GAIN

GUIDELINES AND AUDIT
IMPLEMENTATION NETWORK

A RETROSPECTIVE REGIONAL AUDIT OF PAEDIATRIC ACQUIRED BRAIN INJURY 2003-2009

Dr Mark A. Linden
School of Nursing and Midwifery, Queen's University Belfast.

Dr Claire Lundy
Department of Paediatric Neurology, Guy's and
St Thomas' NHS Foundation Trust.

Dr Bob Taylor
Paediatric Intensive Care Unit,
The Royal Belfast Hospital for Sick Children.

JULY 2011

ACKNOWLEDGEMENTS

We would like to thank all those individuals who kindly contributed to this audit. Without the support of the clinical audit offices in the Belfast, Northern, Southern, South Eastern and Western trusts this project could never have been successful. We must also acknowledge the support of the guidelines and audit implementation network (GAIN) who funded this project. We hope that the information provided in this report will ultimately help improve the treatment and care of children with ABI and will highlight the extent of this condition in Northern Ireland.

CONTENTS

1.0 INTRODUCTION

Acquired brain injury (ABI) has been described as an umbrella term for a range of brain injuries which may have traumatic or disease related origins (Teasdale et al. 2007). These injuries must occur to a previously neurologically intact individual at some point following birth. Therefore, a child or young person could conceivably sustain an ABI by receiving a blow to the head or through contracting a viral or bacterial infection. It is important to realise that ABI is a lifelong condition which has far reaching individual, familial and social consequences.

There has been a lack of data in regard to the numbers of children with ABI largely due to the possible number of conditions ABI includes. Traumatic brain injury (TBI), a sub-component of ABI, has received more attention because it is a more easily defined condition. The prevalence of paediatric (0-14 years of age) TBI in the United Kingdom has been estimated at 5.6 per 100 000 population per year with a figure of 7.3 being suggested for Northern Ireland (NI) (Parslow et al. 2005). Whilst having reliable information on the numbers and causes of TBI is extremely important these figures clearly omit a group of children who acquired their brain injury as the result of illness. It is impossible to plan future services and estimate the demand for these without having accurate and reliable data on the population as a whole.

Guidelines on the standards of care for children with brain injury have been produced by the national institute for health and clinical excellence (NICE), the Department of Health's national service framework (NSF) and NHS Quality Improvement Scotland.

NICE guideline 56 for head injury covers the triage, assessment, investigation and early management of head injury in infants, children and adults and was published in 2007. Given the breadth of age included in this guideline we felt that it was not suitable for the current audit. Nor was the NHS Quality Improvement Scotland's draft clinical standards on Neurological Health Services published in November 2008 which were deemed as being non-specific to childhood ABI. The NSF guidelines were selected due to their focus on childhood brain injury.

The purpose of this audit is to provide accurate figures on the prevalence and characteristics of children with ABI across NI whilst also determining whether standards of care are met.

1.1 STANDARDS

Standards for this audit were based on the Department of Health's (2004) best practice guidelines titled "Acquired Brain Injury, National Service Framework for Children, Young People and Maternity Services" specifically the exemplar 'Jack's Journey'. Aspects of care beyond initial admission into hospital were not assessed. The application of these standards would either be met or not met.

1.2 CRITERIA

A number of criteria taken from the NSF exemplar 'Jack's Journey' were selected for audit. These included:

- Each patient and their family and / or carers should have access to a co-ordinated and holistic treatment plan.

- Treatment should be in a child-friendly environment.

- Each patient should have access to a multidisciplinary range of staff specifically trained for paediatric work.

- Specialist services should be available to all patients as necessary. In the event that this means that the patient needs to be transferred, this should be covered by the hospital.

2.0 METHOD

The audit project began in October 2008 with receipt of data commencing in April 2009 and ending in March 2010. Prior to the commencement of the audit, approval and funding were obtained from the Guidelines and Audit Implementation Network (GAIN). Additionally, approval from the Belfast Health and Social Care Trust audit office was granted. Permission to access case notes from other hospitals was approved by the audit departments of the Northern, Southern, South Eastern and Western Trusts. Principles of good practice, regarding patient confidentiality and data protection measures, were adhered to throughout. Data was anonymously coded and stored in password protected files, on password protected computers. Access to the data was permitted only to members of the team.

2.1 PHASE 1: EPIDEMIOLOGY OF PAEDIATRIC ABI.

Requests for reports on the numbers of children diagnosed with ABI were made to the clinical coding departments of each trust. Information was sought in relation to age, gender, postcode, mortality, diagnoses, procedures performed and length of stay for children attending hospital between 2003-2009. The categories of diagnosis included trauma (e.g. traumatic subdural haemorrhage, focal brain injury), bacterial infections (e.g. meningitis, intracranial and intraspinal abscess and granuloma), viral infections (e.g. Varicella encephalitis, Measles complicated by meningitis), Tumours (e.g. malignant neoplasm of meninges, benign neoplasm of brain and other parts of central nervous system), vascular conditions (e.g. cerebral infarction) and demyelination (e.g. diffuse sclerosis). For a complete list of the codes used see appendix 1.

2.2 PHASE 2: REVIEW OF CASENOTE DATA.

Audit departments in each trust area were contacted and asked to retrieve a random selection of casenotes selected by the authors. Fourteen sets of notes were requested from each site. Not all of these were available and so the casenote review consisted of ten from the Southern HSCT, twelve from the South Eastern HSCT, thirteen from the Northern HSCT and fourteen from the Western HSCT. Due to the Belfast HSCT

possessing the greatest number of cases it was decided to request thirty sets of notes, however only eighteen of these were available for review. This meant that sixty-seven casenotes were reviewed, representing 12% of the total population. An audit tool was created for the purposes of accurately recording, in a consistent manner, the information of interest (see Appendix 2 for audit tool). This tool was intended to record information such as gender, date of birth, admission ward, specialist services involved with care etc.

3.0 RESULTS

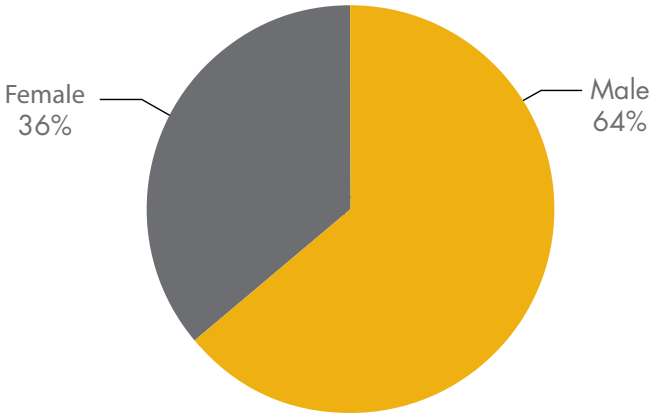
3.1 PHASE 1: FINDINGS FROM CLINICAL CODING DATA

Table 1: Causes of ABI by year for all trusts (excluding deaths).

	2003	2004	2005	2006	2007	2008	2009	Total
Traumatic injuries to head (S00-S09)	16	9	35	30	41	39	11	181
Inflammatory diseases of CNS (G00-G36)	21	24	31	41	27	41	12	197
Demyelination (G36-G37)	0	0	2	2	1	0	0	5
Neoplasms (C69-C80)	15	11	16	12	15	18	4	91
Vascular (G46-164)	1	5	10	5	8	7	1	37
Viral infections & diseases (B00-B26)	3	1	6	3	1	2	0	16
Asphyxiation (T71.X)	3	1	5	7	3	13	2	34
Total	59	51	105	100	96	120	30	561

Table 1 outlines the possible causes of ABI by year for the five Trusts in Northern Ireland. It shows that the most common cause of ABI is inflammatory diseases of the CNS (n = 197), which include meningitis and encephalitis. The second most frequent cause is traumatic injuries to the head (n = 181) with the third being neoplasms (n = 92) (brain tumours). Only the South Eastern and Belfast Trusts held clinical coding data for 2003 and 2004 which explains the reduction in numbers presented above. In addition, data collection commenced in mid 2009 meaning that complete data was not available for this year. Therefore, based on the data for 2005-2008, the average number of ABI's was 105.5 per year. Analysis on a trust by trust basis follows in Tables 3-7.

Figure 1: Pie chart showing the percentage of males and females with ABI



The clinical coding data revealed that 64% (n = 353) of children with possible ABI in NI were male with 36% (n = 199) being female. These figures are based on 552 children as information in relation to gender was not available for 9 children.

Table 2: Numbers of children aged 0-17 living in NI for the period 2005-2008 and numbers of children with ABI.

2005	2006	2007	2008	
434,780	432,014	431,867	432,604	*Total children
105	100	96	120	Total children with ABI

*Data published by the Northern Ireland Statistics and Research Agency.

It is important to determine the prevalence of suspected ABI in relation to the total population of children so we have an accurate picture of the extent of the condition. Taking the arithmetic mean for all children in NI for the four years as 428,316, and the mean for children with ABI as 105.5, the prevalence of ABI in the population is 24.63 per 100,000. If we examine the figures for TBI (Mean = 36.5) the prevalence rate is 8.52 per 100,000.

Table 3: Causes of ABI by year for the Belfast Health and Social Care Trust (BHSCT) (excluding deaths).

	2003	2004	2005	2006	2007	2008	2009	Total
Traumatic injuries to head (S00-S09)	16	9	24	22	28	27	3	129
Inflammatory diseases of CNS (G00-G36)	20	21	17	20	17	22	4	121
Neoplasms (C69-C80)	15	11	13	10	14	16	3	82
Vascular diseases (I60-163.9)	1	5	7	4	8	7	1	33
Viral infections & diseases (B00-B26)	0	1	3	0	0	0	0	4
Asphyxiation (T71.X)	3	1	2	2	0	7	1	16
Demyelination (G36-G37)	0	0	1	0	0	0	0	1
Total	55	48	67	58	67	79	12	386

Table 3 shows the possible causes of ABI between 2003 and 2009 in the BHSCT. The most frequent cause of ABI in this Trust was traumatic injuries to the head with 129 in this seven-year period. The second most common cause was attributable to inflammatory diseases of the CNS (e.g. meningitis and encephalitis). Neoplasms (brain tumours) also contributed significantly to the incidence of ABI (n = 82). This Trust accounts for 69% of the total incidence of ABI in these years. This is not surprising given the Royal Belfast Hospital for Sick Children's (RBHSC) status as a regional centre for referrals involving brain injury.

Data was available for 382 children in relation to home region. This indicated that 90 children lived within the bounds of the NHSCT, 109 came from the BHSCT, 66 from the SEHSCT, 71 from the SHSCT, and 45 from the WHSCT. No postcode data was available for 4 children and one child was resident outside of NI.

Table 4: Causes of ABI by year for the Northern Health and Social Care Trust

	2005	2006	2007	2008	2009	Total
Traumatic injuries to head (S00-S09)	3	2	6	5	3	19
Inflammatory diseases of CNS (G00-G07)	5	5	5	8	6	29
Neoplasms (C69-C80)	0	0	1	1	1	3
Viral infection (A85-B58.2+)	2	2	0	0	0	4
Vascular (G46-I64)	1	0	0	0	0	1
Asphyxiation (T71.X)	1	2	1	1	0	5
Total	12	11	13	15	10	61

Table 4 outlines the frequency of suspected ABI for the Northern HSCT by cause and year. Inflammatory diseases of the CNS were the most common cause of ABI within this Trust with 29 being reported between 2005 and 2009. The second most common cause of ABI in the Northern Trust was attributable to traumatic injuries to the head with 19 being reported in this five-year period. With 61 recorded acquired brain injuries, the Northern HSCT accounts for 11% of the overall incidence of ABI in Northern Ireland.

