The impact of neurological disorders on hospital admissions for children and young people: a routine health data study

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Abstract

Introduction

Neurological conditions are a major and increasing cause of hospitalisation among children and young people, but little is known about the impact of neurological conditions on hospital services in England, nor the factors that influence length of stay and bed days per year.

Objectives

To quantify the hospital usage in children and young people related to neurological conditions, trends over time and variation by ethnicity and deprivation status.

Methods

An ICD10 coding framework identified a cohort of individuals aged 0-19 years with neurological conditions from linked routinely collected healthcare data from England (The Hospital Episode Statistics Admitted Patient Care dataset), from 1 April 2003 to 31 March 2015. Linked outpatient and accident and emergency data were used to supplement missing demographic data. Length of stay and bed days per year per person were calculated. These were separately modelled using random intercept multivariable negative binomial regressions with gender, age, ethnic group, diagnostic group, region of residence and deprivation category as predictors.

Results

524,442 individuals were identified over the study period, increasing from 49,928 in 2003/04 to 102,840 in 2014/15. Neurological conditions account for 8.8% of inpatient bed days in the 0-14 year old age group. Length of stay and bed days per year vary primarily by age group – e.g. Under 1 year olds had 1.85 times (95%CI 1.83-1.86%) longer stays and over double (2.36 times, 95%CI 2.34-2.37 times) the number of bed days per person per year compared to 5 to 9 year olds – and main diagnostic group, with smaller variations by ethnic group, deprivation and region.

Conclusions

Neurological conditions in children and young people have a significant and increasing impact on the NHS in England. Falls in length of stay and bed days per person are more than offset by increasing numbers of children and young people with neurological diagnoses. Variations in length of stay and bed days per year by diagnostic group, ethnic group, age group, deprivation category and region should be taken into account in resource planning.

Introduction

Neurological conditions, such as cerebral palsy, epilepsy and neuromuscular conditions, are a major and increasing [1] cause of hospitalisation among children and young people, accounting for between 5% and 10% of their admissions, around 20% of costs and 14% of bed days in the United States (US)[1,2]. Among children and young people in the US, those with neurological conditions had nearly three times greater intensive care unit (ICU) use than those with other conditions and accounted for nearly half of deaths[2].

In the UK, neurological conditions account for 30-40% of deaths in children and young people aged 1-19 years[3] and are the third most common primary reason for paediatric ICU (PICU) admission[4]. However the only study which has assessed data on hospital usage for children with neurological conditions in the UK was a single centre study in London[5]. Although there are studies which have tracked neurological outcomes for preterm babies[6] and regional disease specific registers e.g. north east cerebral palsy register[7], there are no good quality, national level data sources for the incidence of these neurological conditions in children in the UK. Given

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the demographic differences between London and the rest of England, there is value in a national level study. This study aimed to quantify the hospital usage (admissions, length of stay and bed pays per year) in children and young people related to neurological conditions, trends over time and variation by ethnicity and deprivation status.

Methods

Participants

Cohort identification

An International Classification of Diseases version 10 (ICD10)[8] coding framework for neurological conditions (supplementary material) was developed by a consultant paediatric neurologist (JL) and reviewed by LF. This coding framework aimed to identify all children with a neurological diagnosis who, depending on severity of their condition, may require to be seen by a paediatric neurologist e.g. epilepsy, cerebral palsy, Duchenne muscular dystrophy, Batten disease.

The study cohort included all individuals (0-19 years) who had at least one episode in the Hospital Episode Statistics (HES) admitted patient care (APC – containing hospital inpatient episodes) dataset with one of the neurological codes recorded between 1/4/2003 – 31/3/2015.

Datasets

The HES data are national records of NHS hospital use in England [9]. A request was made to NHS Digital for all HES APC (1/4/2003 -31/3/2015), outpatient (1/4/2003-31/3/2015) and Accident and Emergency (A&E) records (1/4/2007-31/3/2015) for individuals matching the cohort definition. The outpatient and A&E data were used only to supplement missing demographic information in the inpatient data (Figure 1). NHS Digital linked the data across the APC, A&E and outpatient datasets using patient HESID (determined based on NHS number, date of birth, gender, postcode, provider code and local patient ID)[10].

Data management

The datasets were arranged in financial years (e.g. financial year 2003/04 covers the period from 1 April 2003 to 31 March 2004).

Ethnicity was first assigned to one of eight groups in each record: White, Indian, Pakistani, Bangladeshi, Black, Chinese, Mixed or Other. Each individual's ethnic group was then set as the most commonly recorded in the APC dataset, excluding missing values (the APC dataset was preferred as these data were more complete than in the A&E or outpatient datasets). Where ethnic group could not be determined from the APC dataset, data from the outpatient and A&E datasets were used.

Gender was set as the most commonly recorded, again excluding any missing values and preferring the APC dataset, using the outpatient and A&E datasets only where gender was not defined in the APC dataset.

