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Title

Requirements for and current provision of rehabilitation services for children after severe acquired brain injury in the UK: a population-based study

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Abbreviations

ABI	Acquired Brain Injury
CP	Cerebral Palsy
HES	Hospital Episode Statistics
ICD-10	International Classification of Disease, 10th edition
LOS	Length of stay
NHS	(UK) National Health Service
PICU	Paediatric Intensive Care Unit
PSABIR	Probable episode of severe Acquired Brain Injury requiring Rehabilitation (see text)

Abstract

Objectives

Survival with brain injury is an outcome of severe illness that may be becoming more common. Provision for children in this situation has received little attention. We sought to estimate rates of severe paediatric Acquired Brain Injury (ABI) requiring rehabilitation and to describe current provision of services for these children in the UK

Methods

Analysis of Hospital Episode Statistics data between April 2003 and March 2012; supplemented by a UK provider survey completed in 2015. A Probable Severe ABI Requiring Rehabilitation (PSABIR) event was inferred from the co-occurrence of a medical condition likely to cause ABI (such as meningitis) and a prolonged inpatient stay (>= 28 days).

Results

During the period studied, 4508 children aged 1-18 years in England had PSABIRs. Trauma was the most common cause (30%) followed by brain tumours (19%) and anoxia (18.3%). An excess in older males was attributable to trauma. We estimate the incidence of PSABIR to be at least 2.93 (95% confidence interval 2.62-3.26) per 100,000 young people (1-18 years) pa. The provider survey confirmed marked geographic variability in the organisation of services in the UK.

Conclusions

There are at least 350 Probable Severe ABI Requiring Rehabilitation events in children in the UK annually, a health problem of similar magnitude to that of cerebral palsy. Service provision for this population varies widely around the UK, in contrast with the nationally-coordinated approach to paediatric intensive care and major trauma provision.

What is known about this topic

- Survival with significant acquired brain injury is an increasingly common outcome of severe acute illness that would previously have been fatal

- Except for the most severely disabled children, life-expectancy after ABI is near-normal, making a strong health-economic case for early effective rehabilitation

- In contrast to adult rehabilitation services, systematic specification and provision of paediatric rehabilitation has received little attention in the UK

What this paper adds

- Survival with severe ABI is a problem of comparable magnitude to the incidence of cerebral palsy

- Much provision for the early rehabilitation of children with severe ABI has arisen in an *ad hoc*, reactive manner

- There is significant national variation in the organisation and delivery of rehabilitation services after paediatric ABI

Introduction

The term Acquired Brain Injury (ABI) refers to brain injury sustained after a period of normal health and development. In adults, traumatic brain injury (e.g. due to motor vehicle accidents, falls, and in some contexts, blast and gunshot injury) and stroke dominate as the major causes in younger and older age groups respectively (1,2). Although survival from traumatic brain injury is increasing with advances in pre-hospital care (3) the possibility of increased poor-quality survival remains. The situation is similar in children: although efforts at the primary prevention of traumatic brain injury appear to be effective(4), paediatric intensive care unit (PICU) admission rates and case-mix severity are increasing and crude mortality is falling(5). One might expect this to result in increased rates of morbidity, including neurological morbidity, in PICU survivors. In one study 26% of previously healthy survivors of paediatric intensive care admission for severe illness acquired significant new neurological disability (6). There has been growing recognition that the needs of these children may not be well addressed by existing community special-education and health services that evolved to meet the needs of the historically larger group of children with disabilities present from birth (e.g. children with cerebral palsy) (7).

Following the generally disappointing impact of neuroprotective therapies that it was hoped would limit the early deleterious neurochemical consequences of brain injury (8,9), the mainstay of the clinical response to severe ABI remains rehabilitation – i.e. health services that try to promote recovery after ABI through guided practice and re-learning; that compensate for any new changes in ability; and that help child and family to adapt to loss and change. The higher incidence of adult ABI

(particularly adult stroke) has driven the organization and delivery of specialist adult rehabilitation services (10-12). In contrast the provision of rehabilitation services for children after ABI (certainly in the UK) has received much less attention and provision has evolved reactively. The location of a single large third-sector provider of residential rehabilitation services for children in Surrey (south east England) suggests the possibility of significant regional differences in rehabilitation provision. Although data on incidence of conditions *potentially* causing ABI and disability in children (such as motor vehicle accidents, meningitis, stroke and tumours) are available (13-16) there are few data on morbidity (i.e. rates of survival with significant disability) and thus population needs for rehabilitation in children.

The aims of this study were to provide two pre-requisites for informed specification of specialist rehabilitation services for children in the UK: data on population needs, and a clear picture of current provision.

