other boards only the parents/carers of children less than 8 years old were given this survey.*

The following sections detail the results for each part of the survey. It should be borne in mind that the low response rate (11%) impacts on the extent to which the results can be generalised across the paediatric neurosurgical service.

Planning and arriving at hospital

Parents/carers were asked if they were told what was going to happen to their child while they were in hospital for their most recent stay. A score of 9.62 was recorded for this question; with 12/13 parents/carers feeling that they definitely knew what would happen when they took their child into hospital.

All respondents were asked if, when arriving on the ward, they were informed by staff what was going to happen during their stay. Overall the response to this question was very positive with a collective score of 8.14. This can be broken down into 8.25 for parents/carers and 8.04 for children and young people.

The majority of parents/carers (13/20) reported that they were *definitely* told what was going to happen to their child during their stay, whilst 5/9 children and 11/14 young people felt they were *clearly* told what would happen to them.

The ward

Respondents were asked about their perceptions of several aspects of their stay on the ward.

Safety

All respondents were asked about their perception of safety on the ward. A very positive score of 9.77 was recorded for this question, with a score of 9.75 for parents/carers with 19/20 reporting that they thought their child was safe on the ward all of the time. Children and young people also reported feeling safe on the ward, with a collective score of 9.78, 8/9 children and all young people reported that they felt safe all of the time on the ward.

Activities

Parents/carers and young people were asked if there were relevant age appropriate activities (e.g. electronic games, DVDs, magazines) for them/their child to use whilst on the ward. 14/20 parents/carers thought that there were a lot of these materials, whilst 11/14 young people thought the same. The overall score for this question was 8.5 for parent respondents and 8.93 for young people.

Children were asked if the ward staff played with them or undertook activities with them whilst they were on the ward. 5/7 said that that they did, with 4/7 saying that they did a lot. The overall score from children for this question was 6.42.

Food

All respondents were asked whether they/their child liked the food provided by the hospital however many children completing this survey did not have hospital food. Overall this question had a negative score of 4.42 with a score of 6.07 from parents/carers and 4.57 from children and young people. Most parents/carers thought that their children liked the hospital food to some extent (7/14), whilst 6/14 young people sort of liked the food and 4/9 children did not like the food.

Privacy

Children and young people were asked whether they thought they had enough privacy on the ward when receiving treatment. This question was scored as 8.01, with 7/8 children and 10/13 young people feeling that they had enough privacy.

Parents/carers perspectives on how their child was looked after

Neurosurgical team

When asked specifically about the neurosurgical team, parents/carers were overall very positive about their experience with them. All of the parents/carers reported knowing which members of the neurosurgical team were in charge of their child's care, with 17/20 parents/carers stating that they always knew who the neurosurgical team were. This question was scored positively as 9.25.

The vast majority of parents/carers (18/19) said that they had worked with the neurosurgical team to agree a care plan (score 9.47). Parents/carers thought that they had been provided with accessible information from the team, with this question being scored as 9.25. Eighteen out of 20 parents/carers thought they had definitely received such information.

Information and decision making

With regards to working with the medical team in general parents/carers were very positive about their experiences, with 17/20 parents/carers feeling they were definitely involved in decision making, 18/20 feeling they were kept informed of what was happening to their child and 17/20 being asked by staff if they had any questions about their child's care.

Staff treating their child

All parents/carers reported that staff working on the ward their child was staying in introduced themselves to them, with 15/19 saying this happened all of the time (score: 8.95). Most parents/carers (17/20) thought that the staff definitely knew how to look after their child, with 16/19 reporting that the staff definitely communicated with their child in a way that their child could understand (scores of 9 and 9.21 respectively).

The vast majority of parents/carers thought that members of staff were available when their child needed attention, which scored 9.75 as 19/20 parents/carers thought this was the case all of the time.

Overwhelmingly all parents/carers thought that the staff caring for their child worked well together with a score of 10. This was further reflected in questions which asked about communication in the team, 16/20 parents/carers thought that all staff gave them similar information about the care of their child (score 8.75) and 19/20 thought the staff were aware of their child's medical history (score 7.75).

Children and Young People's perspective of how they were looked after

Staff

All children and young people thought that the staff on the ward talked to them about their care in a way that they could understand (score 10). Furthermore all of the children reported that there was someone to talk to on the ward if they had any worries, 11/12 young people thought the same way (combined score of 9.29). When asked whether young people thought staff talked to each other about them as if they were not there, the majority thought that this was not the case (11/13, score 8.5).