Age, Government Office Region of residence (GOR), and deprivation score (Index of Multiple Deprivation (IMD) 2004)[11] could change over time. The first recorded value was used in each financial year (again, preferring APC data, supplementing with A&E and outpatient data where missing in APC). Deprivation scores were assigned to categories (with approximately 20% of the population of England in each) using published populations[12] and IMD 2004 rankings[13] for Lower Super Output Areas (a small-scale geographical area of approximately 1500 people).

Seven diagnostic groups were used, based on the ICD10 chapters: malignant neoplasms (C), benign neoplasms (D), metabolic conditions (E), mental or behavioural conditions (F), nervous system conditions (G), congenital conditions (Q) and other conditions (R). Each record was assigned one or more diagnostic groups based on all the diagnoses present (primary and secondary diagnoses). Each individual was also assigned a main diagnostic group. This was the most common diagnostic group recorded in records for that individual over the study period, using all the diagnosis fields. If there was no most common diagnostic group, the most common diagnostic group associated with primary diagnoses was used. If there was still no most common diagnostic group, records were progressively ignored (starting with the oldest on the basis that diagnoses should become more certain over time) until a most common diagnostic group could be determined.

Finally, continuous inpatient spells ('admissions') were constructed for each cohort member per year[14]. Each admission represents a continuous period of inpatient care, often a single finished consultant episode (FCE, a period of care under one consultant) although they may contain multiple FCEs. In creating admissions, FCEs that were separated by less than 2 days (i.e. those with discharge and admission on the same or consecutive days) and within the same hospital were combined (considered part of a single admission).

Statistical analyses

All data analyses were performed using Stata V.14 (StataCorp. Stata Statistical Software: Release 14. College Station, TX: StataCorp LP, 2015).

Descriptive analyses

Each year, the number of individuals aged 0-19 years with at least one inpatient admission that year with one of the neurological codes was recorded, as was the number with a primary neurological diagnosis.

Length of stay (number of nights in hospital) was calculated for each admission and the number of bed days (length of stay plus one for each admission) was calculated for each cohort member per year. In each year, the analysis was limited to cohort members with an inpatient admission (or part of an inpatient admission) in that year. This ensured that the analysed group was similar in each year. Otherwise, if the whole cohort was analysed each year from first inclusion, then in later years there would be an increasing proportion of 'inactive' cohort members who had an identified condition, had previously had an inpatient admission but were not in that year in need of inpatient care. When admissions spanned a year boundary, they were considered part of the year of admission for analysis of length of stay. For analysis of bed days, these admissions

Figure 1: Construction of the cohort and datasets used. 'HES' refers to Hospital Episode Statistics; 'A&E' refers to Accident and Emergency.
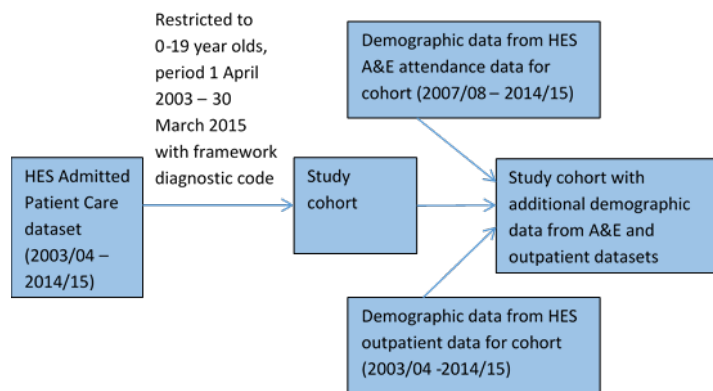
were split at the year boundary and the bed days assigned to the year in which they took place.

Some validation was performed on length of stay: negative length of stay, lengths of stay that were longer than the age of the patient plus one year (to allow for patients that had almost reached their next birthday), and lengths of stay where admission or discharge dates were outside the study period were set to missing. If any length of stay for an individual was missing in a year then the bed days for the individual in that year were also set to missing.

Analyses of length of stay and bed days were split by year, age group, diagnostic group, ethnic group, deprivation category and GOR.

The proportion of inpatient bed days in England attributable to neurological patients was determined, both for admissions with a neurological diagnosis in any field and only for admissions with a primary neurological diagnosis. Aggregate HES data on bed days were only available for the 0-14 year old age group[15] so, for this analysis alone, only 0-14 year old cohort members were included.

Multivariate models

Length of stay and bed days were modelled separately for the whole cohort (0-19 years) using the same strategy. In each year, only cohort members with an admission or part of an admission in that year were included. A two level (random intercept) multivariate negative binomial regression was used. The random intercept accounted for clustering in the data due to dependence in length of stay among multiple admissions and bed days per year among multiple years for a single individual. The following predictors were included: at level 1 (admission level for length of stay; year level for bed days per year) year of admission, age group, primary diagnostic group, deprivation category and GOR; at level 2 (individual level) gender and ethnic group. Interaction terms were included if they decreased the Bayesian Information Criterion (BIC)[16] by more than 2[17]. For the model of bed days, time at risk was included in the model, calculated using year and month of birth provided in the data (day of birth was set to the 15th of the month, except for those admitted as neonates, for whom age in days was provided and so date of birth could be determined

exactly) and date of death (only available for those who died in hospital).