Table 5: Causes of ABI by year for the South Eastern Health and Social Care Trust (excluding deaths).

	2003	2004	2005	2006	2007	2008	2009	Total
Traumatic injuries to head (S00-S09)	0	0	4	2	4	1	1	12
Inflammatory diseases of CNS (G00-G07)	1	3	8	10	4	9	1	36
Neoplasms (C69-C80)	0	0	0	1	0	1	0	2
Viral infection (A85-B58.2+)	3	0	1	1	1	1	0	7
Vascular (G46-I64)	0	0	2	0	0	0	0	2
Asphyxiation (T71.X)	0	0	1	0	1	0	0	2
Demyelination (G36-G37)	0	0	1	0	0	0	0	1
Total	4	3	17	14	10	12	2	62

The possible causes of ABI in the South Eastern HSCT for the years 2003 to 2009 have been recorded in Table 5. The most common cause of ABI in this Trust is inflammatory diseases of the CNS with 36 recorded cases. The second most common cause was traumatic injuries to the head (n = 12). The South Eastern HSCT contributed to 11% of the total incidence of ABI during this period.

Table 6: Causes of ABI by year for the Southern Health and Social Care Trust (excluding deaths).

	2005	2006	2007	2008	2009	Total
Traumatic injuries to head (S00-S09)	1	3	2	3	3	12
Asphyxiation (T71.X)	1	3	1	3	1	9
Total	2	6	3	6	4	21

Table 6 outlines the possible causes of ABI by year for the Southern HSCT. Only two causes of ABI were identified: traumatic injuries to the head and asphyxiation, the

former being more frequently observed (n = 12). The Southern HSCT accounts for 4% of the overall incidence of ABI in NI.

Table 7: Causes of ABI by year for the Western Health and Social Care Trust (excluding deaths).

	2005	2006	2007	2008	2009	Total
Traumatic injuries to head (S00-S09)	3	1	1	3	1	9
Inflammatory diseases of CNS (G00-G07)	1	6	1	2	1	11
Neoplasms (C69-C80)	3	1	0	0	0	4
Viral infection (A85-B58.2+)	0	0	0	1	0	1
Vascular (G46-I64)	0	1	0	0	0	1
Demyelination (G36-G37)	0	2	1	0	0	3
Asphyxiation (T71.X)	0	0	0	2	0	2
Total	7	11	3	8	2	31

Table 7 shows the frequency of suspected ABI within the Western HSCT by cause for the years 2005 to 2009. Again, inflammatory diseases of the CNS (n = 10) and traumatic injuries to the head (n = 9) were the most common causes of ABI. The Western Trust accounts for 5% of the total incidence of ABI in Northern Ireland. The small numbers recorded for this Trust are probably explained by the fact that most children with ABI in Northern Ireland are treated at the RBHSC within the BHSCT.

Table 8: Age and injury type for all HSCTs

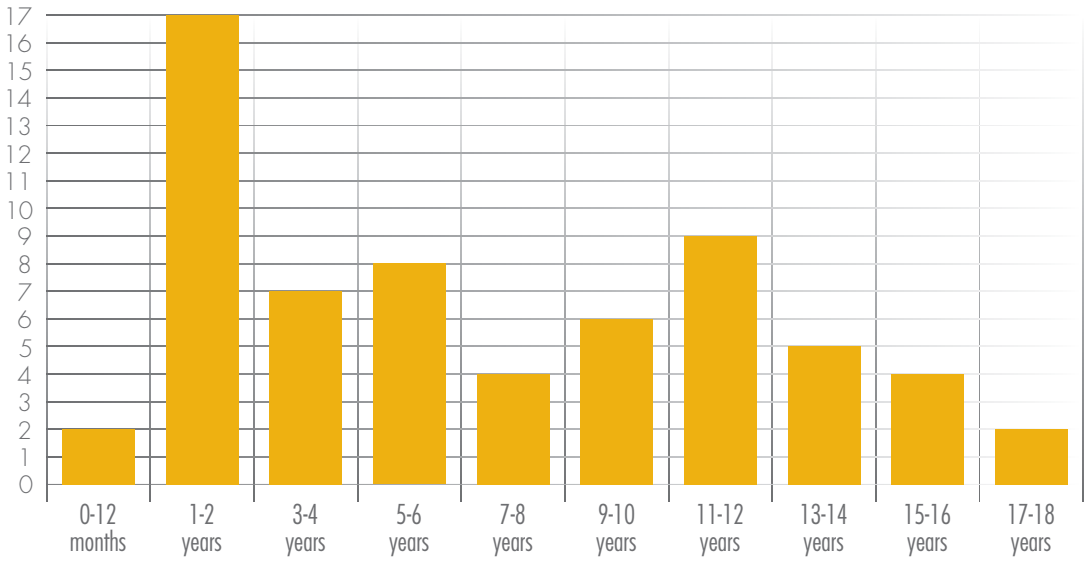
Age	Traumatic injuries to head (S00-S09)	Inflammatory diseases of CNS (G00-G07)	Neoplasms (C69-C80)	Cerebrovascular diseases (G46-164)	Viral infections and diseases (B00-B26)	Asphyxiation (T71.X)	Demyelination (G36-G37)	Total
0	13	101	4	12	1	3	0	134
1	9	12	3	3	2	0	0	29
2	6	5	8	0	1	0	0	20
3	9	16	7	3	0	1	0	36
4	7	5	8	3	0	0	0	23
5	8	4	8	1	1	0	0	22
6	10	4	9	0	3	1	0	27
7	11	4	2	2	2	0	0	21
8	6	0	6	2	0	1	1	16
9	11	2	5	1	0	2	1	22
10	12	5	0	0	0	2	0	19
11	9	3	4	1	1	1	0	19
12	9	7	6	0	0	3	0	25
13	12	5	5	2	0	5	0	29
14	10	6	4	1	0	4	1	26
15	17	9	5	3	0	2	2	38
16	18	9	7	3	5	8	0	50
17	4	0	0	0	0	1	0	5
Total	181	197	91	37	16	34	5	561

The majority of suspected brain injuries occurred in children below the age of one and were largely inflammatory diseases of CNS. This category was also shown to cause of the majority of injuries across all age ranges. The second greatest cause of injuries overall were of a traumatic nature followed by neoplasms.

3.2 PHASE 2: FINDINGS FROM CASENOTE REVIEW

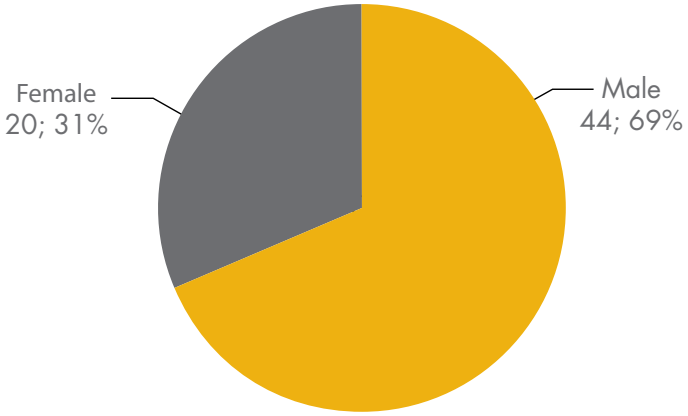
A cross section of casenotes (n = 64) were selected from all trust areas for in-depth review. Data will first be presented on a regional basis followed by individual trust areas.

Figure 2: Age range of children at time of injury for all trusts



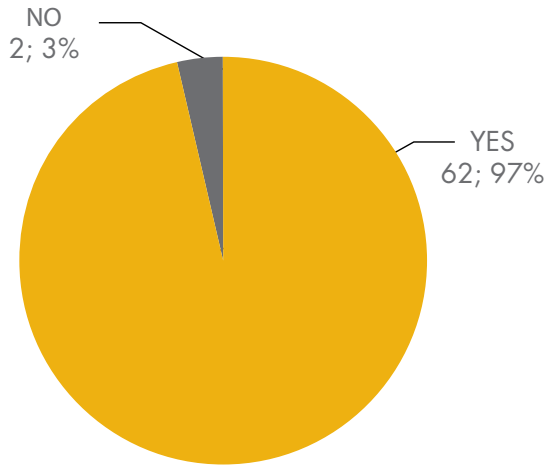
The casenotes of sixty-four children across NI were reviewed to gain a more detailed picture of their care. Figure two shows that the majority of brain injuries occurred in the 1-2 years age range (n = 17; 27%), followed by 9 (14%) children acquiring their brain injury between the ages of 11 and 12. Approximately half of the population (n = 34; 53%) acquired their brain injury when they were age 6 or younger.

Figure 3: Gender of children in casenote review with ABI for all trusts



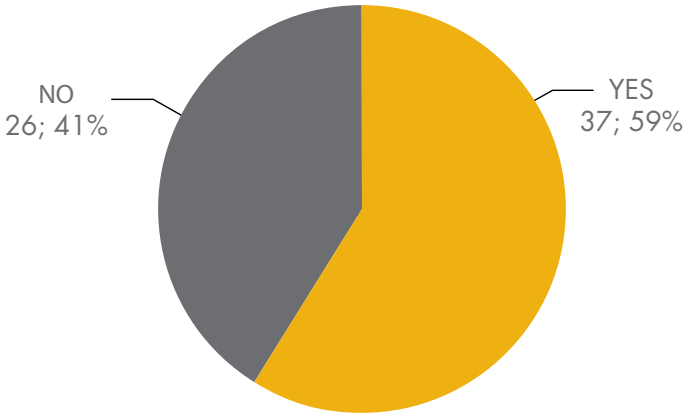
The gender of children selected for the casenote review is shown in figure 3. Similar to the information presented in figure 1 for the clinical coding data it demonstrates that ABI is around twice as common in males than females.

Figure 4: Number of children who received care in a child friendly environment across all trusts



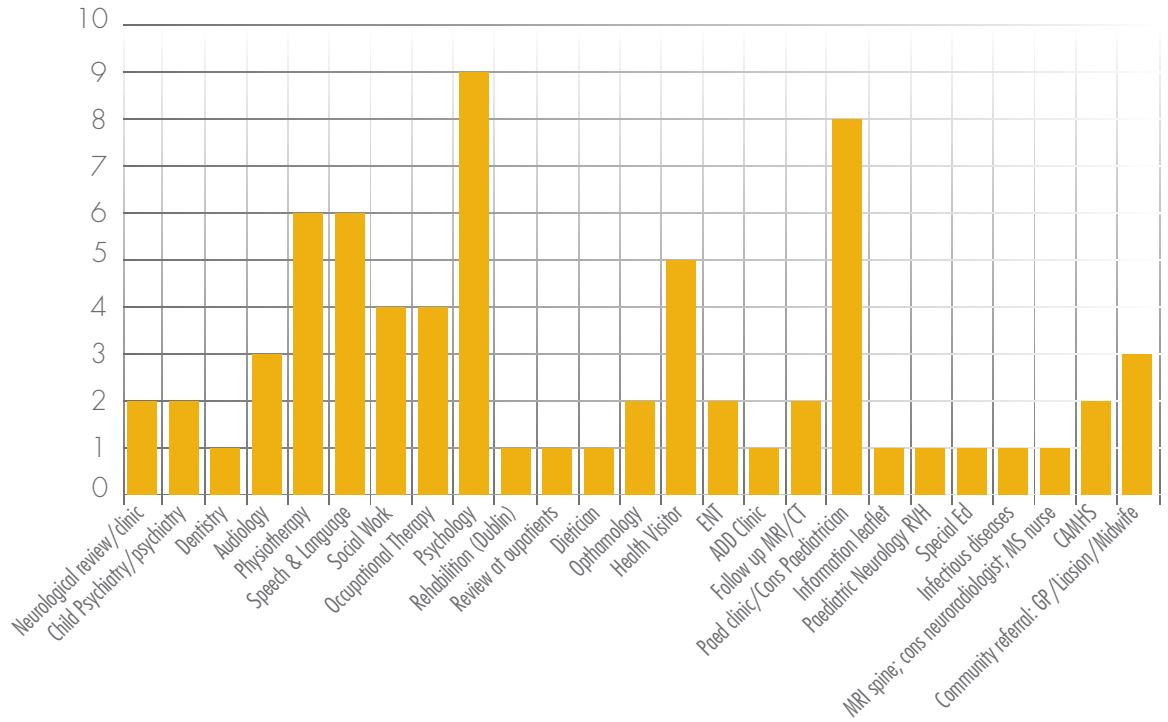
One of the criteria to be met by this audit stated that 'Treatment should be in a child-friendly environment'. Any child or young person who had been treated on a dedicated children's ward were said to have experienced a child-friendly environment. The casenote review showed that the majority of children (n = 62; 97%) did receive care in a child-friendly environment.