Decision making

Like the parent/carer group, young people were asked if they felt they had been involved in decision making regarding their care, all thought that they had at least a little bit, with most thinking they had fully (9/13). This was scored as 8.46. Continuing with the theme of decision making young people were asked if they thought that the people that matter to them were also included in this decision making process. All of the young people reported that they did (score 10).

Operation or Procedure

Before the operation or procedure

All respondents were asked if a member of staff explained what would happen during the operation or procedure, before it took place. A positive score of 9.32 was recorded for this question. All of the young people and 6/8 children reported this had happened, while 15/17 of the parents/carers thought the procedure had been explained completely.

The parents/carers were asked if staff members answered their questions before the operation or procedure in a way that they could understand. This question achieved a score of 9.41 with 16/17 of the parents/carers responding that their questions had been answered completely.

After the operation or procedure

All respondents were asked if, after the operation or procedure, someone from the ward had explained how the procedure had gone in a way they could understand. Again this question received a positive response with a collective total of 9.14. The majority of parents/carers (15/17) thought this had occurred, whilst 6/7 children and 9/11 young people agreed.

Leaving the Hospital

All responders were asked if someone from the ward told them what to do or who to talk to if they were worried when they got home. This scored a very positive 9.43 collectively for all ages. All of the children (6) and parents/carers (15), as well as 11/14 of the young people responded that this had definitely occurred.

Parents/carers and young people were asked if staff told them what would happen after they/ their child left hospital. For 14/15 of the parents/carers, the answer was 'yes, definitely' and for 10/14 young people 'yes, completely'. This question received a combined score of 9.13.

Parents/carers and young people were asked whether staff gave them advice on how to look after themselves/their child after they went home. The majority of young people and parents/carers felt this was the case. The question was scored positively for both groups; 8.21 for young people (10/14) and a slightly higher score of 9.06 for parents/carers (14/16).

The parents/carers and young people were asked whether any written information (such as leaflets) on their/their child's condition or treatment were given to them to take home. The young people were asked specifically if this was 'age appropriate'. The response for the parents/carers was 7/10 for 'yes, definitely' with a score of 7.78. In comparison only 3/7 of the young people responded positively to this question which was reflected in the negative score of 4.29. Four of the young people who responded answered that they had not received such information, but they would have liked it.

Overview of experience

All respondents were asked if they thought they were listened to during their/their child's stay in hospital. All children, young people and the vast majority of parents/carers (19/20) thought this was the case. This question has an overall combined score of 9.42.

All respondents were also asked if they thought that the people looking after them/their child had been friendly, all of the respondents reported that staff had been friendly with 19/20 parents/carers (score 9.75), 13/14 young people (score 9.64) and all children (score 10) reporting this was true all of the time.

In addition parents/carers were asked if overall they felt their child had been well looked after by the staff, all of the parents/carers reported this had definitely been the case. Furthermore, parents/carers were asked if they had been treated with dignity and respect by the people looking after their child, 19/20 (score 9.5) felt this had been their experience.

Overall score

At the end of the survey all respondents were asked to give their overall experience a score out of 10, with 0 being a very poor experience and 10 being a very positive one. The majority of respondents gave their experience a score of 9 or 10. Table 3 summarises the scores given.

Table 3	**Overall satisfaction score**		
	Parents/carers	**Young people**	**Children**
<4	1	0	0
5-8	3	6	1
9-10	16	8	8
Average score	**8.95**	**9.07**	**9.11**

What else did our patients and their families want to tell us?

All respondents to the survey where asked if there was anything else they would like to say about their experience.

Comments from Children:

The majority of the comments received from children were positive (6 comments out of 9) and were mainly related to the care they had received from members of staff:

> *"The play room team are good at bringing art-craft + games to your room"*

> *"My stay in hospital was good considering what I was in for. The nurses and doctors were great. I enjoyed the food."*

Three slightly more negative comments were received, which were more focused on areas that could be improved, one child noted:

> "*Nursing staff do an amazing job in very difficult circumstances. Medicine trolley could be brought round a wee bit earlier as I go to bed early and sometimes need to be woken up."*

The other two comments focused on the food which one child felt "*could be improved*".