Individuals with missing data were excluded from the models for the years in which data were missing. For ethnic group a sensitivity analysis was performed modelling only years 2009/10 onwards where data were more complete.

Results

There were 524,442 cohort members in total; 272,250 had a primary neurological diagnosis. 49,928 had an admission with a neurological diagnosis in 2003/04, rising to 102,840 in 2014/15 (Table 1). There were 1,665,575 admissions (7,431,723 bed days) with a neurological diagnosis, 651,357 of which (2,971,390 bed days) had a primary neurological diagnosis. Children (0-14 years) with neurological conditions accounted for an increasing percentage of bed days (2003/04: 6.66%, 95%CI 6.64-6.68%; 2014/15: 8.83%, 95%CI 8.81-8.86%) but for primary diagnoses the share was relatively static (around 3%, Figure 2).

The data were largely complete: apart from ethnic group (8.7% missing in 2003/04, dropping to 2.0% in 2014/15), only bed days ($\leq$0.3% in all years), length of stay ($\leq$0.2%) gender ($<$0.05% in all years) and deprivation category (1.4% in 2008/09 to 2010/11; $\leq$0.5% in other years) had missing data.

There were more males (300,326) than females (224,006) in the cohort. White individuals made up the largest group (398,781 individuals, 76%); individuals in the Pakistani and Black ethnic groups were over-represented (respectively, 5% and 6% of the cohort in 2011/12 compared to 2% of population for each in 2011)[18]. 1 to 4 year olds were the largest group (27,494 in 2014/25), but $<$1 year olds were proportionately more likely to have inpatient admissions (14,789 in 2014/15). Overall, the most common diagnoses were epilepsy (26% of admissions), cerebral palsy (14%) and developmental disorders of scholastic skills (10%). The most deprived category contained approximately double the number of individuals compared to the least deprived (30,373 versus 15,013 in 2014/15). The North West had the largest number of admissions in most years (2014/15: 15,142); the North East had the fewest (2014/15: 5,349).

Table 1: Characteristics of the cohort and its hospital use, by year.

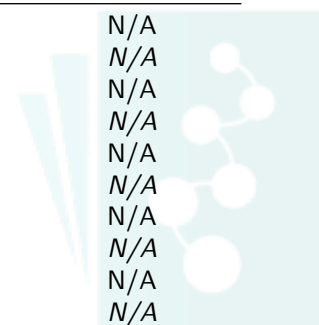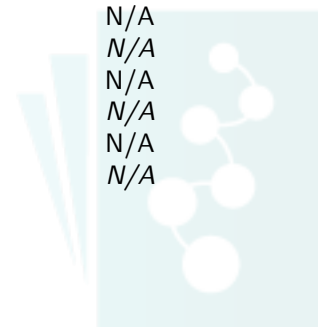| | Financial years | | | |
	2003/04-2006/07	2007/08-2010/11	2011/12-2014/15	Overall in cohort
Persons with an inpatient admission				
any neur. diagnosis	213991	278696	371965	524442
primary neur. diagnosis	109634	131469	155535	272250
Inpatient admissions				
any neur. diagnosis	438642	536496	690437	1665575
primary neur. diagnosis	196508	214514	240335	651357
Bed days				
any neur. diagnosis	2103226	2449850	2878647	7431723
primary neur. diagnosis	955387	977225	1038778	2971390
Persons with unknown bed days in year	522	656	753	N/A
	0.2%	*0.2%*	*0.2%*	*N/A*
Persons with an inpatient admission by gender				
Male	121089	158992	213864	300236
	56.6%	*57.0%*	*57.5%*	*57.2%*
Female	92861	119633	158013	224006
	43.4%	*42.9%*	*42.5%*	*42.7%*
Unknown	41	71	88	200
	0.0%	*0.0%*	*0.0%*	*0.0%*
Persons with an inpatient admission by ethnic group				
White	166151	217309	283097	398781
	77.6%	*78.0%*	*76.1%*	*76.0%*
Indian	3880	5658	7829	10485
	1.8%	*2.0%*	*2.1%*	*2.0%*
Pakistani	9204	13640	19056	21372
	4.3%	*4.9%*	*5.1%*	*4.1%*
Bangladeshi	2358	3535	5124	6379
	1.1%	*1.3%*	*1.4%*	*1.2%*
Black	8661	13910	21351	27648
	4.0%	*5.0%*	*5.7%*	*5.3%*
Chinese	429	700	1038	1348
	0.2%	*0.3%*	*0.3%*	*0.3%*
Mixed ethnicity	4320	7701	12787	15477
	2.0%	*2.8%*	*3.4%*	*3.0%*
Other ethnicity	5643	9530	15672	19476
	2.6%	*3.4%*	*4.2%*	*3.7%*
Unknown	13345	6713	6011	23476
	6.2%	*2.4%*	*1.6%*	*4.5%*
Persons with an inpatient admission by age group				
Under 1	30080	41469	53162	N/A
	14.1%	*14.9%*	*14.3%*	*N/A*
1-4	50270	67766	98312	N/A
	23.5%	*24.3%*	*26.4%*	*N/A*
5-9	47664	58598	81228	N/A
	22.3%	*21.0%*	*21.8%*	*N/A*
10-14	45115	55777	69365	N/A
	21.1%	*20.0%*	*18.6%*	*N/A*
15-19	40862	55086	69898	N/A
	19.1%	*19.8%*	*18.8%*	*N/A*