Figure 5: Percentage of casenotes to record presence of a discharge plan across all trusts



A second criteria for the audit stated 'Each patient and their family and / or carers should have access to a co-ordinated and holistic treatment plan'. As no single factor would allow a judgement to be made on this criteria two pieces of information were collected which are suggestive of efforts to address this. The first of these was whether a single individual had been identified who was responsible for care of the child or young person. In all of the casenotes reviewed a named lead had been identified to co-ordinate care. The second piece of information looked for reference to the presence of the planning of care beyond the acute phase. The casenotes of 37 (59%) children recorded information referring to a discharge plan compared to 26 (41%) who did not. It must be noted that the above criteria is somewhat broad in its approach to care and is difficult to assess from the available medical data. For example, no record is kept within the children's casenotes of efforts to meet any of the needs of the family and or carers.

Figure 6: Discharge to community services across all trusts



Additional information was collected in relation to the services children with brain injuries were referred to on discharge. Figure 6 shows that nine children were referred to psychology services on discharge and 8 were referred to either a consultant paediatrician or a paediatric clinic. Six children were referred to physiotherapy and another 6 were referred to speech and language therapists. Four children were referred to social work, 4 were referred to occupational therapy, and 5 were referred to a health visitor. Referrals to services such as special education, dentistry and the dietician were generally low in the casenote sample reviewed. Out of 64 casenotes only one made mention of the provision of an information leaflet on brain injury.

Table 9: Occurrence of brain injury for casenotes reviewed across all trust areas.

ABI	N	TBI	N
Query Encephalitis/meningitis	1	Injured while playing sport	3
Sub-acute chronic subdural haemorrhage	1	Asphyxiation	2
Acute disseminated encephalomyelitis	1	Road Traffic Accidents (RTA)	7
Stroke	2	Sustained occipital injury	2
Extra dural haematoma	1	Head injury NOS	1
Meningitis	16	Fall	11
Hypothalamic astrocytoma	1	Depressive of left parietal lobe	1
Acute disseminated encephalomyelites	1	TBI intracranial injury NOS	1
Demyelination	1	Accidental airway obstruction	1
Post chicken pox cerebralitis	1	Overdose	1
Focal demyelination	1		
Viral infection NOS encephalitis	1		
Non-orthropod-borne viral disease of CNS NOS	1		
ABI NOS	1		

Table nine details the manner through which the children acquired their injuries. These have been broadly classified according to acquired and traumatic means and show equal numbers in each category i.e. 30 ABI and 30 TBI. It was not possible to determine the cause of injury for four of the casenotes reviewed. Table nine shows that the greatest cause of ABI is meningitis whilst the most frequent case of TBIs are falls followed by RTAs.

Casenote review in the Belfast HSCT (n = 17 children)

Figure 7: Age range of children at time of brain injury in the BHSCT

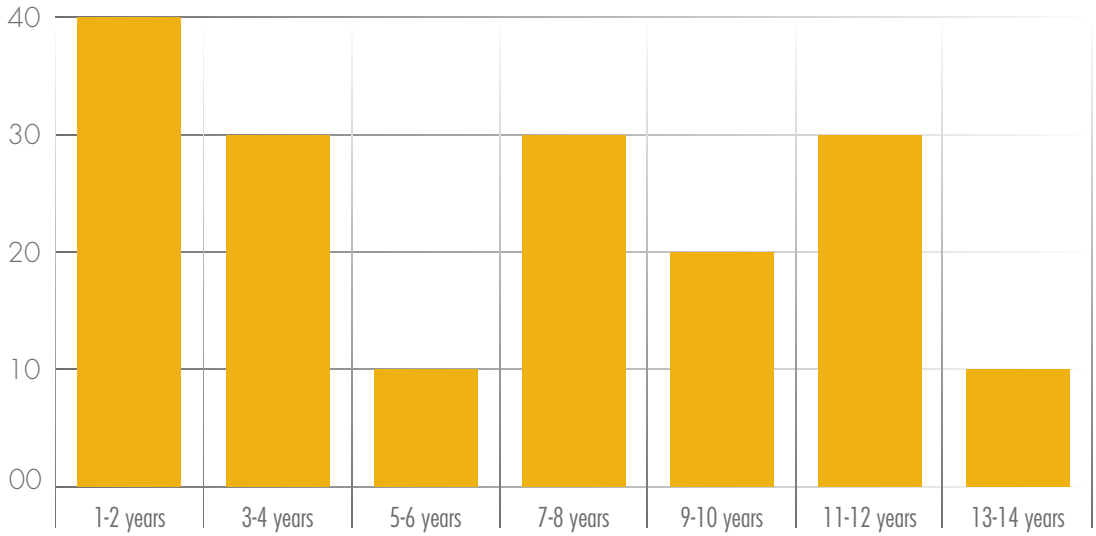
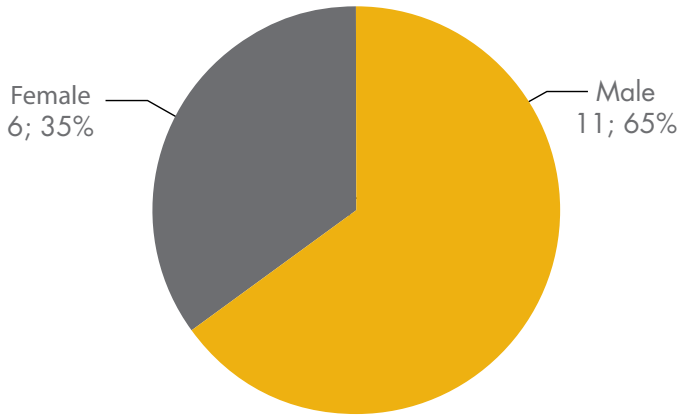


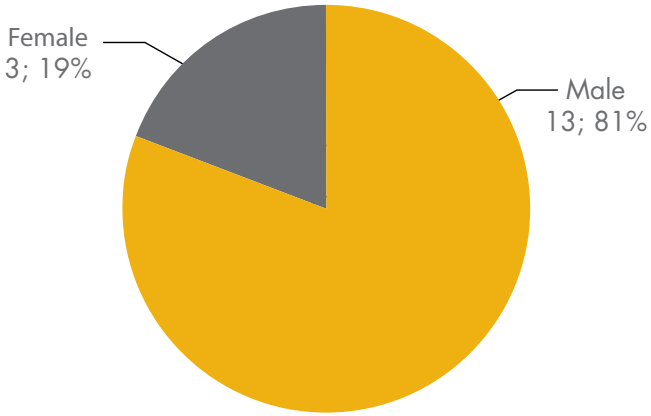
Figure 7 shows that the majority of suspected acquired brain injuries occurred in the youngest age group (n = 4; 23.5%: 1-2 years). 3 (17%) children acquired their brain injury at age 3-4 years, another 3 (17%) acquired their brain injury at age 7-8 years and a further 3 (17%) acquired their brain injury at age 11-12 years.

Figure 8: Gender of children with acquired a brain injury



The majority of children who acquired a brain injury within the Belfast trust were male (n = 11: 65%), with a smaller number of females (n = 6: 35%) acquiring a brain injury in the time frame audited. All children were shown to receive their treatment in a child friendly environment.

Figure 9: Presence or absence of a discharge plan in the BHSCT



* Please note that 1 child has been excluded from this calculation as a discharge plan was not applicable due to death.

The greater majority of children from the BHSCT (n = 13: 81%) received a discharge plan with a relatively small proportion of the casenotes showing no evidence of such as plan (n = 3: 19%).

Figure 10: Community services that children were referred to on discharge in the BHSCT

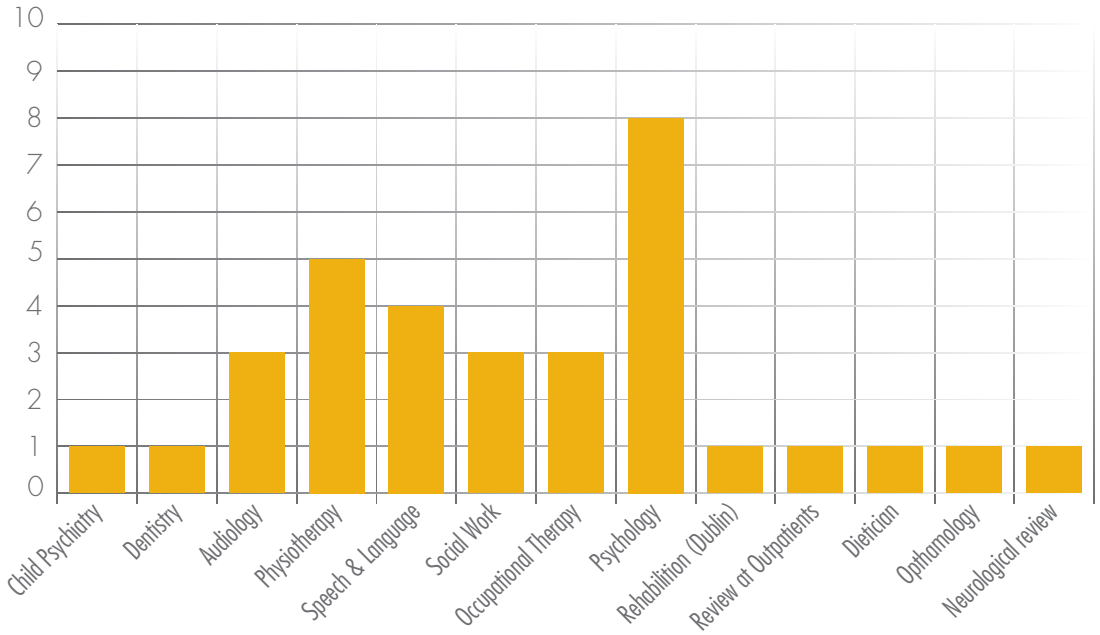


Figure 10 shows that eight (50%) of the children from the BHSCT had a referral to psychology (i.e., clinical and/or educational) upon discharge. Five (31%) had

a referral to physiotherapy and 4 (25%) had a referral to speech and language therapy.