Comments from Young People:

As with the children, all of the positive comments made by the young people (4 comments out of 7) were praising the clinical team. There were no negative comments made about the clinical team.

Negative comments were directed at facilities in rooms, or at things that could be improved.

> *"Door system doesn't work for months – hate disturbing busy nurses to come open door for me."*

> *"I would have preferred tablets rather than liquid medicine. All the staff were lovely and I felt well looked after."*

Comments from Parents/Carers:

The comments from parents/carers fell into one of three categories: staff, facilities and housekeeping.

In relation to comments about staff the majority were positive and praised the care their children had received.

> *"My husband and I were both extremely pleased to have the doctors and nurses look after our daughter so well and know that they all worked hard to achieve the best outcome for her."*

> *"Every nurse and doctor we came in contact with was very kind and professional. Neurosurgery team were amazing. Very well looked after. Nursing staff understanding and comforting when I was upset."*

Parents/carers made some comments about how the facilities on the ward could be improved, this included facilities in the rooms, communal areas, and access to the ward.

> *"When we arrived on [ward name], Day 1 we were told to come at 10am – however no nurse or Dr saw us until 2pm. We sat in the childcare play room but there were no adult seats, only children's plastic seats. My husband is 6ft4!"*

> *"The baby cots with metal bars are not great for infants that can pull themselves up and/or stand. Our son fell and banged his head quite hard on the metal bars, resulting in swelling and bruising. These cots should either be padded or their use discontinued for all but small babies with limited movement."*

A small number of parents/carers made comments about the cleanliness of the ward and the odour on the ward.

> *"I wish that the ward would be a lot cleaner as I was very disappointed by the lack of cleanliness."*

> *"The ward itself was fine and kept clean but there was a very unpleasant strong smell which did make us uncomfortable at times which the staff did try and help with by putting fans and air fresheners."*

Conclusion – MSN Patient Experience Survey

The results from these surveys show a snap shot of the experiences of parents/carers, children and young people with paediatric neurosurgical services in the four centres across Scotland.

On the whole the majority of responses reflected a positive experience, with all three age groups of respondents feeling well cared for, informed and included in decision making whilst in hospital. On the vast majority of items parents/carers, young people and children all gave similar responses, reflecting that children and young people are being included in decisions about their care along with their parents/carers.

This survey has highlighted some areas that could be improved on. All three groups, and specifically the children, scored their experience of hospital food low. Children also drew attention to a lower satisfaction with the time ward staff spent playing with them. Finally young people reported feeling dissatisfied with the availability of age appropriate written information given post operatively, this is in contrast to parents/carers who felt relatively positive about the information they received.

The response rate was disappointing, particularly given the effort that was sustained across the year to ensure that patients and their families were given a survey to complete. It is within the normal range of response rates to surveys of this sort however we intend simplifying the survey and making it available for online completion in the future.

In conclusion this survey reports, on the whole, positive experiences from parents/carers, young people and children regarding paediatric neurosurgery hospital stays with only minor issues highlighted that could be improved.

Quality Performance Indicators

What did we do and how did we do it?

Quality Performance Indicators (QPIs) are a tool to enable reporting on compliance with clinical standards which are focused on care and patient outcomes. The binary nature of QPIs (a yes/no response) makes reporting on compliance measureable. QPIs should be evidence based, or should take direction from recognised Clinical Guidelines; the stronger the evidence is in support of the indicator, the greater the benefit from implementing it[5].

Quality performance indicators were developed for central nervous system (CNS) tumours and traumatic brain injury (TBI).

Primary Central Nervous System (CNS) tumours are uncommon, with brain tumours being the most frequent. There is often a poor prognosis with CNS tumours. Such tumours are referred to as ‘high grade’ i.e. tumours which grow rapidly and are aggressive, and ‘low grade’ i.e. tumours which grow slowly and may or may not be treated successfully. Following the WHO classification of tumours ‘high grade’ tumours would be grade 4 and 3, whilst ‘low grade’ tumours would be grade 1 and 2. This work will cover all CNS tumour types.

There are seven indicators for children who presented with a newly diagnosed CNS tumour. The CNS tumour QPI was developed by the MSN to measure the quality of care throughout the patient pathway. The QPI focuses on access to timely imaging, input from a multidisciplinary team, and timely and planned interventions following best practice guidance set out by NICE[6, 7].