Table 1 Cont.: Characteristics of the cohort and its hospital use, by year.

| | Financial years | | | |
	2003/04-2006/07	2007/08-2010/11	2011/12-2014/15	Overall in cohort
Persons with an inpatient admission by diagnostic group				
Malignant neoplasms (C)	3876	4397	4401	N/A
	1.8%	*1.6%*	*1.2%*	*N/A*
Benign neoplasms (D)	521	634	743	N/A
	0.2%	*0.2%*	*0.2%*	*N/A*
Metabolic (E)	4665	6062	6828	N/A
	2.2%	*2.2%*	*1.8%*	*N/A*
Mental/behavioural (F)	43150	66505	116996	N/A
	20.2%	*23.9%*	*31.5%*	*N/A*
Nervous system (G)	136018	167785	213273	N/A
	63.6%	*60.2%*	*57.3%*	*N/A*
Congenital (Q)	43246	57135	71826	N/A
	20.2%	*20.5%*	*19.3%*	*N/A*
Other (R)	17685	27598	42013	N/A
	8.3%	*9.9%*	*11.3%*	*N/A*
Persons with an inpatient admission by main diagnostic group				
Malignant neoplasms (C)	3515	3993	3846	4360
	1.6%	*1.4%*	*1.0%*	*0.8%*
Benign neoplasms (D)	297	347	405	666
	0.1%	*0.1%*	*0.1%*	*0.1%*
Metabolic (E)	4179	5263	5913	5598
	2.0%	*1.9%*	*1.6%*	*1.1%*
Mental/behavioural (F)	30089	45083	77749	103058
	14.1%	*16.2%*	*20.9%*	*19.7%*
Nervous system (G)	127542	155656	191688	284879
	59.6%	*55.9%*	*51.5%*	*54.3%*
Congenital (Q)	34239	45998	57933	58941
	16.0%	*16.5%*	*15.6%*	*11.2%*
Other (R)	14130	22356	34431	66940
	6.6%	*8.0%*	*9.3%*	*12.8%*
Persons with an inpatient admission by deprivation category				
1 (most deprived)	62767	81488	109895	N/A
	29.3%	*29.2%*	*29.5%*	*N/A*
2	45559	59414	82435	N/A
	21.3%	*21.3%*	*22.2%*	*N/A*
3	38091	48932	67762	N/A
	17.8%	*17.6%*	*18.2%*	*N/A*
4	34545	43475	57211	N/A
	16.1%	*15.6%*	*15.4%*	*N/A*
5 (least deprived)	32925	42119	54636	N/A
	15.4%	*15.1%*	*14.7%*	*N/A*
Unknown	104	3268	26	N/A
	0.0%	*1.2%*	*0.0%*	*N/A*

Table 1 Cont.: Characteristics of the cohort and its hospital use, by year.

	Financial years			
	2003/04-2006/07	2007/08-2010/11	2011/12-2014/15	Overall in cohort
Persons with an inpatient admission by Government Office Region of residence				
North East	13019	16441	20038	N/A
	6.1%	*5.9%*	*5.4%*	*N/A*
North West	33430	44040	55140	N/A
	15.6%	*15.8%*	*14.8%*	*N/A*
Yorkshire and Humber	21295	27026	36615	N/A
	10.0%	*9.7%*	*9.8%*	*N/A*
East Midlands	18339	22639	27332	N/A
	8.6%	*8.1%*	*7.3%*	*N/A*
West Midlands	24361	32165	43138	N/A
	11.4%	*11.5%*	*11.6%*	*N/A*
East of England	20550	27093	38036	N/A
	9.6%	*9.7%*	*10.2%*	*N/A*
London	29304	40389	60829	N/A
	13.7%	*14.5%*	*16.4%*	*N/A*
South East	32112	41994	56273	N/A
	15.0%	*15.1%*	*15.1%*	*N/A*
South West	21581	26909	34564	N/A
	10.1%	*9.7%*	*9.3%*	*N/A*