Table 10: Occurrence of brain injury in the BHSCT

ABI	N	TBI	N
Query Encephalitis/meningitis	1	Injured while playing sport	1
Sub-acute chronic subdural haemorrhage	1	Asphyxiation	1
Acute disseminated encephalomyelitis	1	Road Traffic Accidents (RTA)	3
Stroke	2	Sustained occipital injury	1
Meningitis/viral meningitis	2	Head injury NOS	1
Extra dural haematoma	1		
Hypothalamic astrocytoma	1		

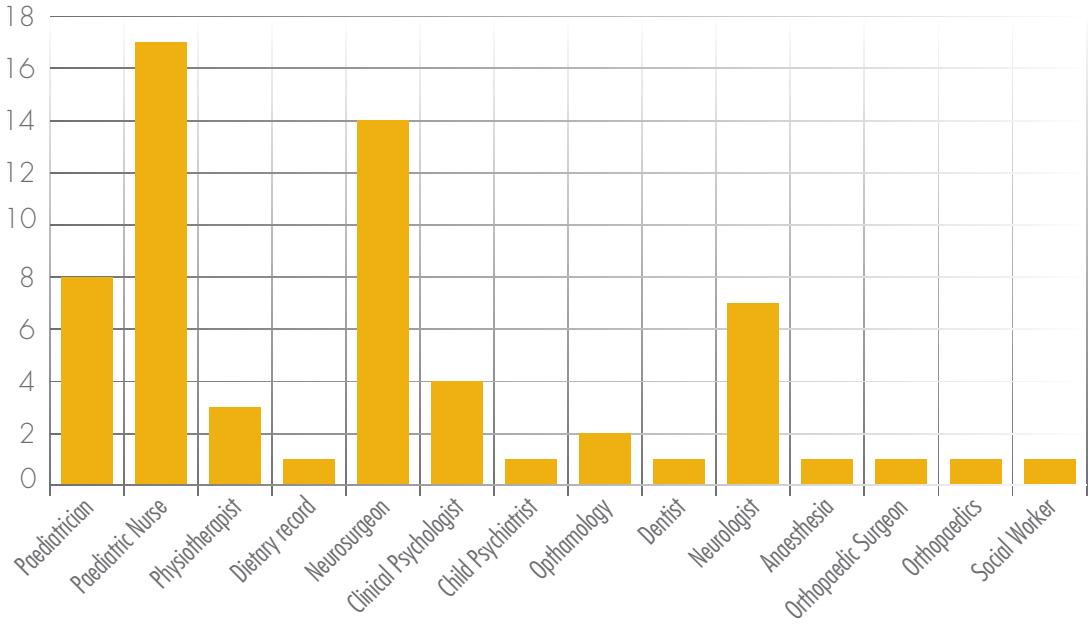
Of the 17 casenotes reviewed in the BHSCT nine children were shown to obtain their injury through organic means with a further seven injuries caused by trauma. One case was excluded from table 10 due to death following meningitis.

Table 11: Glasgow coma scale scores for children in the BHSCT

GCS Score	Number of Children
15	6
14	3
13	1
6	1
3	4
2	1
None stated	1

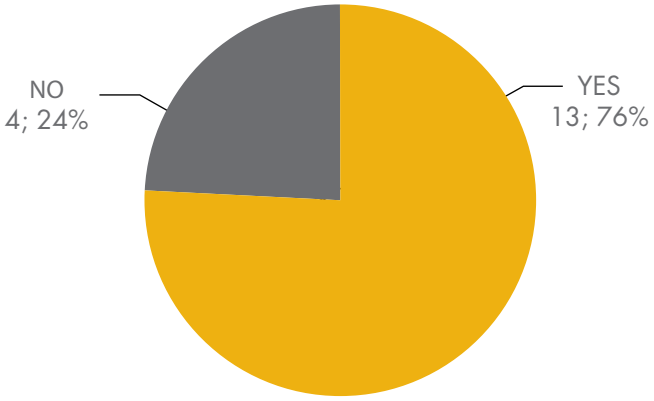
Review of the casenotes showed that the majority of children (n=10) had injuries which fell within the mild GCS classification ($\geq$ 13). The rest of the children fell within the severe ($\leq$ 8) category of the scale. GCS score was unavailable for one child.

Figure 11: Graph showing members of staff involved in the patients care in the BHSCT



The majority of staff involved in the child's care were paediatric nurses (n=17), neurosurgeons (n=14), paediatricians (n=8) and neurologists (n=7).

Figure 12: Children who experienced a transfer while attending the BHSCT



Of the seventeen casenotes reviewed 13 children were transferred to Belfast from other hospitals. 3 from the Ulster; 1 from Erne; 1 from Antrim; 1 from Altnagelvin; 1 from Causeway; 2 from Daisy Hill; 2 from Craigavon and 2 from Mid Ulster.

Casenote review in the Northern HSCT (n = 13 children)

Figure 13: Age range of children at time of brain injury in the NHSCT

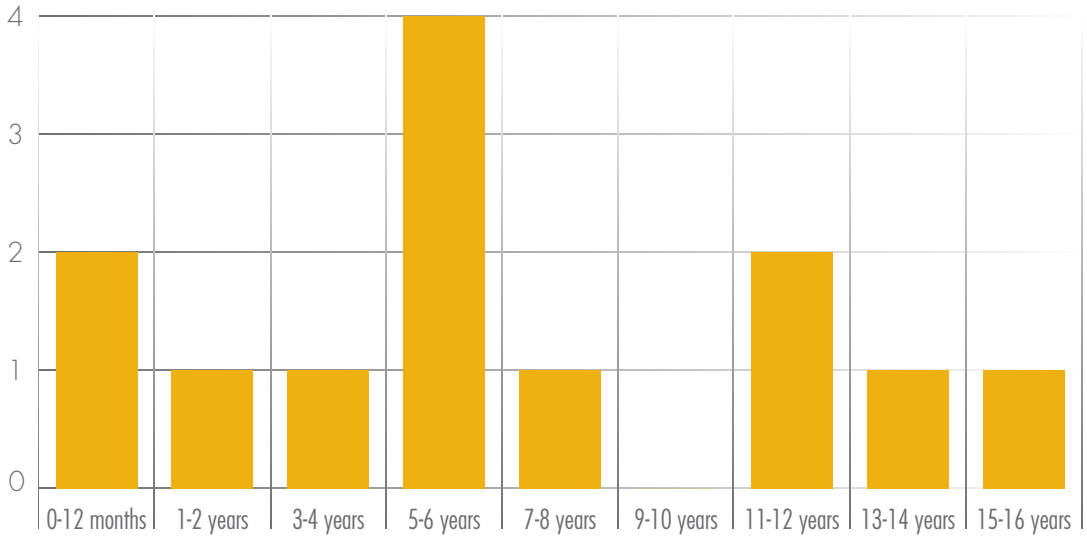


Figure 13 shows that the majority of brain injuries occurred in the 5-6 years of age group (n = 4; 31%). Two (15%) children acquired their brain injury between the ages of 1-2 years, and a further 2 (15%) children acquired their brain injury at age 11-12 years.

Figure 14: Pie chart showing gender of children who acquired a brain injury

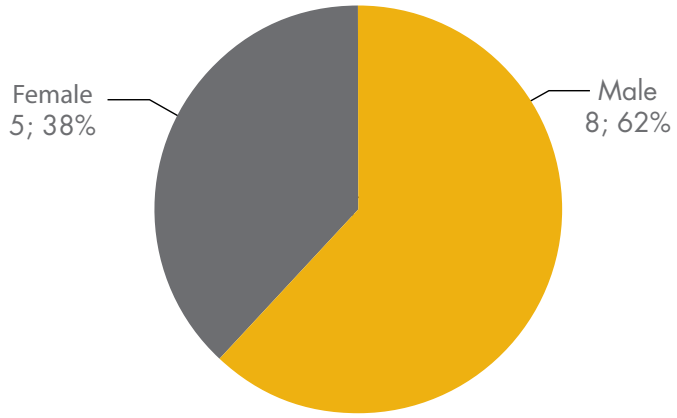
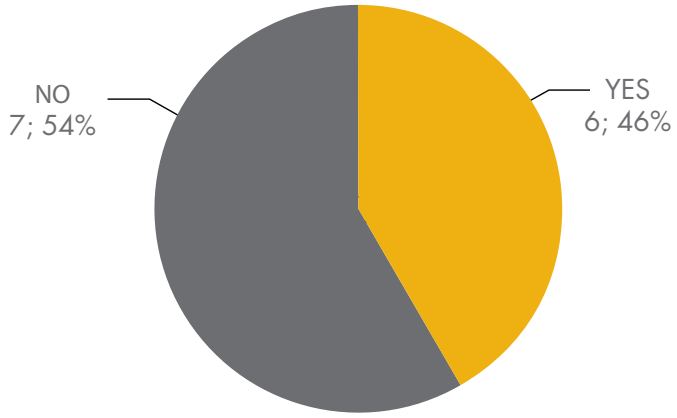


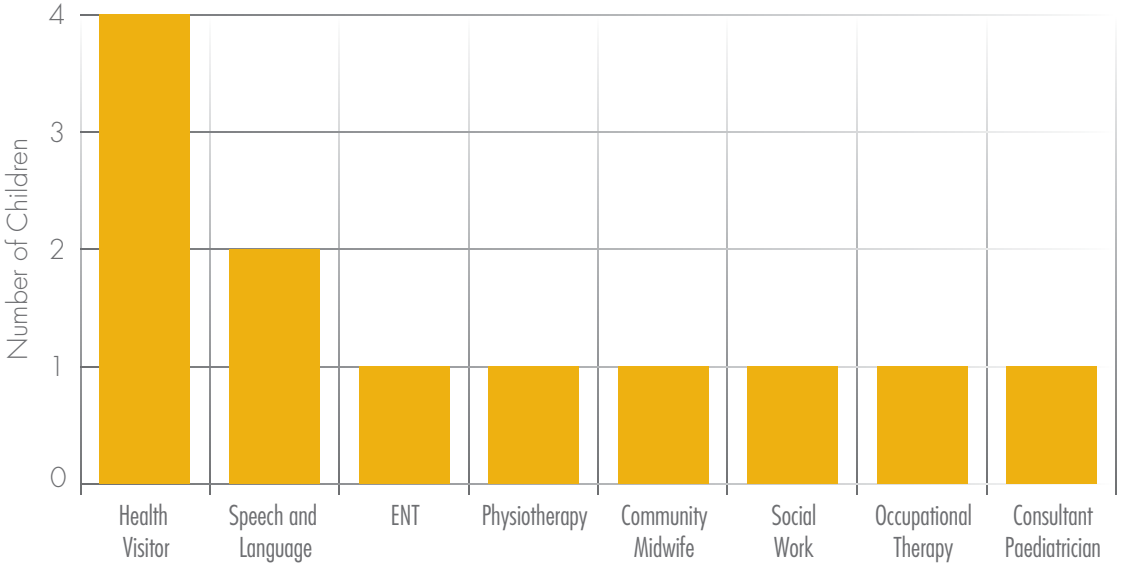
Figure 14 shows that 62% of children who acquired their brain injury in the time period audited were males (n = 8), with the remaining 38% being female (n = 5). The majority of these children received treatment in a child friendly environment (n = 12). One child received their treatment on an adult ward.

Figure 15: Notation of discharge planning in the NHSCT



In the Northern HSCT there was evidence that six (46%) children had received some form of discharge plan, whilst seven did not have clear evidence in the casenotes (54%).

Figure 16: Community services that children were referred to on discharge in the NHSCT



As shown in figure 14, four (31%) children were referred to the health visitor on discharge, and 2 (15%) were referred to a speech and language therapist. There were no recorded instances of clients receiving information about brain injury among the 13 casenotes in the NHSCT.