Traumatic Brain Injury (TBI) is defined as a traumatic event such as a fall, bang to the head, road traffic accident, sporting injury, or crush injury. Children with a TBI usually present to Emergency Department (ED), where their status will need to be assessed. Assessment includes the patient’s presenting status and the level of consciousness in the form of the Glasgow Coma Scale (GCS) or Paediatric Coma Scale (PCS) for children under 5 years old. A moderate TBI is classed as a GCS/PCS of 9-12 on admission or evidence of loss of consciousness for 15 minutes to 6 hours; a severe TBI is classed as a GCS ≤=8 on admission or evidence of loss of consciousness for more than 6 hours[8]. This work will address both moderate and severe TBI.

There are six indicators for children presenting with a TBI. The TBI QPI focuses on assessment on admission, timely investigations and interventions, review within 24 hours and shared care. The indicators reflect the guidance outlined in SIGN 110[8].

In each of the four neurosurgical centres, the MSN Audit Facilitator extracted data from hospital admission and operative systems to identify children and young people who met the following criteria:

- Were admitted between June 1st 2016 and May 31st 2017;
- Were under the age of 16 years (15 years 364 days) at the time of presentation;
- *For CNS tumours:* were **not** diagnosed with tumour recurrence; and
- *For TBI:* were admitted with a TBI under the care of a neurosurgeon.

The relevant QPI proforma was completed for each case (*see appendix 2 for CNS proforma and appendix 3 for TBI proforma*) and the data entered into a site-specific database. Databases from each of the four centres were then anonymised and merged to indicate national performance for CNS QPIs and also TBI QPIs. Each centre retained their own data, therefore should a team wish to review any case that did not meet the standard this can be carried out at a local level.

What did we show for Primary Central Nervous System (CNS) tumour patients?

In total 32 patient episodes were identified in the CNS cohort. These were related to 27 children diagnosed with a CNS tumour during the QPI collection period. Five of these children presented to NHS Tayside (Tayside Children's Hospital) or NHS Grampian (Royal Aberdeen Children's Hospital). As these centres do not carry out tumour resection surgery, these children were transferred to NHS Lothian or NHS Greater Glasgow and Clyde. Of the 27 children included in this analysis, 22 first presented to a neurosurgical centre.

When interpreting these results, it is important to be mindful of the small numbers included. One case failing the QPI can disproportionately skew the data.

Imaging

The QPIs outlined that children with a first presentation of a primary CNS tumour should have a diagnostic MRI scan. In addition children who have had a surgical resection of a primary CNS tumour should have post-operative imaging within 72 hours of surgery. This was based on NICE guidelines and clinical experience, supported by the literature[9,10,11] which recommends that children receive post-operative imaging to review the surgical margins and ensure the tumour has been removed completely within 72 hours of surgery.

Table 4	**CNS imaging**			
	Numerator	**Denominator**	**Target**	**Performance**
QPI 1: Diagnostic MRI scan	30	30	100%	100%
QPI 6: Post-operative MRI within 72 hours of surgery	18	19	100%	95%

Multidisciplinary Team (MDT) Working

In relation to multidisciplinary team working, the QPIs outlined that children admitted with a first presentation of a CNS tumour should be discussed at the neuro-oncology MDT meeting. Furthermore management by an MDT is critical for patients with CNS tumour as MDT meetings increase the likelihood of timely, appropriate treatment along with continuity of care. Therefore treatment of children with a first presentation of a primary CNS tumour will be in accordance with the treatment plan agreed by the MDT meeting.

In addition, NICE guidelines recommend that each centre treating children and young people with CNS tumours has a paediatric neuro-oncology nurse specialist, who is a core member of the multi-disciplinary team. Therefore the QPI outlined that these children should be referred to a Paediatric Oncology Nurse Specialist.