Methods

Identification of Probable Severe ABI requiring Rehabilitation events in children.

We used anonymised, individual patient-level Hospital Episode Statistic (HES) data from the English Health and Social Care Information Centre (HSCIC, now NHS Digital) (17), which provides ICD-10 diagnostic codes for inpatient admissions, to infer "Probable Severe ABI Requiring Rehabilitation" (PSABIR) events. This was necessary because ICD-10 does not provide specific codes either for generic ABI as a diagnosis, nor for provision of rehabilitation as a healthcare procedure. The occurrence of a PSABIR event was inferred from the co-occurrence of one or more ICD-10 codes from a pre-defined list of primary diagnoses that could potentially cause brain injury (such as various forms of meningitis, motor vehicle accidents, falls, tumours and stroke, listed in full in Supplementary Table S1) *and* a prolonged inpatient stay of >=28 days. ICD-10 codes were grouped into broad aetiological categories: trauma, tumour, anoxia, infection (meningitis or encephalitis), vascular insults (stroke), metabolic, toxic and other insults. The inpatient stay threshold was set at >=28 days on the basis that (with the possible exception of children with brain tumours, see Discussion) the narrowly-defined medical treatment of most of the conditions listed in Table S1 (such as the antibiotic treatment necessary for meningitis) should be completed by then. Extended admission may therefore reflect other factors delaying discharge such as need for rehabilitation and/or an inability to return to the family home without adaptations, both of which imply significant ABI. As a secondary analysis of fully anonymised data previously collected in the course of normal care, formal NHS Research Ethics review was not required. The data sharing was approved by HSCIC (now NHS Digital).

Data were obtained for 9 annual data periods (2003-4 through 2011-12) for all paediatric admissions (aged 1-18 years at admission) with one or more of the pre-specified ICD-10 codes (Table S1) in any of the first three (of 19 available) diagnosis code fields in the HES data. The ICD-10 code list was adapted from the list of all ICD-10 codes in children identified as sustaining ABI in a long-established diagnostic database maintained by RF in the Department of Paediatric Neurology, Royal Victoria Infirmary, Newcastle upon Tyne (see Discussion). A "hospital episode" represents a period of care under one treating Consultant (equivalent to a North American "Attending Physician"). Several episodes may occur sequentially and together are known as a "spell" that ends with discharge out of the UK National Health Service (NHS), or death. Each episode record contains an anonymizing, but unique patient identifier that allows record linkage between episodes under different consultants and/or in different hospitals and thus the identification of intra- and inter-hospital transfers occurring as part of a single spell. Data were also available for age; sex; ethnicity; first 4 characters of postcode; socioeconomic deprivation as measured by the postcode-derived Index of Multiple Deprivation (IMD) (18); date, method and source of admission; date and destination of discharge; and a code identifying the NHS or other unit where admitted.

Duplicate records and records with inconsistent date information were removed. It was recognised that brief home stays during phased discharges occurring as part of rehabilitative community integration might result in the erroneous recording of the end of a spell. To account for this, episodes separated by an interval of less than 5 days were consolidated and considered a single episode. Thus PSABIR events were defined as admissions with pertinent ICD-10 codes (table S1) and a consolidated hospital length of stay (LOS) of >= 28 days.

Analyses were performed using SPSS (version 22) and R (19). Data are summarised using means, medians and proportions, as appropriate. PSABIRs are presented as numbers and rates per 100,000 with 95% confidence intervals. Census data for England provided age and sex specific population denominator estimates. Chi-square tests were used to examine the relationship between patient characteristics (ethnicity, region of residence and Index of Multiple Deprivation) for the PSABIR subset compared to all admissions with conditions listed in Table S1. Logistic regression was used to examine the relationship between discharge to a non-NHS facility and patient characteristics.

Survey of units providing paediatric rehabilitation

To understand the current picture of provision of rehabilitation services, UK hospitals with designated Paediatric Intensive Care Units (PICUs) were identified from data provided by the UK Paediatric Intensive Care Audit Network (www.picanet.org.uk). Clinical leads for the rehabilitation services at each centre were identified and they, or nominated deputies were asked to provide data about local rehabilitation provision via an online survey. Questions addressed service configuration and settings, staffing levels, the nature and limits of services provided, and patterns of referral on to other providers. Non-responders received up to three reminder emails or telephone calls. The survey was conducted over a period of four months between June and September 2015.