Table 12: Table showing how brain injury was acquired

ABI	N	TBI	N
Meningitis	6	Intracranial injury NOS	1
Viral infection NOS	1	Fall	2
Non-orthropod-borne viral disease of CNS NOS	1		

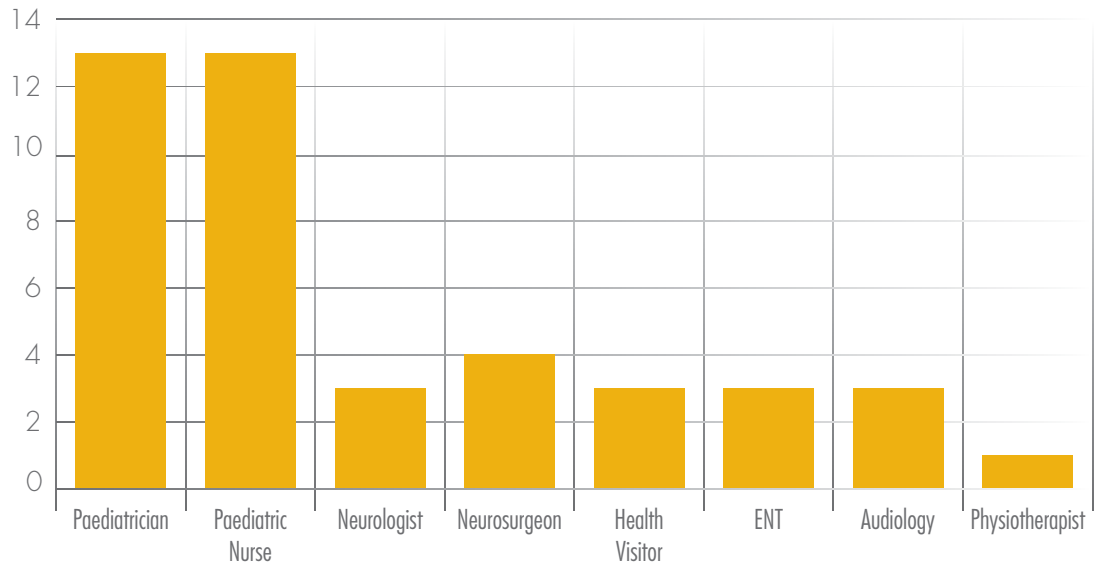
Table 12 shows that eight children in the NHSCT received their injury through organic means whilst 3 were the result of a traumatic event. The cause of injury for two of the casenotes reviewed was not recorded.

Table 13: Glasgow coma scale scores for children in the NHSCT

GCS Score	Number of Children
15	8
14	2
11	1
N/A	2

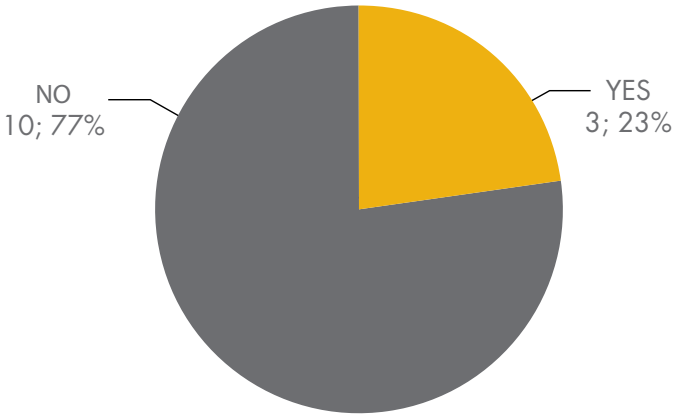
The available data shown in table 13 illustrates that 10 children had sustained a mild injury (≥13) with a further 1 falling into the moderate (9-12) category.

Figure 17: Graph showing members of staff involved in the patients care



The majority of staff involved in the child's care were paediatricians (n=13) and paediatric nurses (n=13).

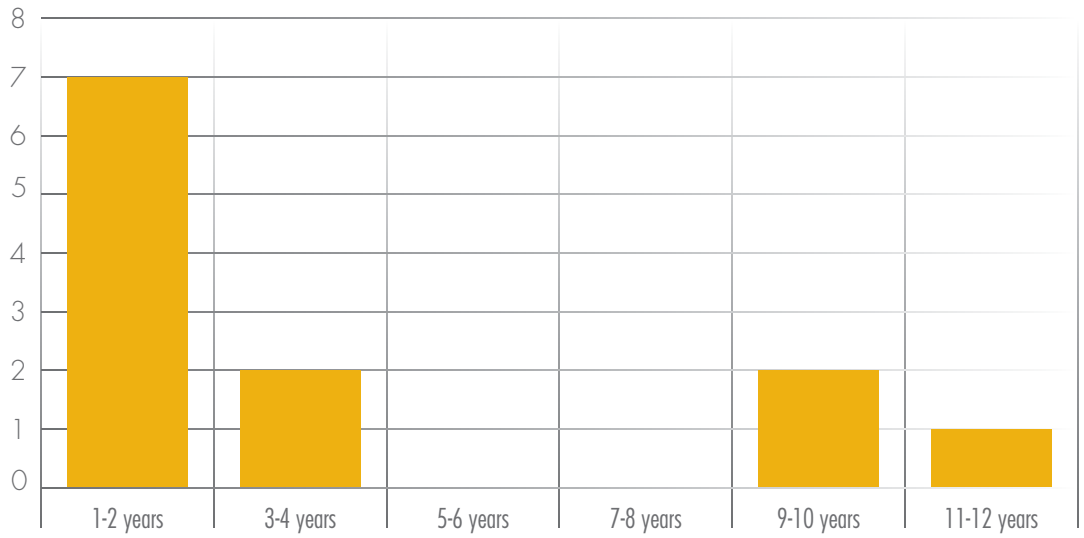
Figure 18: Children who experienced a transfer while attending the NHSCT



One child was transferred from the NHSCT to the RBHSC. Two further children were transferred to the NHSCT from another hospital.

Casenote review in the South Eastern HSCT (n = 12 children)

Figure 19: Age range of children at time of brain injury in the SEHSCT



The majority of brain injuries in the SEHSCT occurred in the youngest age group (n = 7; 58%; ages 1-2 years). Two (17%) children received their brain injury between

3-4 years, another 2 (17%) acquired their brain injury at age 9-10 years and one received their brain injury between the ages of 11-12 years (8%).

Figure 20: Pie chart showing gender of children who acquired a brain injury

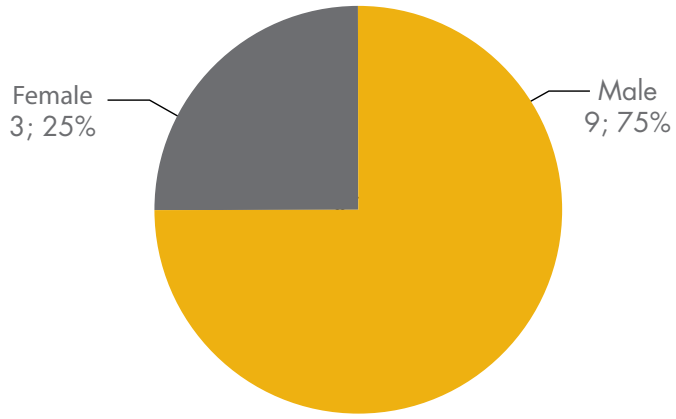
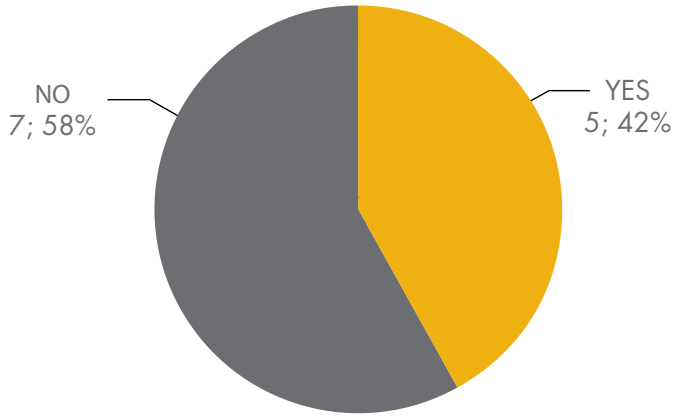


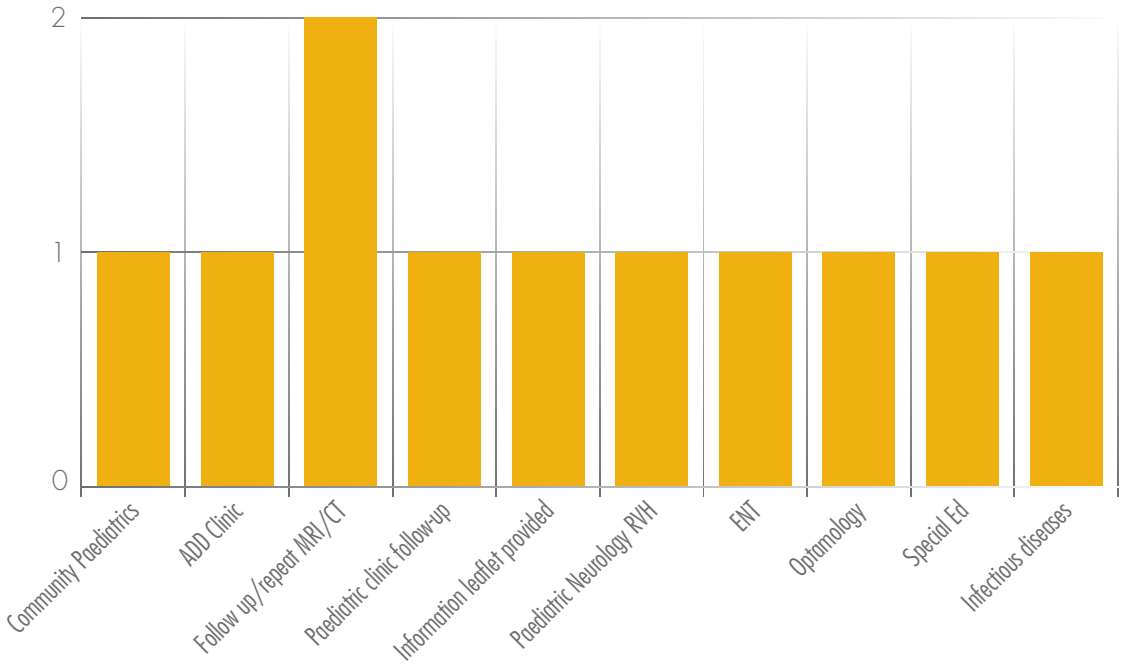
Figure 16 shows that nine (75%) males and 3 (25%) females acquired a brain injury in the SEHSCT during the time period audited. The casenotes reviewed also showed that the majority of the children received their treatment in a child friendly environment (n = 11).

Figure 21: Notation of discharge planning in the SEHSCT



The casenotes showed evidence that five (42%) of the children who acquired their brain injury in the SEHSCT received some form of discharge plan, whilst seven did not (58%).

Figure 22: Community services that children were referred to on discharge in the SEHSCT



The casenotes data in regard to referrals in following discharge in the SEHSCT showed that two (17%) children had been referred for follow-up MRI examination. Only one instance was recorded in the casenotes of information given on discharge.