Table 5 **CNS multi-disciplinary team working**

	Numerator	Denominator	Target	Performance
QPI 2: Discussion at the neuro-oncology multi-disciplinary team (MDT) meeting	27	27	100%	100%
QPI 3: Compliance with multi-disciplinary team (MDT) treatment decisions	27	27	100%	100%
QPI 4: Paediatric Oncology Nurse Specialist available	20	26	100%	77%

Intervention

The recommended time from first diagnosis to treatment is within 31 days. Thus the QPI measured children with a first presentation of a primary CNS tumour having their first treatment within 31 days of the decision to treat being made at the Neuro-MDT meeting. Clinical evidence supported by the literature shows the best outcomes are achieved through maximum tumour clearance[12, 13, 14, 15]. This often requires a second procedure within 30 days of the first surgery. The QPI took this advice forward and measured children with first presentation of a primary CNS tumour having re-operation to maximise tumour clearance up to 30 days post surgery.

Nineteen of the 27 children required surgery at this stage of their journey. One child had a planned re-operation.

Table 6 **CNS neurosurgical intervention**

	Numerator	Denominator	Target	Performance
QPI 5: First treatment within 31 days of a decision to treat	24	26	100%	92%
QPI 7: Planned re-operation	1	1	100%	100%

Adverse Events

In addition to the core QPI set, the MSN also collected data pertaining to adverse events related to these children.

Category of Surgery

The MSN has defined three categories of paediatric neurosurgery: ranging from Category 1 where all four units should be able to provide care for paediatric patients requiring emergent neurosurgical intervention, through to Category 3, where cases should always be referred to specialist services in NHS Greater Glasgow and Clyde or NHS Lothian. These categories may reflect the need for post-operative critical care, in which case the surgery must be undertaken in the units in Glasgow or Edinburgh where there are paediatric intensive care units[1].

In this cohort, 22 episodes of surgery were carried out. These ranged from immediate interventions required for transfer, for example the insertion of an external ventricular drain (EVD), to tumour resection. As the table below clearly shows the majority of the surgical episodes carried out were category 3, and were tumour resections.

Table 7	**Episodes of surgery by category (CNS)**
	Number of surgical episodes
Category 1	1
Category 2	3
Category 3	18

Unplanned events

Incidents of unplanned return to theatre and return to hospital were also recorded. The incidents of these were low throughout the data collection period. Two children who had surgery required an unplanned return to theatre, whilst four children had an unplanned readmission (under the care of a neurosurgeon) within 30 days of being discharged.

Mortality

Mortality was recorded at 30 days post discharge and at one year. No children had died within 30 days of discharge. Four children died within one year: three of the children (including one child transferred from Tayside) were looked after in Lothian and one child was looked after in GG&C.

Conclusions: Primary Central Nervous System (CNS) tumour QPI

Overall the results of these CNS tumour QPIs are positive. During the initial part of the patients' pathway, performance is achieving the optimum 100% level with children diagnosed with MRI being discussed at MDT and the decisions of the MDT being implemented.

Children are receiving treatment within a timely period and are more often than not re-scanned within 72 hours of surgery. Both of these QPIs just fell short of the target range.

It would appear from these findings that more work is required on involving the paediatric oncology nurses, this QPI fell short of the target in six cases. However it appears that the involvement of these specialist nurses differs across centres, with different criteria for involvement specified by health boards. It would also appear that the attendance of the paediatric oncology nurse at appointments may also not always be fully recorded in the patient's notes. Further examination of cases which did not meet the standard may be carried out at a local level.

In conclusion, this set of QPIs measuring the care of children with a first diagnosis of central nervous system tumour has indicated a high level of compliance with the standards.

What did we show for patients with a traumatic brain injury (TBI)?

In total 78 patient episodes were identified in the TBI cohort. These were related to 75 children being admitted with a TBI during the QPI collection period. Three of these children presented to NHS Tayside (Tayside Children's Hospital) or NHS Grampian (Royal Aberdeen Children's Hospital). For these children it was deemed that they could require the services of Paediatric ICU and were therefore transferred to NHS Lothian or NHS Greater Glasgow and Clyde. Of the 75 children included in this analysis, 61 first presented to a neurosurgical centre.

Again, when interpreting these results, it is important to be mindful of the small numbers included. One case failing the QPI can disproportionately skew the data.

Assessment

Taking guidance from SIGN 110[8] which demonstrates that the Glasgow Coma Score (GCS) provides a reliable indication of the severity of brain injury and change in condition over time, this QPI stated that children admitted under the care of a neurosurgeon with a head injury should have their GCS documented in the ED.

The GCS should be broken down to include a score of Eye, Verbal and Motor (E/V/M). For children under 5 years old the Paediatric Coma Score (PCS) should be recorded.