Results

HES data

A total of 204,863 admission episodes to NHS hospitals in England were identified in children aged 1-18 years at the start of an admission that began between 1 April 2003 and 31 March 2012, and with a Table S1 ICD-10 diagnosis in one or more of the first three diagnosis fields in the HES record. These represented 70,500 individual patients. Of these, 4,508 children (6.4%) met our operational definition of having a PSABIR event (relevant ICD-10 code with a hospital LOS >= 28 days). The proportion of admitted individuals with >=28 day LOS varied for each aetiology were: other, 2.6%; toxic, 2.7%; encephalitis, 4.7%; anoxic, 4.8%; trauma, 5.5%; meningitis, 7.5%; metabolic, 11.1%; vascular, 14.8% and tumour 16.2%. 3894/4508 (86%) of patients had more than one admission recorded (Figure 1). Characteristics of patients admitted with a PSABIR during the study period are summarised in Table 1. Almost half of the PSABIR episodes occurred in children admitted from areas within the two most deprived quintiles of Index of Multiple Deprivation (IMD).

INSERT FIGURE 1 ABOUT HERE

Analysis of ethnicity associations between the PSABIR subset and the 70,500 children of the full dataset were complicated by high rates of missing data for ethnicity in the full dataset (62%). If we assume this data is missing at random, children of black, mixed race or other ethnicity were over-represented (combined proportion 7.6% vs. 5.9%) and children of white ethnicity under-represented (55.4% vs 57.6%) in the PSABIR subset.

INSERT TABLE 1 ABOUT HERE

INSERT TABLE 2 ABOUT HERE

Table 2 shows PSABIR events grouped by aetiological category. Trauma was the most common cause, accounting for 30% of all events, followed by brain tumour (19.2%) and anoxia (18.3%). An excess of PSABIR events in males (mean number of events 5.25 [95% CI 4.66, 5.87] per 100,000 *vs* 3.71 [3.23, 4.27] per 100,000 per year in females; $p < 0.001$) was attributable to trauma in adolescent males (Figure 2). When trauma was excluded, PSABIR event rates were 3.31 [2.86, 3.82] in males and 2.96 [2.54, 3.48] in females ($p = 0.342$). PSABIR rates were high in children aged between 12 and 24 months (see Figure 2, and Discussion). PSABIR rates excluding children under 24 months of age at admission were 4.26 [3.87, 4.67] (2.85 [2.54, 3.20] excluding trauma).

INSERT FIGURE 2 ABOUT HERE

Median length of stay for PSABIR cases (recalling that by definition this excludes admissions shorter than 28 days) was 48.0 days (interquartile range 35-79 days). Unexpectedly, rates of PSABIR declined from 5.35 [4.93, 5.80] in 2003-4 to 2.93 [2.62, 3.26] in 2011-12 (*p* for trend <0.001). This decline was seen across all etiological groups except stroke and encephalitis where rates stayed relatively constant (Supplementary Table S2). PSABIR events as a proportion of all admissions (i.e. the fraction of all admissions with pertinent ICD-10 codes that were >= 28 days long) fell markedly during the study period from 15.6% in 2003-4 to 0.64% in 2011-12 (see Discussion).

Almost three-quarters (72%) of children with a PSABIR event were admitted to a tertiary centre (defined as a centre with a PICU) at some point in their spell. Of these, 86% were directly admitted to the tertiary centre. 11% were initially admitted to a district hospital, with later transfer to a tertiary centre. The remaining 3% initially presented to other services, including mental health services and primary care (Table 3). There was evidence of a secular trend toward increased centralisation of care with the proportion of children admitted to a tertiary centre increasing from 65.2% in 2003-4 to 77.5% in 2011-12 ($p < 0.001$). For traumatic PSABIR events the figures were 48.5% admitted to a tertiary centre in 2003-4 *vs* 67.6% in 2011-12 ($p = 0.006$) and, for the remaining non-traumatic PSABIR events, the figures were 71.5% and 81.3% ($p < 0.001$) respectively. Patients admitted to a tertiary centre had slightly, but significantly, shorter median stay in hospital than those who were never admitted to a tertiary centre (47 nights vs 50 nights; $p = 0.005$).

INSERT TABLE 3 ABOUT HERE

The first recorded discharge for patients admitted to a tertiary centre was to their usual place of residence for 52% and to another NHS hospital for 45% (Table 3), although rates of discharge direct to home varied widely between tertiary centres from 27% to 80%. The figures for patients who were never admitted to a tertiary centre were 48% and 47% respectively. Approximately 4% of patients were discharged to a non-NHS hospital or hospice, either at their first or final discharge. The final discharge destination recorded for patients by the end of the study period was home for 85% of

patients (83% for patients never admitted to a tertiary centre) and to another NHS hospital for 6% (9% of patients never admitted to a tertiary centre).