Table 14: Acquisition of brain injury in the SEHSCT

ABI	N	TBI	N
Meningitis	7	Fall	3
Acute disseminated encephalomyelites	1	Injury through sport	1

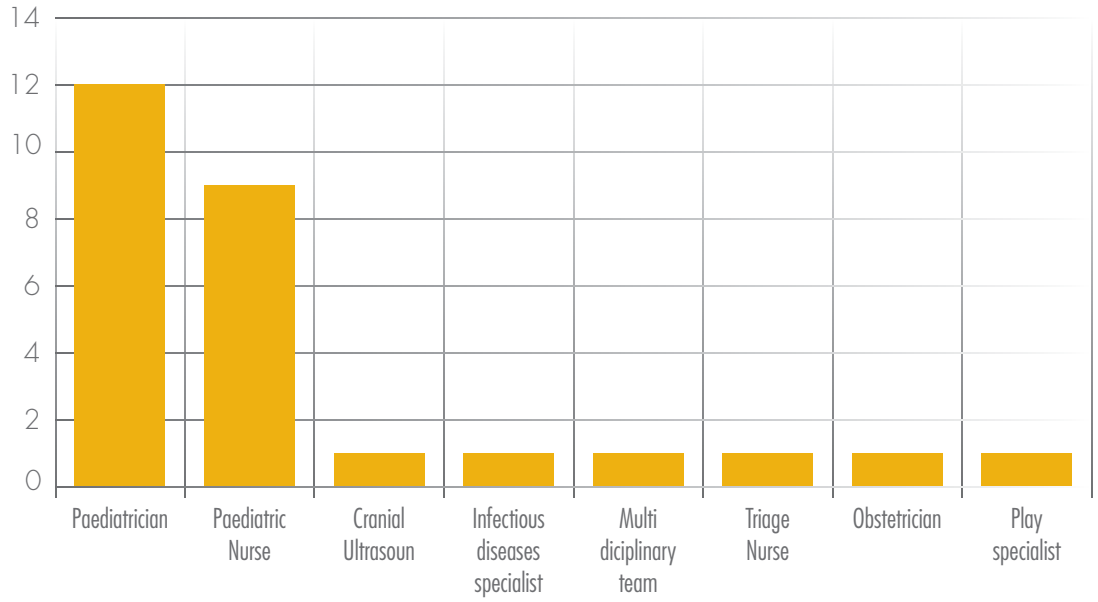
The majority of brain injuries in the SEHSCT were acquired through organic means.

Table 15: Glasgow coma scale scores for children in the SEHSCT

GCS Score	Number of Children
15	6
14	1
N/A	5

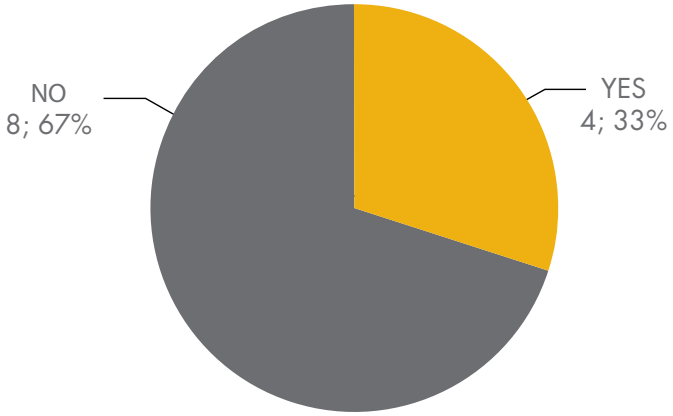
The available data displayed in table 15 shows that seven children had sustained a mild (≤ 13) brain injury in the SEHSCT.

Figure 23: Members of staff involved in the patients care in the SEHSCT



The majority of staff involved in the child's care were paediatricians (n=12), followed by paediatric nurses (n=9).

Figure 24: Children who experienced a transfer while attending the SEHSCT



Three of the four children who experienced a transfer whilst in the SEHSCT went to the BHSCT with a further one transferred from within the SEHSCT.

Casenote review in the Southern HSCT (n = 9 children)

Figure 25: Age range of children at time of brain injury in the SHSCT

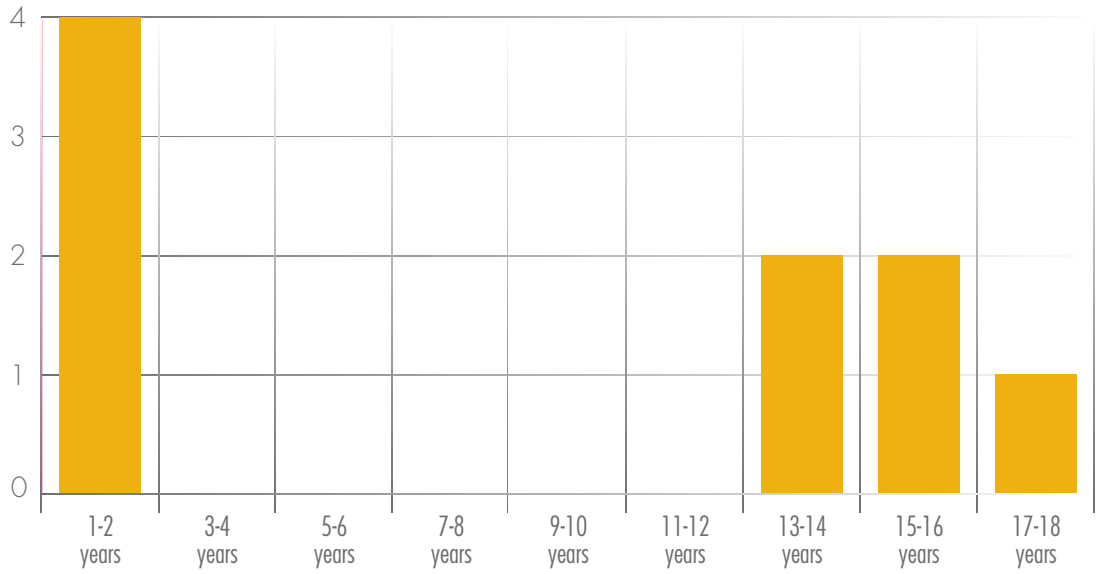


Figure 25 shows that the majority of brain injuries occurred between the ages of 1-2 years (n = 4; 45%). Two (22%) children acquired their brain injury between the ages of 13-14 years and a further 2 (22%) between the ages of 15-16 years.

Figure 26: Pie chart showing gender of children who acquired a brain injury

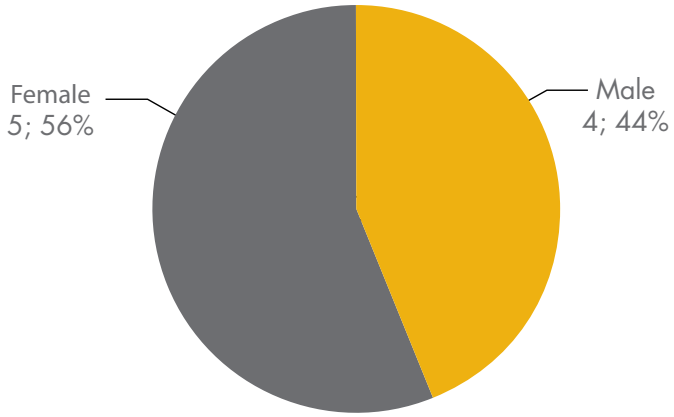
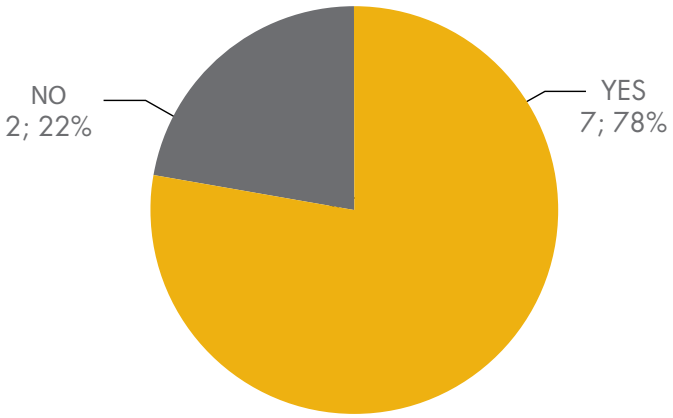


Figure 26 shows that 44% of children who acquired their brain injury in the time period audited were males (n = 4), with the remaining 56% being female (n = 5). All children in the SHSCT received their care in a child friendly environment.

Figure 27: Notation of a discharge plan in the SHSCT



Review of the casenotes revealed that seven (78%) of the children had some form of discharge plan, whilst 2 (22%) did not.

Figure 28: Community services that children were referred to on discharge in the SHSCT.

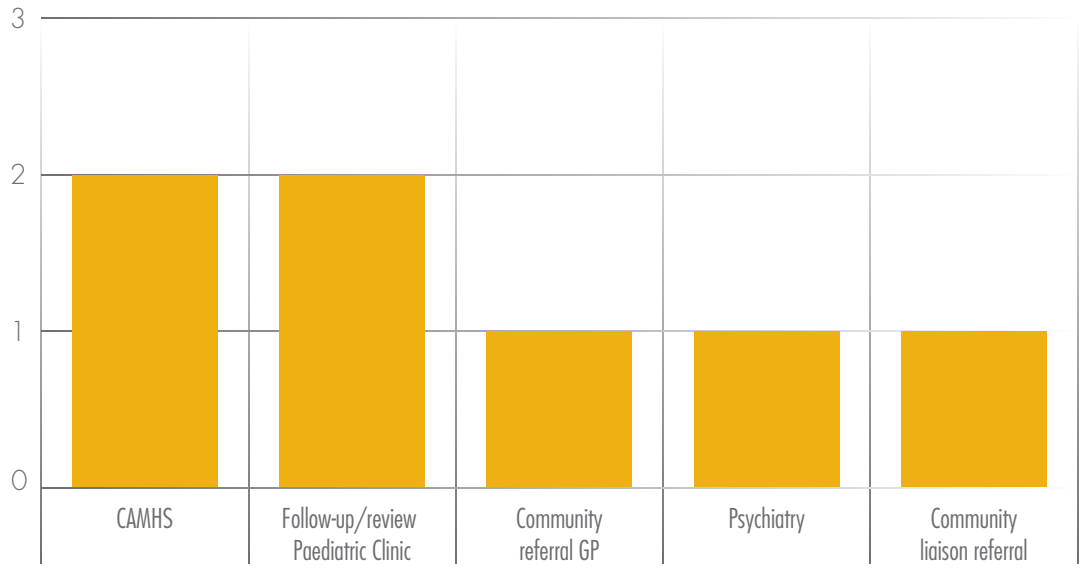


Figure 24 shows that two (22%) children were referred to Child and Adolescent Mental Health Services (CAMHS), with a further 2 (22%) being referred to the paediatric clinic on discharge. There was no evidence that any information on brain injury had been given to the families at this point.