Table 8	**TBI assessment in the Emergency Department**			
	Numerator	**Denominator**	**Target**	**Performance**
QPI 1: GCS/PCS on admission to the Emergency Department (ED).	35	75	100%	47%

Investigation

There are specific criteria for immediate (within 1 hour) and urgent CT scanning (within 8 hours) being carried out outlined in SIGN 110[8]. It has been established that intracranial lesions can be detected via CT scan prior to the presentation of clinical indicators. Scanning early reduces the delay in detecting and treating such lesions. These QPIs recorded whether children meeting the criteria were scanned within the designated period.

Table 9:	**TBI investigation**			
	Numerator	**Denominator**	**Target**	**Performance**
QPI 2a: Immediate CT scan (within 1 hour)	20	29	95%	69%
QPI 2b: Urgent CT scan (within 8 hours)	24	39	95%	62%

Intervention

It is estimated that approximately 30% of children and young people with a severe TBI will require emergency surgery[16]. Rapid access to surgical intervention may impact on the outcome of treatment in some cases. This QPI states that children requiring emergency surgery should be transferred to theatre within one hour of the decision to operate being made. For some children this will require a transfer to another hospital site for specialist paediatric neurosurgery and/or intensive care facilities. Noting that transfer of patients with impaired consciousness can result in secondary insults, and that such events can be minimised by high level monitoring and care during transfer, this QPI requires that emergency transfer from another hospital to the neurosurgery unit should be undertaken by a ‘suitably trained’ transfer team with experience in the transfer of critically ill children.

The QPI defines ‘suitably trained’ as “*the national service (SCOTSTAR) or a transfer team from the referring hospital comprising a nurse with paediatric and ITU experience and a consultant anaesthetist or a specialist trainee anaesthetist who has completed his/her paediatric training*”.

Table 10:	**TBI intervention**			
	Numerator	**Denominator**	**Target**	**Performance**
QPI 3: Transfer to a neurosurgery unit	-	23	100%	
QPI 6: Time to emergency surgery	4	7	100%	57%

Of the 23 children transferred to a neurosurgical unit, four transfers did not involve the Scottish Ambulance Service (road or air) but none appeared inappropriate on the basis of available information. In future a clinical opinion will be sought on the appropriateness of means of transport on a case by case basis. All children who are transferred should be discussed as part of the CAPNA audit (Clinical Audit of Paediatric Neurosurgical Activity) so the opinion of the referring and receiving clinicians can be obtained at that time.

Consultant Review

The QPI outlined that appropriate treatment and management decisions of the care of a child with a TBI, who has been admitted under the care of a Consultant Neurosurgeon, should take place within 24 hours of admission to the ward. This is widely accepted as best practice.

Table 11	**TBI consultant review**			
	Numerator	**Denominator**	**Target**	**Performance**
QPI 5: Consultant Paediatric Neurosurgeon Review	50	75	100%	67%

Shared care

In relation to issues of child protection the QPI outlined that where a child is admitted under the care of a neurosurgeon with a head injury in whom the mechanism of injury is uncertain, or where the mechanism of injury reported does not match the injuries observed, these children should be reviewed by a consultant paediatrician responsible for child protection to consider non-accidental injury as part of the mechanism of injury. The QPI measured whether this child protection policy had been adhered to.

Table 12	**TBI shared care**			
	Numerator	**Denominator**	**Target**	**Performance**
QPI 4: Child Protection: *Review by a Consultant Paediatrician*	11	12	100%	92%

Adverse Events

In addition to the core QPI, the MSN also collected data pertaining to adverse events related to these children.

Category of Surgery

The MSN has defined three categories of paediatric neurosurgery: ranging from Category 1, where all four units should be able to provide care for paediatric patients requiring emergent neurosurgical intervention, through to Category 3, where cases should always be referred to specialist services in NHS Greater Glasgow and Clyde or NHS Lothian. These categories may reflect the need for post-operative critical care, in which case the surgery must be undertaken in the units in Glasgow or Edinburgh where there are paediatric intensive care units[1].

In this cohort, 8 episodes of surgery were carried out. All of these were Category 1.