We examined factors associated with discharge to a non-NHS hospital by multivariable logistic regression. Region of residence and length of stay, but not ethnicity or age, were significantly associated with discharge to a non-NHS hospital: in particular, 3.4% of children from south east England were discharged to non-NHS hospitals (c.f. 0.8% in northern England). Children discharged to a non-NHS hospital had a longer initial NHS admission on average (median length of stay 79 nights compared to 48 nights; $p<0.001$) suggesting more severe injuries. A higher proportion of those discharged to non-NHS hospitals had a diagnosis of anoxia or trauma (aetiologies known to be associated with more prolonged recoveries, see Discussion) and fewer had meningitis or vascular insults. An excess of males being discharged to a non-NHS hospital was again due to the association with trauma (OR 1.64, 95% CI 1.16, 2.22). Increasing IMD quintile (indicating higher deprivation) was associated with reduced likelihood of discharge to a non-NHS hospital (OR 0.88, 95% CI 0.79, 0.98). In PSABIR children in south east England admitted to non-NHS hospitals, 33% were in the highest (least deprived) quintile vs 12.3% in the rest of the country ($p <0.001$) and a lower proportion in the lowest (most deprived) quintile (8.6 vs 33.1%, $p <0.001$).

Provider Survey

Thirty-one units in England, Scotland and Wales were invited to participate in the provider survey. Two units declined to provide data stating that they referred children to other providers for rehabilitation. Twenty-six responses were received from NHS tertiary centres. There were three responses from stand-alone paediatric rehabilitation units. Two based in south east England provide rehabilitation services to the NHS: one of these is a large third-sector provider (The Children's Trust, see Discussion). There was one response from a private provider based in London. Table 4 summarises the characteristics of units included in the survey. All provision outside the South East was based in tertiary acute hospitals, generally co-located with paediatric intensive care and paediatric neurosurgery and almost all in designated Major Trauma centres. Only units based in London and the South East responded that they did not serve a clearly defined geographical area.

INSERT TABLE 4 ABOUT HERE

A minority of the tertiary centres (6/26) indicated that they had designated paediatric rehabilitation beds. Common factors cited as prolonging inpatient lengths of stay were: lack of options for "step down" rehabilitation in district hospitals closer to home, inability of existing generic community paediatric therapy services to provide necessary intensity of rehabilitation, and need for home adaptations prior to discharge. Most centres accepted referrals irrespective of the aetiology of the child's ABI. Most units would not accept individuals over 16 years of age. Many providers commented on the challenge of providing rehabilitation services in acute hospital settings. This was particularly true of providing services for children with behavioural difficulties. Access to specific professional disciplines (e.g. psychology/neuropsychology and speech and language therapy) was an issue for some units.

Discussion

This paper describes the population needs for rehabilitation after severe paediatric ABI, and presents important findings on aspects of current provision for this patient group. We confirm a conservative estimate of the rate of PSABIR events at a rate of approximately 3 per 100,000 young people (1-18 years old) per annum, suggesting approximately 350 new events annually in the UK. Strengths of the study include the completeness of the health-care activity picture captured by the NHS Hospital Episode Statistics system, and that of the responses to the Provider Survey. The main limitation of this study is the use of Length of Stay (LOS) as a proxy for the occurrence of a significant ABI with early rehabilitation needs, necessary because Hospital Episode Statistics data neither capture "acquisition of significant brain injury" as a diagnosis, nor rehabilitation as a care procedure. The assumption that prolonged admission necessarily reflects ongoing rehabilitation needs alone is likely to be weakest for children with brain tumours. Although they are indeed at high risk of acquiring neurological deficits as a result of the tumour or its resection and thus are very likely to need rehabilitation, they may also be receiving continuing inpatient chemotherapy. Even though such admissions may be brief they may be frequent and captured by our decision to consolidate admission episodes separated by <5 days. Unsurprisingly, brain tumour children had the highest total numbers of admissions.

It is very important to appreciate that these PSABIR events represent only the extreme tip of the ABI severity pyramid, and a small proportion of total post-ABI morbidity. It is well recognised that paediatric ABI can result in "walking wounded" patterns of reasonable motor recovery but poor

social, educational and vocational outcomes(20), the impact of the latter tending to become increasingly evident with time(21). Such patterns are seen with ABI of different aetiologies including trauma(22,23), tumours(16) and infection(24); and can lead to erroneously sanguine beliefs about outcome after ABI at young ages(25,26). This morbidity will be severely under-represented in this PSABIR data which represent only those children requiring access to early inpatient rehabilitation services for predominantly motor impairments.