Figure 2: The proportion of inpatient bed days for 0-14 year olds in England in admissions that either had a neurological condition among diagnoses or a neurological condition as the primary diagnosis.
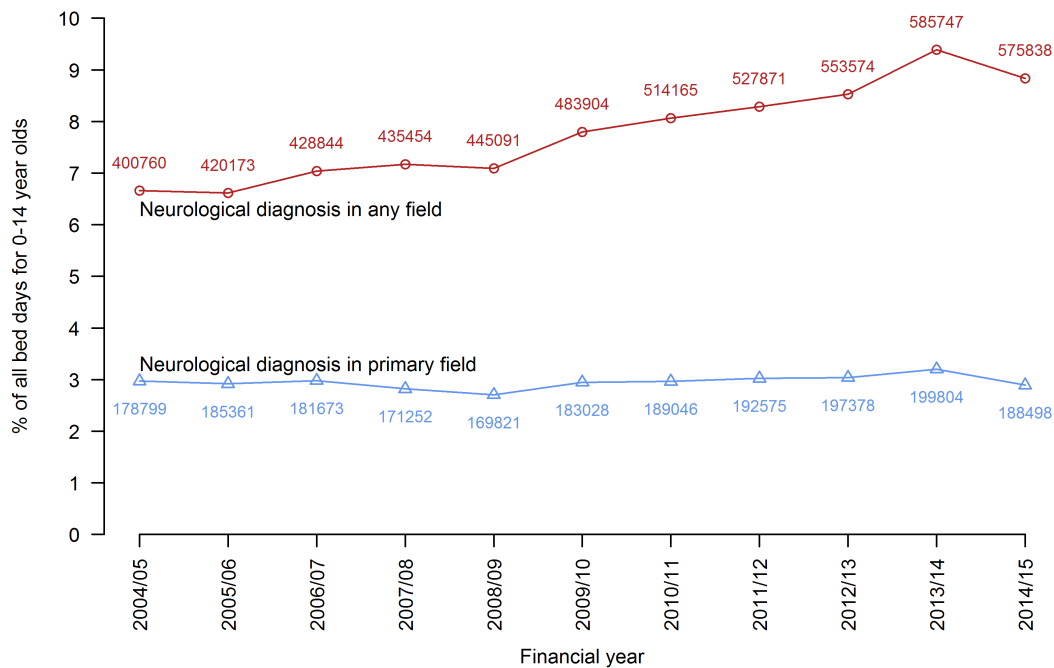
Length of stay

Admissions shortened over the study period – those with no overnight stay increased from 35.5% (95%CI 35.2-35.8%) to 50% (supplemental Table S1). Admissions longer than 14 days decreased from 4.3% (95%CI 4.2-4.4%) to 3.5% (95%CI 3.4-3.6%). Between 38 and 62 individuals each year had admissions longer than one year.

Minority ethnic groups had more stays over 14 days – over 5% of admissions for all groups except Mixed (4.4%), unknown (3.8%) and White (3.8%). Children <1 year showed variable admission length, with 31% in the 0 day group, but 22% in the 2 to 4 day group and 12% staying over 14 days. For all other age groups, 0 days was the largest group (>50% of admissions).

Admissions with no overnight stay were most common for individuals with a malignant central nervous system (CNS) tumour; other diagnostic groups had more overnight stays (42% to 59%, compared to 29% for malignant CNS tumours).

The least deprived had more admissions with no overnight stay than the most deprived (47.3%, 95%CI 47.1-47.5% compared to 45.2%, 95%CI 45.1-45.3%) and fewer admissions over 14 days (3.6%, 95%CI 3.5-3.7% compared to 4.6%, 95%CI 4.5-4.7%). There were small differences by GOR: admissions over 14 days were more common in London (5.1%) than other regions (3.0% to 4.5%).

Bed days

The number of bed days per person per year has decreased over the study period (supplemental Table S2). 27.0% (95%CI 26.6-27.4%) of individuals (13,235) had a single bed day in 2003/04 compared to 35.1% (95%CI 34.8-35.4%) (36,080) in 2014/15. The proportion having more than 14 bed days fell from 14.4% (95%CI 14.1-14.7%) to 9.4% (95%CI 9.2-9.6%).

White individuals were most likely to have only 1 bed day per year (33%), while Black individuals were most likely to have 2 to 4 (35%). Under 1 year olds were most likely to have more bed days (26% had over 14) while 5 to 9 year olds were most likely (40%) to have only 1 bed day.

Individuals with a malignant CNS tumour were most likely to have over 14 bed days per year (41%) compared to other main diagnoses (all <24%). Those with mental or behavioural disorders were most likely to have only 1 bed day per year (49%).

The least deprived were slightly more likely to have only 1 bed day (33.3%, 95%CI 33.0-33.6% versus 32.1%, 95%CI 31.9-32.3%) and less likely to have over 14 bed days (11.1%, 95%CI 10.9-11.3% versus 12.3%, 95%CI 12.2-12.4%) than the most deprived. There were only minor variations between GORs.