Table 16: Acquisition of brain injury in the SHSCT

ABI	N	TBI	N
ABI NOS	1	Fall	3
		Accidental airway obstruction	1
		RTA	2
		Overdose	1
		Asphyxiation	1

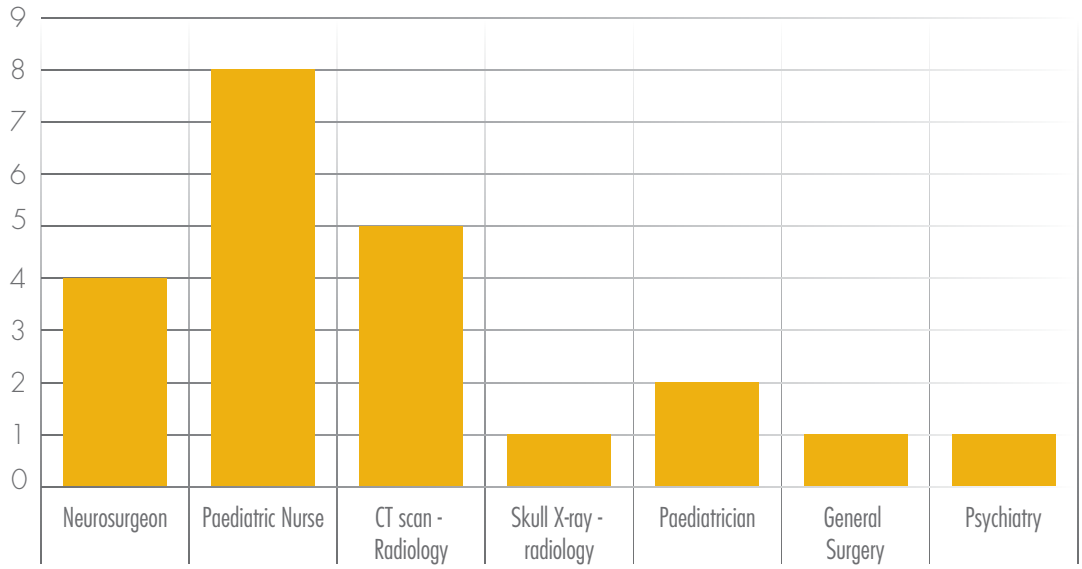
The majority (n = 8) of children whose casenotes were reviewed in the SHSCT received their injury as the result of a traumatic event.

Table 17: Glasgow coma scale scores for children in the SHSCT

GCS Score	Number of Children
15	3
14	3
12	1
9	1
High but no final figure found	1

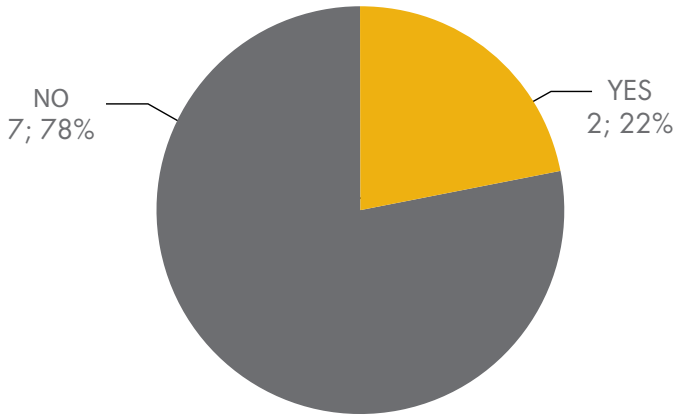
The casenotes of six children in the SHSCT revealed that they had sustained a mild (≥ 13) brain injury with a further two falling within the moderate (9-12) category. GCS data on one child was not available.

Figure 29: Members of staff involved in the patients care



The majority of staff involved in the child's care were paediatric nurses (n=8), followed by radiology (n=6).

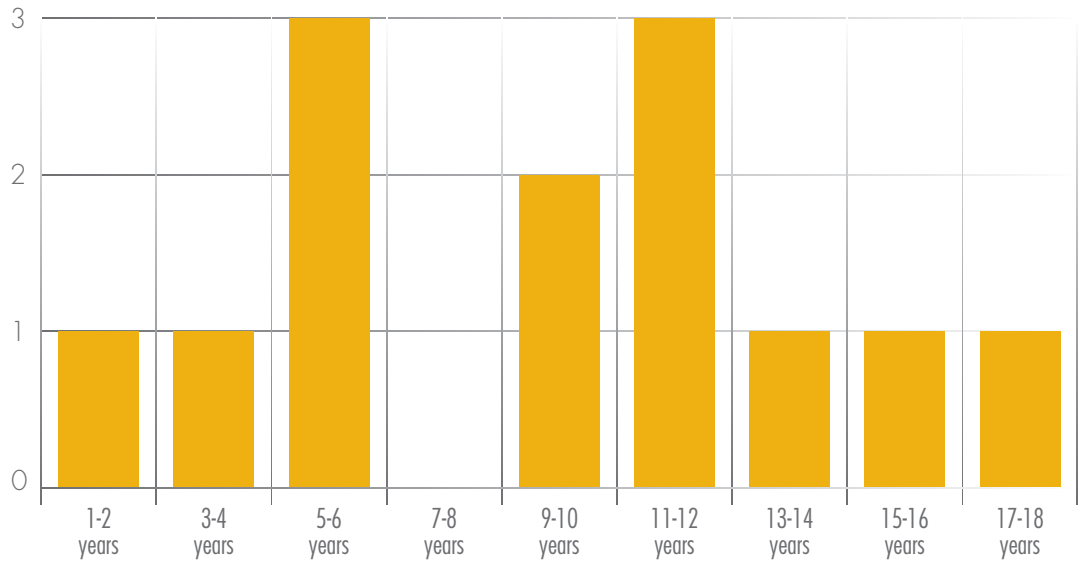
Figure 30: Children who experienced a transfer while attending the SHSCT



Two of the nine children attending the SHSCT required transfer to the BHSCT.

Casenote review in the Western HSCT (n = 13 children)

Figure 31: Age range of children at time of brain injury in the WHSCT



The majority of acquired brain injuries occurred in the 5-6 years of age group (n = 3; 23%) and the 11-12 years of age group (n=3; 23%). Two (15%) children acquired their brain injury at ages 9-10 years.

Figure 32: Gender distribution of children with brain injury in the WHSCT

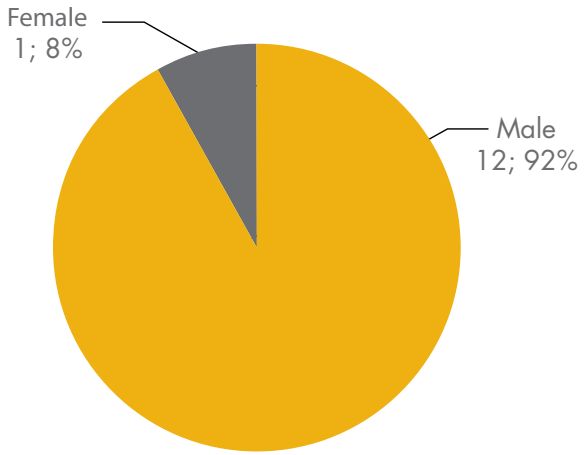


Figure 32 shows that 92% of children who acquired their brain injury in the time period audited were males (n=12), with the remaining 8% being female (n=1). All

of these children were shown to have received their treatment in a child friendly environment.

Figure 33: Pie chart showing notation of discharge planning

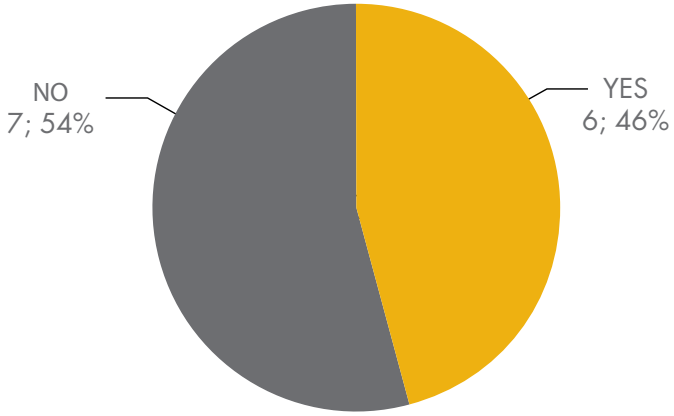
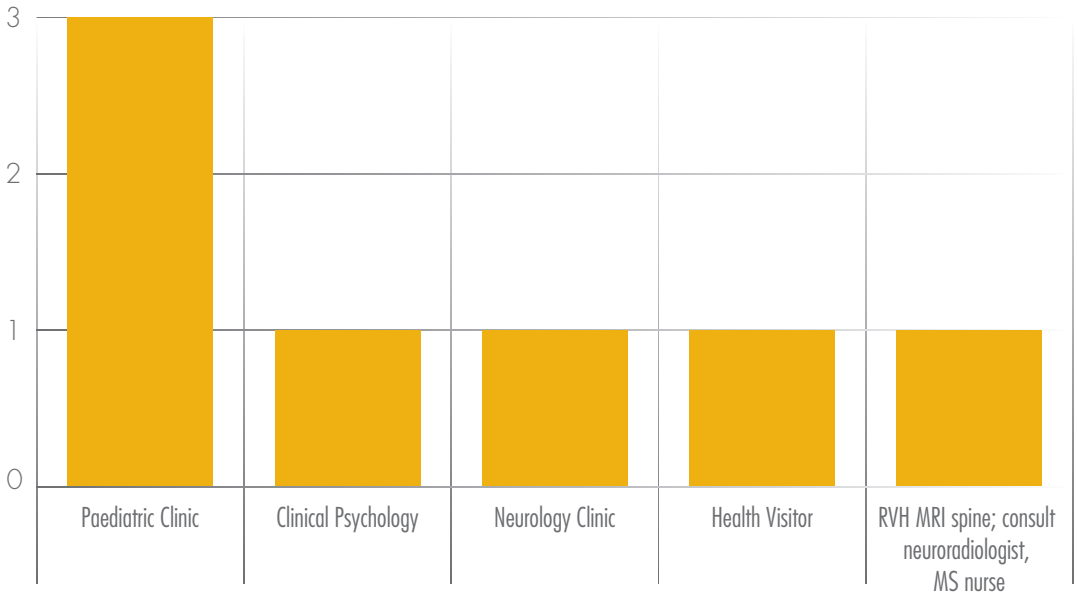


Figure 33 shows that six (46%) casenotes included evidence of the presence of a discharge plan in the WHSCT, whilst seven showed no such evidence (54%).

Figure 34: Community services that children were referred to on discharge in the WHSCT.



Out of thirteen casenotes reviewed information on discharge was available for referral to seven services. Three (23%) of these made reference to the paediatric clinic. No mention was made to the provision of information on brain injury on discharge in the WHSCT.

Table 18: Table showing how brain injury was acquired

ABI	N	TBI	N
Meningitis	1	Fall	3
Demyelination	1	Depressive of left parietal lobe	1
Post chicken pox cerebralitis	1	Road Traffic Accident (RTA)	2
Focal demyelination	1	Injury through sport	1
		Sustained occipital injury	1

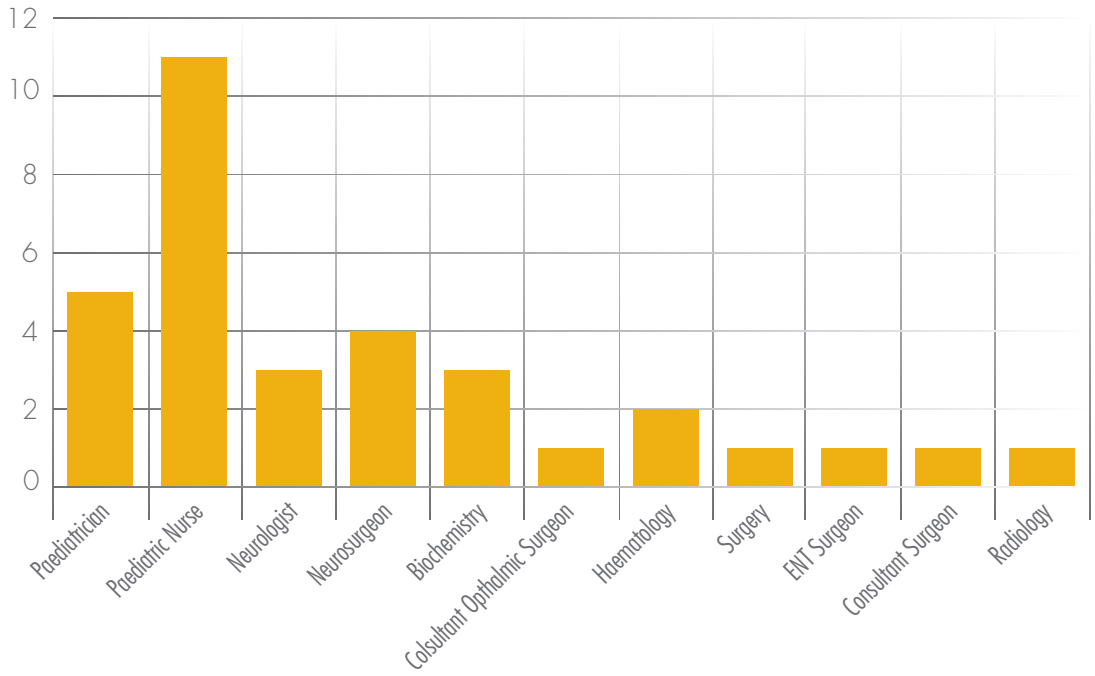
Table 18 shows that the majority (n = 8) of brain injuries reviewed in the WHSCT were caused by traumatic means, with half as many due to organic causes. Details as to the cause of brain injury for one child were not available.