The Provider Survey confirms that a need for an intensity of rehabilitative therapy that cannot be met in community settings, and/or a need for new home adaptations (implying major new mobility and self-care needs) are important reasons for delayed discharge. However LOS is subject to other confounding factors that may also underlie the unexpected decline in PSABIR events between 2003-4 and 2011-12 that was identified. Although it is possible that this is a genuine decrease in PSABIR rates for example due to improvements in primary prevention of head trauma from road traffic accidents(4), crude mortality in UK intensive care units has fallen from 5.3% to 3.7% whilst overall admissions and case-mix severity have somewhat increased over the period covered by these data (5). We had hypothesised this would lead to increasing PSABIR event rates. However other secular trends evident in our data (such as the increasing centralisation of care with a rising proportion of PSABIR events being managed in tertiary centres) and particularly the marked fall in the fraction of PSABIR events as a proportion of all admissions (i.e. the fraction of all admissions with pertinent ICD-10 codes that were $\geq$ 28 days long) from 15.6% in 2003-4 to 0.64% in 2011-12 suggest that this apparent decline in PSABIR rates is in part artefactual: for example increasing service efficiency pressures over the decade may have led to more prompt discharge of less severely injured children where at all possible. The fraction of PSABIR events as a proportion of all admissions stabilised at ~1% from 2009 onwards, equivalent to a rate of 2.93 [2.62, 3.26] per 100,000 children and young people

between 1 and 18 years of age or approximately 350 children in the UK per annum) and we believe this is a robust, conservative estimate of the number of PSABIR events. The corresponding rate for the young people aged 1-16 is 3.6 per 100,000 (4.4 for males and 3.3 for females). We considered other factors that might confound PSABIR estimates. Children sustaining severe ABI at an older age are more likely to need home adaptations (by virtue of their size) than very young children (who remain portable) which might delay discharge leading to longer LOS. However, there was evidence of higher PSABIR rates in the over 16s only (Table 1). The reason for the slight but statistically significantly decreased PSABIR rate in children of white ethnicity (and conversely slightly higher rates in black, mixed raced and other ethnicity children) is unclear.

Comparison with published literature is difficult because most reports are of incidence of conditions with the potential to cause significant brain injury, sometimes qualified by severity or severity proxies, rather than actual morbidity rates. Chan et al (27) have recently published a study similar to ours, obtaining its data from (Canadian) hospital admission statistics identified by pertinent ICD-10 codes, although they studied non-traumatic ABI only. Their data are consistent in reporting an overall admission rate for illnesses capable of causing (non-traumatic) ABI of 82.3 per 100,000 admissions (0-19 years of age), with 28% having a hospital LOS > 12 days (the highest LOS threshold subgroup they report). Other estimations of PSABIR rates can be extrapolated from the literature. The rate of admission to UK PICU with traumatic brain injury is 5.6/100,000 (28). In a US cohort of PICU survivors 22% were discharged from acute care to a rehabilitation facility (29) suggesting about 1.2/100,000 PSABIRs of traumatic origin. For non-traumatic coma (i.e. infection, toxic, metabolic and other insults) we have previously estimated an incidence of 6/100,000 (14) and a very conservative rate of survival with new disability of 7% (30) (i.e. about 0.4/100,000 PSABIRs of non-traumatic origin). Extrapolation of Scandinavian data (31) suggests approximately an additional

1.2/100,000 children sustaining PSABIRs as a result of brain tumours and their treatment. Together these total 2.8/100,000 PSABIRs, a figure that excludes stroke. Incidence of paediatric arterial ischaemic stroke in the UK has recently been calculated as 1.6/100,000 annually.(15): this figure excludes brain haemorrhage as a cause of stroke, and does not provide any data on need for early rehabilitation.

Recent Dutch data (32) report a combined incidence for "severe" traumatic and non-traumatic brain injury of 3.6 per 100,000 children under 14 years of age per annum with an additional 9.5 per 100,000 per annum in the 15-24 years age range. Over 80% of those in the group aged 15 years and older was attributable to *traumatic* brain injury, again predominantly in older male adolescents with access to motor vehicles (as drivers or passengers), a trend that is partially supported by our data (Figure 2).

High rates of traumatic brain injury in those aged 16-18 years highlights the importance of provision for this group. The HES dataset used in this study included young people up to the age of 18 years at admission, irrespective of whether they were admitted to adult or paediatric services. In our Provider Survey, 12 of 29 centres reported that age over 16 years would "often" or "always" be a contraindication to admission to their (paediatric) service; with 26 of 29 responding thus for age over 18 years. Decisions as to whether young people between 16 and 18 years enter paediatric or adult pathways are often taken "upstream" of the rehabilitation phase (e.g. tending to be determined by whether first admitted to paediatric or adult intensive care) but this represents an important group who are probably not well served by typical adult or paediatric service models.