Multivariate models

Length of stay

There was a decrease in length of stay over the study period, by 4% per year (Table 2). Length of stay for females was 2% (95%CI 2-3%) higher than for males. Individuals in the black (by 5%, 95% CI 4-6%) and Mixed (by 4%, 95%CI 2-6%) had longer stays than those in the White group. The Indian (by 6%, 95CI4-7%), Pakistani (1%, 95%CI 0-3%) and Chinese (by

13%, 95%CI 9-18%) ethnic groups had shorter length of stay than those in the White group. <1 year olds had stays nearly twice (1.85 times, 95%CI 1.83-1.86) as long as 5 to 9 year olds. Older groups also had longer stays: 24% (95%CI 23-25%) longer for 10 to 14 year olds and 39% (95%CI 38-41%) longer for 15 to 19 year olds than 5 to 9 year olds. 1 to 4 year olds had stays 3% shorter (95% CI 2-4%) than 5 to 9 year olds.

Compared to nervous system conditions, all other groups had shorter stays – by 63% for those with malignant neoplasms (95%CI 63-64%), 26% for benign neoplasms (95%CI 20-32%), 17% for metabolic disorders (95%CI 16-19%), 5% for mental or behavioural conditions (95%CI 4-5%), 18% for congenital conditions (95%CI 17-19%) – or were not significantly different (Other conditions).

There was some observed variation in length of stay with deprivation: the least deprived had 3% (95%CI 2-4%) shorter stays than the most deprived, however those in the middle deprivation category had 3% (95%CI 2-4%) longer stays than the most deprived. There were variations by GOR with up to 21% longer stays (Yorkshire & Humber, East Midlands, West Midlands and South East) compared to the North West.

To put these variations in context, in 2010/11 the mean expected length of stay for a White girl aged <1 year old, with a nervous system condition, living in an area in the most deprived category in the East Midlands was 6.6 days. A boy, in the Indian ethnic group, aged 5 years, also with a nervous system condition, living in an area in the least deprived category in the North West, had a mean expected length of stay of 2.6 days, a difference of 4.0 days.

Bed days per person per year

There was a decrease in bed days per person per year over the period, by 2% per year. Females had 1% (95%CI 0-1%) more bed days than males (Table 2). Individuals in the Indian, Pakistani, Black and Other (largest difference, 5%, 95%CI 3-6%) ethnic groups had more bed days than White individuals. <1 year olds had 2.36 (95%CI 2.34-2.37) times as many bed days as 5 to 9 year olds. Older groups also had more bed days: 13% (95%CI 12-13%) more for 10 to 14 year olds and 22% (95%CI 22-23%) more for 15 to 19 year olds compared to 5 to 9 year olds. 1 to 4 year olds had 5% more bed days (95%CI 4-5%) than 5 to 9 year olds.

Compared to nervous system conditions, three groups had more bed days: malignant CNS tumours (by 24%, 95%CI 21-27%), benign CNS tumours (17%, 95%CI 9-25%) and metabolic disorders (13%, 95%CI 11-15%). Three groups had fewer bed days than nervous system conditions: mental or behavioural conditions (by 13%, 95%CI 12-13%), congenital conditions (2%, 95%CI 1-2%) and 'Other' conditions (26%, 95%CI 26-27%).

There was a small gradient in bed days with deprivation: the least deprived had 2% (95%CI 1-3%) fewer bed days than the most deprived. There were minor variations by GOR, with up to 4% more bed days (East Midlands, 95%CI 3-5%) compared to the North West.

Illustrating these differences, in 2007/08 a girl in the Pakistani ethnic group, aged <1 year, with a malignant CNS tumour, living in an area in the most deprived category in the East Midlands had a mean expected total of 17.3 bed days

Table 2: Two level random intercept negative binomial regression models for length of stay and bed days per person per year. IRR is incidence rate ratio compared to the reference category – the ratio of expected length of stay or number of bed days.