Table 19: Glasgow coma scale scores for children in the WHSCT

GCS Score	Number of Children
15	7
11	1
8	1
N/A	3
None stated	1

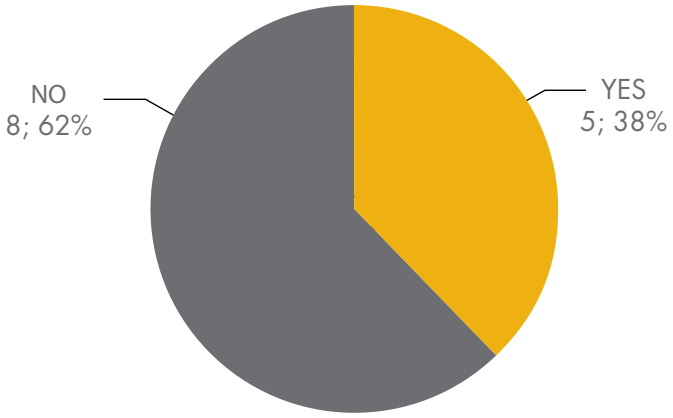
Table 19 shows that seven children in the WHSCT had sustained a mild (> 13) brain injury and two had sustained a moderate (9-12) injury. Data on four children was not available from the casenotes.

Figure 35: Graph showing members of staff involved in the patients care



The majority of staff involved in the children's care were paediatric nurses (n=11), followed by paediatricians (n=4). Neurosurgeons and neurologists were also involved (n=4 & 3 respectively).

Figure 36: Children who experienced a transfer while attending the WHSCT



Review of the thirteen casenotes revealed that five children were transferred to the BHSCT.

4.0 DISCUSSION

The figures show that the 0-1 years of age group of children is the largest at risk of acquiring a brain injury and that the main conditions were inflammatory diseases of the CNS. Across all injury types, inflammatory diseases were again the greatest cause of possible ABI followed by traumatic injuries and neoplasms.

Review of the casenote data show that, in regard to healthcare utilisation, psychology services are most frequently accessed followed by paediatrics, physiotherapy and speech and language therapy.

Findings suggest relatively small numbers of brain injuries (24.63 per 100,000 ABI; 8.52 per 100,000 TBI) in comparison to other UK based studies. For example, Hawley et al (2003) suggest a prevalence rate of 280 per 100,000 for TBI alone. A 2003 audit of the management of patients with severe traumatic brain injury in NI showed that 871 children were admitted to acute care with 'suspected head injury symptoms' between April 2001 and March 2002 with 70 requiring neurosurgical intervention (Cooke et al 2003). However, Parslow et al (2005) estimated the prevalence of childhood TBI to be 7.3 per 100,000 for NI. The discrepancy in these figures is undoubtedly due to the methods used in the gathering and availability of data. The retrospective nature of this audit has forced a reliance on clinical coding data which may not adequately capture the full range of severity associated with TBI. One of the issues with traumatic brain injury lies in its accompaniment with orthopaedic injuries which are readily identified and may be coded to the exclusion of a mild or moderate brain injury. Therefore, it is likely that a reduced amount of clinical coding data is available for large numbers of children who have received a mild or moderate brain injury. In addition this was simply an audit of available information and did not involve further assessment of the children or their neuro-imaging.

4.1 AUDIT STANDARDS

Two pieces of information were used to assess whether 'each patient and their family and / or carers should have access to a co-ordinated and holistic treatment plan'. To examine the co-ordinated aspect of this statement review of the casenotes was undertaken for a named lead who would hold responsibility for care. All casenotes showed evidence of a named lead. The phrase 'access to a holistic treatment plan' was interpreted in a broader sense which included whether the children had received any form of consideration beyond the acute phase. Therefore, the audit sought evidence regarding the presence or absence of a discharge plan. Fifty-nine percent of the casenotes reviewed showed evidence of discharge planning while forty-one percent did not. No evidence was found which suggested that the needs of the family and or carers were taken into consideration. This is perhaps not surprising given the notes refer solely to the child receiving treatment, however, the health of the family has a direct impact on recovery of the child (Smith & Smith 2000) and should be taken into consideration. Gaps in service provision which appear to exist include the lack of a co-ordinated discharge plan and co-ordination of neurorehabilitation follow-up in the community. Current guidance recommends thatparents and families having access to suitable forms of written information that will help them understand the child's new difficulties. It is hoped that the work of the Regional Acquired Brain Injury Implementation Group will go some way to addressing these issues on a regional basis.

To assess whether the children had received care in a child friendly environment the ward in which they had received their treatment was examined. If this was deemed as a dedicated children's ward then the criteria were determined to have been met. If the ward also included adult patients then the criteria were not met. The audit showed that 97% of children received care in a child friendly environment.

Access to a multidisciplinary team of paediatric specialists was explored through an examination of those individuals recorded as caring for the children in their casenotes. It was determined that all children were treated by specialists who were mainly paediatric nurses or paediatricians.

The transfer of children to other hospitals to avail of specialist services was examined and showed that children were moved between trusts as required. Many of these transfers were to the BHSCT where the Royal Belfast Hospital for Sick Children (RBHSC) is located.

Increased funding is necessary to conduct a prospective regional audit of paediatric brain injury in NI. Until accurate prevalence figures are available it is impossible to successfully plan future service delivery.

It is recommended that re-audit of these standards should be completed in two years following the implementation of a regional care pathway for children with brain injuries.

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APPENDIX 1

ICD10 codes for paediatric acquired brain injury

TRAUMA

S06.1	Traumatic cerebral oedema
S06.2	Diffuse brain injury
S06.3	Focal brain injury
S06.4	Epidural haemorrhage
S06.5	Traumatic subdural haemorrhage
S06.6	Traumatic subarachnoid haemorrhage
S06.7	Intracranial injury with prolonged coma
S06.8	Other intracranial injuries
S06.9	Intracranial injury, unspecified
T71	Asphyxiation

BACTERIAL INFECTIONS

A17	Tuberculosis of nervous system
G00	Bacterial meningitis, not elsewhere classified
G01	Meningitis in bacterial diseases classified elsewhere
G02+	Meningitis in other infectious and parasitic diseases classified elsewhere
G02.1	Meningitis in mycoses
G02.8	Meningitis in other specified infectious and parasitic diseases classified elsewhere
G03	Meningitis due to other and unspecified causes
G04	Encephalitis, myelitis and encephalomyelitis
G05	Encephalitis, myelitis and encephalomyelitis in diseases classified elsewhere
G06	Intracranial and intraspinal abscess and granuloma
G07	Intracranial and intraspinal abscess and granuloma in diseases classified elsewhere

VIRAL INFECTIONS

A85	Other viral encephalitis, not elsewhere classified
B00.4	Herpesviral encephalitis
B01.0+	Varicella meningitis
B01.1	Varicella encephalitis
B02.0+	Zoster encephalitis
B02.1+	Zoster meningitis
B05.0+	Measles complicated by encephalitis
B05.1+	Measles complicated by meningitis
B26.1+	Mumps meningitis
B26.2+	Mumps encephalitis
B45.1	Cerebral cryptococcosis
B58.2+	Toxoplasma meningoencephalitis

TUMOURS

C70	Malignant neoplasm of meninges
C71	Malignant neoplasm of brain
C79.3	Secondary malignant neoplasm of brain and cerebral meninges
D33	Benign neoplasm of brain and other parts of central nervous system

VASCULAR CONDITIONS

G46	Vascular syndromes of brain in cerebrovascular diseases
I62	Other nontraumatic intracranial haemorrhage
I63	Cerebral infarction
I64	Stroke, not specified as haemorrhage or infarction

DEMYELINATION

G36	Other acute disseminated demyelination
G37	Other demyelinating diseases of central nervous system
G37.1	Diffuse sclerosis

APPENDIX 2

Title: A regional audit examining the prevalence of childhood acquired brain injury.

N/A = Unknown / Missing information
Number: / 30

Audit Form 1: To be completed by ED Pharmacist

FROM PATIENT CASENOTES.

A. HOSPITAL ADMISSION DATA

1. Gender: Male Female
(Circle one)

2. Casenote #: .....

3. Date of Birth: ☐☐ ☐☐ ☐☐ (DD/MM/YY)

4. Age: .....

5. Postcode (area): BT .....

6. Date of Data Collection: ☐☐ ☐☐ ☐☐ (DD/MM/YY)

7. PICU admission date start: ..... end: .....

8. Ward admission date start: ..... end: .....

9. Specialty on admission: .....

10. Consultant Name: .....

11. First recorded GCS / LOC / PTA Scores: .....

Details:

.....

.....

.....

12. Was the patient transferred to / from another hospital? Y / N

(a) If yes, which?

.....

.....

(b) Reason:

.....

.....

.....

(c) Date of

.....

B. POST ADMISSION

13. Brain areas affected: (please tick the appropriate box)

14. List the members of staff involved with the patient's care.

Frontal		**Temporal**		**Parietal**		**Occipital**	
Right	Left	Right	Left	Right	Left	Right	Left
☐	☐	☐	☐	☐	☐	☐	☐

Haemorrhage		**Skull Fracture**	
Right	Left	Right	Left
☐	☐	☐	☐

Neurologist	Y / N
Neurosurgeon	Y / N
Paediatrician	Y / N
Paediatric Nurse	Y / N
Social Worker	Y / N
Clinical psychologist	Y / N
Physiotherapist	Y / N
Speech and Language Therapist	Y / N

Other:

.....

.....

.....

15. Was there a named lead? (NB maybe same person named in 10) Y / N

(a) If yes, please detail.

.....

.....

.....

.....

.....

.....

16. Did the patient receive treatment in a child-friendly environment? Y / N

Details:

.....

.....

.....

.....

.....

.....

17. Have community services been contacted?
(Has there been a discharge planning meeting?) Y / N

Physiotherapy	Y / N
Speech and Language Therapy	Y / N
Social work	Y / N
Educational Psychology	Y / N
Occupational Therapy	Y / N

Other (please provide details)

.....

.....

.....

.....

NOTES

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GAIN Office
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BT4 3SQ
Telephone: 028 9052 0629
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ISBN: 978-1-906805-27-2