Historically, the large majority of children with neurological disabilities acquired these before or at around birth. Such children are described as having cerebral palsy (CP). Both CP and ABI have a

wide variety of causes. The justification for grouping these heterogeneous children is in each case an operational one in that, irrespective of cause, these groups of children have similar needs. Our conservative estimate of at least 350 of the severest ABIs per year in the UK suggests a health need of comparable magnitude to the ~1300 new diagnoses annually of CP of any, including the mildest, severity (33). Most authorities would also use the term CP to include children sustaining early post-natal injury. The age at injury beyond which one should consider a child to have ABI rather than CP is not well defined. Some epidemiological studies of CP have used age at injury limits of up to 24 months (34,35). We have included children between 12 and 24 months at admission in our PSABIR figures (Figure 2). Beyond this age the fact of a significant period of normal development prior to injury begins to have important neurobiological, and service provision implications. It is easier to re-learn a previously-acquired behaviour after injury than to acquire a not-yet-learned skill in the presence of injury (36,37). This means that greater expectations of at least partial recovery of function in the weeks and months after injury after ABI than CP are realistic, and put a premium on prompt, expert provision of adequate rehabilitative therapy services (38). Whilst the universal health and education services for children with CP and other disabilities of developmental origin have potential as a foundation for services for children with ABI, they need to adapt to meet the particular needs of the latter group (7). High quality rehabilitation services are necessary to follow-through on investments in acute care (12). The cost-effectiveness of rehabilitation after severe ABI has been demonstrated in adults (11) but not yet in children. Given that, except after the most severe injuries, life expectancy after paediatric ABI is near-normal (39) one might anticipate the economic case for paediatric rehabilitation to be even stronger given the remaining life-years over which to recoup gains: even more so as the full effects of paediatric ABI can take time to fully manifest, resulting in under-attribution of late morbidity to paediatric ABI (7).

Given these strong arguments for paediatric neurorehabilitation our data give cause for concern in highlighting national variation in provision that contrasts with a nationally-consistent system for paediatric intensive care and major trauma provision. It is clear from the Provider Survey that approaches to the provision of rehabilitation in the South East differ markedly to the rest of the country (Table 4). Our data also show that rates of discharge to non-NHS care were higher and PSABIR rates (which reflect NHS stays only) were lower in SE England than elsewhere. Although data-confidentiality considerations prevented independent confirmation of this we presume these findings partially reflect transfers to The Children's Trust, the large third-sector provider of inpatient rehabilitation services located in Surrey. A higher proportion of those discharged to non-NHS hospitals had a diagnosis of anoxia or trauma and fewer had meningitis or vascular insult which is consistent with poorer recoveries (38), and with what is known about admissions to the Children's Trust (38). The fact that social deprivation (reflected by IMD quintile) appears to be a barrier to discharge to non-NHS facilities suggests health inequities in access, at least during the period of study 2003-2012.

Our Provider Survey confirmed that away from the south east of England, the majority of neurorehabilitation for children currently (2015) takes place on a non-commissioned basis, often in general-purpose wards, in the same tertiary hospital as the PICU. Only 6 of 29 units had designated paediatric rehabilitation beds. Only 12 units routinely collate functional outcome data which is a central part of rehabilitation assessment and management. Conversely however, such co-location allows rehabilitation to begin at an early stage and to be incorporated in acute care rather than being deferred until transfer to a separate provider. Whether such differences in service delivery result in differences in severity-adjusted outcome are currently unclear but the situation lends itself to a natural experiment design to explore these issues. There is an urgent need to nationally review and harmonise provision for paediatric neuro-rehabilitation in both the acute and sub-acute phases.

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Authors' contributions

RF conceived the study, secured funding and wrote the first draft of the paper. LH analysed the HES data and contributed to the article. SS oversaw the Provider Survey and contributed to the article. MP supervised HES data analysis and contributed to the article. RF is guarantor of the article. All authors read and approved the final manuscript.