	Length of Stay			Bed days per year		
	IRR	95% CI	P value	IRR	95% CI	P value
Financial year						
Change per year	0.96	0.96 0.96	<0.01	0.98	0.98 0.98	<0.01
Gender						
Male	1 (ref)			1 (ref)		
Female	1.02	1.02 1.03	<0.01	1.01	1 1.01	0.02
Ethnic group						
White	1 (ref)			1 (ref)		
Indian	0.94	0.93 0.96	<0.01	1.03	1.02 1.05	<0.01
Pakistani	0.99	0.97 1	0.03	1.04	1.02 1.05	<0.01
Bangladeshi	1.01	0.98 1.03	0.58	1.02	1 1.04	0.12
Black	1.05	1.04 1.06	<0.01	1.03	1.02 1.04	<0.01
Chinese	0.87	0.82 0.91	<0.01	1.01	0.97 1.06	0.6
Mixed	1.04	1.02 1.06	<0.01	1	0.99 1.02	0.74
Other	1	0.99 1.02	0.52	1.05	1.03 1.06	<0.01
Age group						
Under 1	1.85	1.83 1.86	<0.01	2.36	2.34 2.37	<0.01
1 to 4	0.97	0.96 0.98	<0.01	1.05	1.04 1.05	<0.01
5 to 9	1 (ref)			1 (ref)		
10 to 14	1.24	1.23 1.25	<0.01	1.13	1.12 1.13	<0.01
15 to 19	1.39	1.38 1.41	<0.01	1.22	1.22 1.23	<0.01
Main diagnostic group						
Malignant neoplasms (C)	0.37	0.36 0.37	<0.01	1.24	1.21 1.27	<0.01
Benign neoplasms (D)	0.74	0.68 0.8	<0.01	1.17	1.09 1.25	<0.01
Metabolic (E)	0.83	0.81 0.84	<0.01	1.13	1.11 1.15	<0.01
Mental/behavioural (F)	0.95	0.95 0.96	<0.01	0.87	0.87 0.88	<0.01
Nervous system (G)	1 (ref)			1 (ref)		
Congenital (Q)	0.82	0.81 0.83	<0.01	0.98	0.98 0.99	<0.01
Other (R)	0.99	0.98 1.01	0.29	0.74	0.73 0.74	<0.01
Deprivation category						
1 (most deprived)	1(ref)			1 (ref)		
2	1.01	1 1.02	0.03	0.99	0.99 1	0.01
3	1.03	1.02 1.04	<0.01	0.99	0.98 1	0.01
4	0.98	0.98 0.99	<0.01	0.98	0.97 0.99	<0.01
5 (least deprived)	0.97	0.96 0.98	<0.01	0.98	0.97 0.99	<0.01
Government Office Region of Residence						
North East	1.15	1.14 1.17	<0.01	1	0.99 1.01	0.75
North West	1 (ref)			1 (ref)		
Yorkshire and Humber	1.21	1.2 1.23	<0.01	1.02	1.01 1.03	<0.01
East Midlands	1.21	1.19 1.22	<0.01	1.04	1.03 1.05	<0.01
West Midlands	1.21	1.2 1.23	<0.01	1.01	1 1.02	0.04
East of England	1.15	1.14 1.16	<0.01	1.03	1.02 1.04	<0.01
London	1.06	1.05 1.08	<0.01	1.03	1.02 1.04	<0.01
South East	1.21	1.2 1.23	<0.01	1.03	1.02 1.04	<0.01
South West	1.07	1.06 1.08	<0.01	1	0.99 1.01	0.97
Model parameters						
Degrees of freedom		34			34	
Log likelihood		-3072235			-2379091	
BIC		6144956			4758646	

per year. A White boy, aged 7 years, also with a malignant CNS tumour, living in an area in the least deprived category in the North East had a mean expected total of 6.6 bed days per year, a difference of 10.7 days.

Discussion

There are growing numbers of children and young people with neurological conditions being admitted to hospitals in England, representing a growing proportion of the inpatient population. The distribution of length of stay has changed over the study period with half of all admissions being day-cases. However approximately 6,500 cohort members had hospital stays of longer than 14 days in 2014/15.

8.8% of inpatient bed days for 0-14 year olds in England in 2014/15 were for children with a neurological condition (among any of their diagnoses). This figure lies between the results of two studies from the US which showed neurological diagnoses or impairment accounted for 5.2% [1] and 10.3% [2] of child hospital admissions but is lower than the only other UK study which was a single centre study in London[5]. This study found that children with neurological diagnoses accounted for 15.3% of all inpatients and 17.7% of all inpatient admission episodes. It is not clear whether day case patients were included in this study or not which may account for the difference[5]. The increasing use of resources by children with neurological conditions mirrors that of the US study which assessed trends[1]. These trends are important in terms both of recruitment and retention of clinical paediatric neurological specialists but also in terms of designing services.

The commonest diagnoses were epilepsy (26%) and cerebral palsy (14%). Again these are similar to those identified by the US study[1], but the London study found that children with genetic, chromosomal and syndromic conditions had the highest number of hospital admissions followed by children with epilepsy[5]. There is some evidence that cerebral palsy prevalence is increasing in the UK[19] which would fit with our results. However, there is evidence that, within primary care in the UK, the incidence of epilepsy in children is decreasing over time[20]. Our results may therefore be showing that GPs are not involved in the care of children with epilepsy or that families simply bypass GPs straight to hospital.

It is unfortunately not possible within the HES data to make any assessment of changes in severity of these neurological conditions over time. The coded data included in the HES data did not allow us to assign these admissions as avoidable or not, nor assess whether they could have been managed by primary care or other community services. However some non-emergency day-case admissions may have the potential to be treated in the non-acute hospital setting – there is some evidence that hospital admissions can be reduced through care plans[21]. There may also be variations over time in clinical coding, with incentives to more accurately record neurological comorbidities (this is supported by the increasing proportion of all admissions that include a neurological diagnosis, but the static proportion that have a primary neurological diagnosis). However, as the survival of these children improves over time due to increasing use of medical technologies and aggressive treatment of complications, these results may demonstrate a genuine increase in admissions for comorbid conditions.