Table 13	**Episodes of surgery by category (TBI)**
	Number of surgical episodes
Category 1	8
Category 2	0
Category 3	0

Unplanned events

Incidents of unplanned return to theatre and return to hospital were also recorded. During the data collection period there were no unplanned returns to theatre, whilst there were 4 unplanned readmissions (under the care of a neurosurgeon) within 30 days of being discharged.

Mortality

Mortality rates were recorded at 30 days post discharge and at one year. One child died within 30 days of discharge; there were no subsequent deaths within one year.

Conclusions: Traumatic Brain Injury (TBI) QPI

Overall the results of these TBI QPIs are disappointing, with a failure to meet the target performance rage. Poor documentation in patients' notes of decisions, reviews or findings from assessments have resulted in a failure to meet the target for a number of the QPIs.

It appears that at the start of the patient pathway, assessment and scanning of these children is falling below the target level. In many cases the GCS score has been recorded as a whole number. With the exception of a score of 15/15, this was not acceptable to achieve the QPI as it was specified that the score needed to be broken down into the eye, verbal and motor scores.

It is possible that due to a number of these children presenting as multiple trauma cases, scanning is not possible until they are stable. This may also explain some of the delay in starting surgery within an hour of the decision to operate being made. The QPI pertaining to patient review required that the patient is reviewed by a Consultant Neurosurgeon within 24 hours of admission was not achieved. This may be explained by middle grade doctors undertaking the review, or the Consultant review taking place during the morning ward round but it not being appropriately documented.

On a more positive note, the QPIs relating to patient transfer and child protection are being well managed, with both of these QPIs just falling short of the target set.

In conclusion, these QPIs measuring the early management of children who present with a TBI and are admitted under the care of a neurosurgeon highlight several areas of possible improvement in order to comply with the standards. Further examination of cases which did not meet the standard may be carried out at a local level.

The plan for 2018

Throughout 2018 the MSN will continue its programme of paediatric audit with the main focus being the development of the Clinical Audit of Paediatric Neurosurgical Activity (CAPNA) as the national paediatric governance system for Scotland.

Currently information is collected on all operative cases in each of the four centres with additional data being collected in relation to all admissions or calls for advice in NHS Grampian and NHS Tayside. Each case is allocated a category of surgery code and then the centre's data is collated in a national database.

It is the intention of the Paediatric Advisory Group (PAG) that activity will be reported at each quarterly PAG meeting and cases for audit will be presented at the meeting.

Conclusion

This report presents an insight into paediatric neurosurgery in Scotland. It demonstrates that the activity level has remained relatively stable and that the categorisation of paediatric neurosurgery developed in earlier work is functioning well.

Positive patient experience feedback has been reported through the paediatric survey showing parents/carers, children and young people felt well cared for, informed and included in decision making. Though minor areas of improvement were highlighted the overall response is an encouraging one. The response rate of 11% however was disappointing. An online survey will be considered in future.

The two quality performance indicators carried out delivered a mixed response. Whilst high levels of compliance were reported regarding central nervous system tumours, disappointing compliance was found with regards to traumatic brain injury.

The MSN will move forward with the development of CAPNA as the national governance system and will continue work collaboratively with all four neurosurgical units.

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Appendix 1

The table below provides the score for each individual question. Not all questions appeared on each age group specific survey, this is indicated with a dash. In each survey the wording of the question was specific to that group, in this table the wording has been made generic.

	Parents/carers score	**Young people's score**	**Children's score**
Planning & arriving at hospital			
Being told what would happen before arriving at hospital.	9.62	-	-
Being told what was going to happen during the stay by ward staff.	8.25	9	8.57
The ward			
Feeling safe on the ward.	9.75	10	9.44
Appropriate activities on the ward.	8.50	8.93	6.43
Hospital food.	6.07	6	3.89
Privacy.	-	8.46	9.38
How their child/they were looked after			
New members of staff introducing themselves.	8.95	-	-
Knowing members of the Neurosurgical team.	9.25	-	-
Receiving information from the Neurosurgical team.	9.25	-	-
Agreeing a plan with the Neurosurgical team.	9.47	-	-
Staff communicating in an appropriate way.	9.21	10	10
Involved in decisions.	9	8.46	-
Important people being involved in decisions.	-	10	-
Talking about worries on the ward.	-	9.58	10
Staff talking about you as if you were not there. (*Reversed scoring*)	-	8.50	-
Being informed of what was happening whilst on the ward.	9.50	-	-
Asking if you had any questions.	9	-	-
Being given consistent information.	8.75	-	-
Staff being aware of medical history.	7.75	-	-
Meeting individual/special needs.	9	-	-
Staff availability.	9.75	-	-
Staff working as a team.	10	-	-
Operation/procedure			
Being told before the operation what would happen.	9.12	10	9
Questions being answered before the operation.	9.41	-	-
After the operation being told how it went.	9.12	9.09	9
Leaving hospital			
Advice for caring for your child at home.	9.06	-	-
What to do if you had worries when you were home.	10	8.57	10
What would happen when you left hospital.	9.67	8.57	-
Written information when you were leaving.	7.78	4.29	-
Overall			
Listened to.	9.25	9.64	9.44
Friendly.	9.75	9.64	10
Well looked after.	10	-	-
Treated with dignity and respect.	9.50	-	-
Overall score (mean score).	8.95	9.07	9.11