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Tables

Table 1. Characteristics of children admitted to a hospital in England for a period of at least 28 days with an ICD10 diagnosis code indicating a potential serious ABI requiring rehabilitation (PSABIR) between 1 April 2003 and 31 March 2012

	Males (n=2694)		Females (n=1814)		All (n=4508)	
	n	(%)	n	(%)	n	(%)
Age (years)						
Pre-school (1-4)	663	(24.6)	545	(30.0)	1208	(26.8)
Primary school (5-10)*(-)	526	(19.5)	345	(19.0)	871	(19.3)
Secondary school (11-16)	887	(32.9)	638	(35.2)	1525	(33.8)
16-18*(+)	618	(22.9)	286	(15.8)	904	(20.1)
Ethnicity						
White*(-)	1479	(54.9)	1019	(56.2)	2497	(55.4)
Asian	151	(5.6)	110	(6.1)	261	(5.8)
Black*(+)	103	(3.8)	74	(4.1)	177	(3.9)
Chinese	5	(0.2)	10	(0.6)	15	(0.3)
Mixed race*(+)	40	(1.5)	36	(2.0)	76	(1.7)
Other*(+)	62	(2.3)	29	(1.6)	91	(2.0)
Not known	395	(14.7)	252	(13.9)	647	(14.4)
Not stated	460	(17.1)	284	(15.7)	744	(16.5)
Region						
North East & Cumbria	151	(5.7)	104	(5.8)	255	(5.8)
North West*(+)	439	(16.7)	301	(16.9)	740	(16.7)
Yorkshire & Humber	289	(11.0)	175	(9.8)	464	(10.5)
East Midlands	220	(8.4)	141	(7.9)	361	(8.2)
West Midlands	255	(9.7)	173	(9.7)	428	(9.7)
East of England	135	(5.1)	128	(7.2)	263	(6.0)
South East*(-)	361	(13.7)	219	(12.3)	580	(13.1)
South West	299	(11.4)	182	(10.2)	481	(10.9)
London*(+)	452	(17.2)	344	(19.3)	796	(18.0)
Other*(+)	32	(1.3)	19	(1.1)	51	(1.1)
IMD quintile						
1 (most affluent)*(-)	354	(13.7)	302	(17.2)	656	(15.1)
2	436	(16. 8)	250	(14.2)	686	(15.8)
3	491	(18.9)	344	(19.6)	835	(19.2)
4	548	(21.1)	326	(18.6)	874	(20.1)
5 (most deprived)*(+)	763	(29.4)	535	(30.4)	1298	(29.8)

Ethnicity – 'not stated'=person declined to provide the information; 'not known'=person not asked
Region= based on home address; 'other' included Scotland, Wales, Ireland, The Channel Isles and Isle of Man

* Indicates that there is a statistically significant difference ($p<0.05$) between those with a PSABIR and all children admitted with an ABI. A (+) indicates that the proportion in the PSABIR group was higher; a (-) that it was lower.

Table 2. Aetiologies of episodes of probable severe ABI requiring rehabilitation by sex (1 April 2003 to 31 March 2012)

	Males		Females	
	n	%	N	%
Trauma	996	(37.0)	367	(20.2)
Brain tumour	473	(17.6)	393	(21.7)
Anoxia	419	(15.6)	407	(22.4)
Meningitis	353	(13.1)	249	(13.7)
Vascular insults	203	(7.5)	154	(8.5)
Encephalitis	116	(4.3)	125	(6.9)
Metabolic encephalopathy	28	(1.0)	30	(1.7)
Other brain injury	22	(0.8)	26	(1.4)
Toxicity	84	(3.1)	63	(3.5)
Total	**2694**		**1814**	

Table 3. Origin and disposition of children with probable severe ABI requiring rehabilitation events.

	At least one episode in tertiary centre (n=3149)		**No contact with tertiary centre (n=1229)**	
	n	(%)	n	(%)
Site of initial presentation[1]				
Tertiary centre	2704	(85.9)	-	-
Other (secondary) hospital	348	(11.1)	991	(80.6)
Mental health services	2	(0.1)	18	(1.5)
Community services	4	(0.1)	12	(1.0)
Primary care	32	(1.0)	38	(3.1)
Other	59	(1.9)	170	(13.8)
Initial discharge destination[2]				
Home/usual place of residence	1383	(52.3)	506	(47.9)
Temporary accommodation	25	(0.9)	11	(1.0)
Penal establishment	-	-	1	(0.1)
NHS hospital	1180	(44.7)	497	(47.1)
Local Authority care	7	(0.3)	8	(0.8)
Died	21	(0.8)	13	(1.2)
Non-NHS care	26	(1.0)	20	(1.9)
Final discharge destination[3]				
Home/usual place of residence	2613	(85.2)	987	(82.8)
Temporary accommodation	27	(0.9)	19	(1.6)
Penal establishment	1	(0.03)	1	(0.1)
NHS hospital	198	(6.3)	110	(8.6)
Local Authority care	10	(0.3)	6	(0.5)
Died	162	(5.3)	41	(3.4)
Non-NHS care	55	(1.8)	28	(2.3)
	Median	IQR	Median	IQR
Length of stay	47	(35, 77)	50	(36, 84)