There were large differences by age group, with <1 year olds having admissions lasting 1.9 times as long as 5 to 9 year olds and having over twice as many bed days per year. Older children and young people also had longer stays (24% longer and 39% longer for 10-14 and 15-19 year olds compared to 5-9 year olds) and more bed days per year (13% more and 22% more for 10-14 and 15-19 year olds respectively compared to 5-9 year olds). These differences may reflect disease progression in older children and young people and increased severity or risk of complications in the very young (extremely premature babies commonly have neurological conditions)[22].

The different patterns of healthcare usage by children and young people with different underlying conditions are to be expected. For example, multiple day-case stays but higher numbers of bed days over the year would be expected in a child receiving treatment for a malignant CNS tumour.

The variations seen by ethnicity are more difficult to explain. Many non-white ethnic groups had higher numbers of bed-days than the white population (at $p < 0.01$, although effect sizes were small at 2-4%). These may be explained by different conditions between ethnic groups (within the broad diagnostic groups used in the model) or differences in severity within the same condition (which are not reflected in the data used). They may also represent different health seeking behaviours. Interestingly these results differ from a previous study in the UK in which South Asian children were more likely to use GP services but less likely to use hospital services than white children[23]. Changes in primary and secondary healthcare in the England in the intervening time period could partly explain these differences.

There is variation with deprivation for both length of stay and bed days – the least deprived have shorter stays (3% shorter for least deprived compared to most deprived group) and fewer bed days per year (2% lower for least deprived compared to most deprived group). This may be due to variations in healthcare provision and practices in different geographical areas or may be linked to different conditions within different deprivation categories. The differences are small for individuals, but larger when aggregated. For example, if bed days per person per year for the most deprived could be reduced to the level of the least deprived, the model suggests over 31 thousand bed days (over 84 bed years) could have been saved over the study period.

There are also geographical differences, with length of stay up to 21% longer (Yorkshire & Humber, East Midlands, West Midlands and South East) than the reference region (North West). The East Midlands also had 5% more bed days per person per year than the North West. There may be geographical variation in conditions (within the diagnostic groups included in the model). There may be differences in outreach or other community services affecting decisions on when to admit to hospital and when to discharge. While the observed geographical differences may not be clinically significant at the individual level, at the population level they represent larger variations in hospital use. For example, if the bed days per person per year in the East Midlands were reduced to the level of the North West then the model suggests over 17,000 bed days (over 47 bed years) could have been saved over the study period.

Strengths and limitations

This study utilised routinely collected, national level health-care data. The coding framework was developed with a consultant paediatric neurologist, but the ICD10 coding system does not always provide sufficient granularity to isolate all diagnoses. For the analyses, diagnoses have been grouped by ICD10 chapter, but diagnoses within a chapter may have very different care needs, affecting length of stay and bed days per year.

Missing data are few for most variables, but recording of ethnic group is poor in earlier years, of possible concern for the results regarding ethnicity. A sensitivity analysis was performed (supplementary Table S3), repeating the length of stay and bed day models only for data from 2009/10 to 2014/15 where ethnicity data were more complete ($\leq$2.1% missing). This supports the observation that non-White groups had similar or more bed days per person per year than White individuals. The HES data are provided by individual care providers and there are concerns about the accuracy of clinical coding and variations between suppliers[24]. Linkage between datasets is also imperfect[25]. It is possible that this may have an impact on variations observed over time or between geographical areas. Further, increasing use of electronic health records and changes in numbers of diagnoses recorded may explain some of the increase in bed days for individuals with neurology diagnoses observed over the study period. Individuals were only known to have died if they died in hospital. This may have some impact on the modelling of bed days as time at risk may be overestimated for those who died out of hospital.

Conclusions

Neurological conditions account for significant and growing share of inpatient bed days for 0-14 year olds in England. Reductions in length of stay and bed days per person are more than offset by increasing numbers of CYP with neurological diagnoses. Length of stay and bed days per year vary by diagnostic group, ethnic group, age group, deprivation category and by region. These variations should be taken into account in future resource planning for this growing hospital population.

Acknowledgements

Statement on conflicts of interest

The authors declare that they do not have any conflicts of interest.

Supplementary Appendices

1. Coding framework for neurological conditions

2. Supplementary results

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Abbreviations

A&E	Accident and Emergency
APC	Admitted Patient Care
BIC	Bayesian Information Criterion
CNS	Central nervous system
FCE	Finished consultant episode
GOR	Government Office Region
HES	Hospital Episode Statistics
HESID	Hospital Episode Statistics Identifier
ICU	intensive care unit
ICD10	International Classification of Diseases, 10th Edition
IMD2004	Index of Multiple Deprivation 2004
IRR	Incidence rate ratio