Appendix 2

MSN Neurosurgery QPI: CNS Tumour

CHI:		**Proforma ID:**	☐☐☐☐ - ☐☐☐☐
Patient Name:			
Admission (*date & time*):	_ _ / _ _ / _ _ _ _:_ _	**Source Hospital:**	☐☐☐☐
1. Did the child have a diagnostic MRI scan?			☐
2. Was the child discussed at the neuro-oncology MDT?			☐
3. Did the child's treatment comply with the MDT plan?			☐
Date of MDT:	_ _ / _ _ / _ _		
4. Was the child seen by a paediatric oncology nurse specialist?			☐
5. Was first treatment delivered within 31 days?			☐
Date of first treatment:	_ _ / _ _ / _ _	Date of surgery:	_ _ / _ _ / _ _
6. Did the child have a post-operative MRI within 72 hours of surgery?			☐
Date of scan:	_ _ / _ _ / _ _	Time of scan:	_ _ : _ _
7. If the child had a planned re-operation, was it performed within 30 days?			☐
Date of 2nd operation:	_ _ /_ _ /_ _		

7. Additional Information			
Consultant Name:			
7.1 Category of Surgery			
Surgical Procedure:		Category:	☐
7.2 Was there an unplanned return to theatre?			☐
7.3 Was there an unplanned re-admission to hospital within 30 days of discharge?			☐
Re-admission (date):	_ _ **/** _ _ **/** _ _		
7.4 Mortality: Outcome at 30 days			☐
7.5 Mortality: Outcome at 1 year			☐

Comments

Appendix 3

MSN Neurosurgery QPI: Traumatic Brain Injury

CHI:		**Proforma ID:**	☐☐☐☐ ☐☐☐☐	
Patient Name:				
Admission *date & time*:	__ / __ / __ __:__	**Admitted to:** ☐	**Source Hospital:** ☐☐☐☐	

1. Recording of GCS/PCS

Was the child's GCS/PCS recorded appropriately in the ED? ☐

2. Imaging

a) Did the child meet the criteria for **1 hour scanning**? ☐

Scan (*date & time*): __ / __ / __ __:__	Scanned within **1 hour**? ☐

b) Did the child meet the criteria for **8 hour scanning**? ☐

Scan (*date & time*): __ / __ / __ __:__	Scanned within **8 hours**? ☐

3. Transfers

If the child was transferred from another hospital, was the transfer team suitably trained? ☐

4. Child Protection

If the mechanism of their injury is either unknown or does not match the injuries sustained, was the child reviewed by a consultant paediatrician? ☐

5. Consultant Neurosurgeon Review

Ward Admission (*date & time*): __ / __ / __ __:__	Consultant Review (*date & time*): __ / __ / __ __:__	Reviewed within 24 hours? ☐

6. Time to Emergency Surgery

Decision to operate (*date & time*): __ / __ / __ __:__	Surgery (*date & time*): __ / __ / __ __:__	Surgery within 1 hour of decision? ☐

8. Additional Information			
Consultant Name:			
8.1 Category of Surgery			
Surgical Procedure:		Category:	☐
8.2 Was there an unplanned return to theatre?			☐
8.3 Was there an unplanned re-admission to hospital within 30 days of discharge?			☐
Re-admission (date):	_ _ / _ _ / _ _		
8.4 Mortality: Outcome at 30 days			☐
8.5 Mortality: Outcome at 1 year			☐

Comments