[1]Data on place of initial admission available for 4378; [2] Data on initial discharge available for 3698; [3] Data on final discharge available for 4258

Table 4. Descriptive characteristics of the units that responded to survey

Region	**Located in designated Major Trauma Centre**		**Unit context***		**Defined population served**		**Services on site**					**Longest journey time by road (hours)**
							PICU	**Major trauma centre (paediatric)**	**Paediatric neuro-surgery**	**Paediatric neuro-oncology**	**Paediatric cardiac unit**	
		n (%)		n (%)		n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	Median (IQR)
London (n=8)	Yes	4 (50)	Standalone	-	Yes	4 (50)	8 (100)	3 (38)	4 (50)	4 (50)	3 (38)	2.25 (1.88, 4.75)
	No	4 (50)	Tertiary	6 (75)	No	4 (50)						
South of England (n=4)	Yes	2 (50)	Standalone	2 (50)	Yes	2 (50)	2 (50)	2 (50)	2 (50)	2 (50)	2 (50)	3.75 (2.0, 6.63)
	No	2 (50)	Tertiary	1 (25)	No	2 (50)						
Midlands and East of England (n=6)	Yes	4 (67)	Standalone	-	Yes	6 (100)	6 (100)	5 (83)	4 (67)	5 (83)	2 (33)	2.0 (1.25, 2.73)
	No	2 (33)	Tertiary	5 (83)	No	-						
North of England (n=6)	Yes	6 (100)	Standalone	-	Yes	6 (100)	6 (100)	6 (100)	6 (100)	5 (83)	3 (50)	2.25 (1.15, 3.0)
	No	-	Tertiary	5 (83)	No	-						
Wales (n=1)	Yes	1 (100)	Standalone	-	Yes	1 (100)	1 (100)	1 (100)	1 (100)	1 (100)	1 (100)	1.0
	No	-	Tertiary	1 (100)	No							
Scotland (n=4)	Yes	4 (100)	Standalone	-	Yes	4 (100)	3 (75)	2 (50)	4 (100)	4 (100)	1 (25)	2.5 (2.0, 3.75)
	No	-	Tertiary	3 (75)	No							

*6 units reported 'other' for unit context.

Legends to Figures

Figure 1. Individuals aged 1-18 years admitted to a hospital in England for a period of at least 28 days with an ICD10 diagnosis code indicating an ABI between 1 April 2003 and 31 March 2012

Figure 2. Rates of probable severe ABI requiring rehabilitation by age (April 2003 to March 2012)

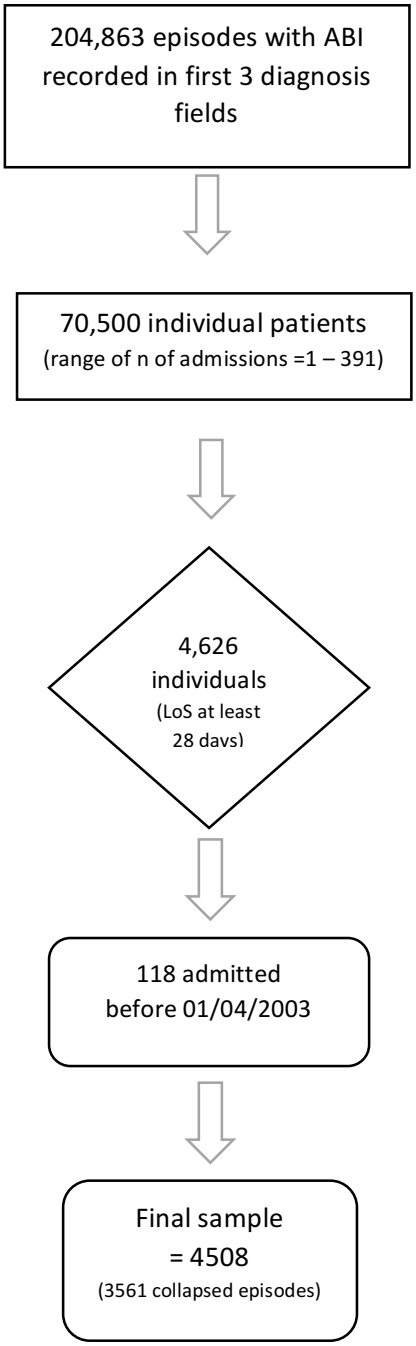

Figure 1. Individuals aged 1-18 years admitted to a hospital in England for a period of at least 28 days with an ICD10 diagnosis code indicating an ABI between 1 April 2003 and 31 March 2012

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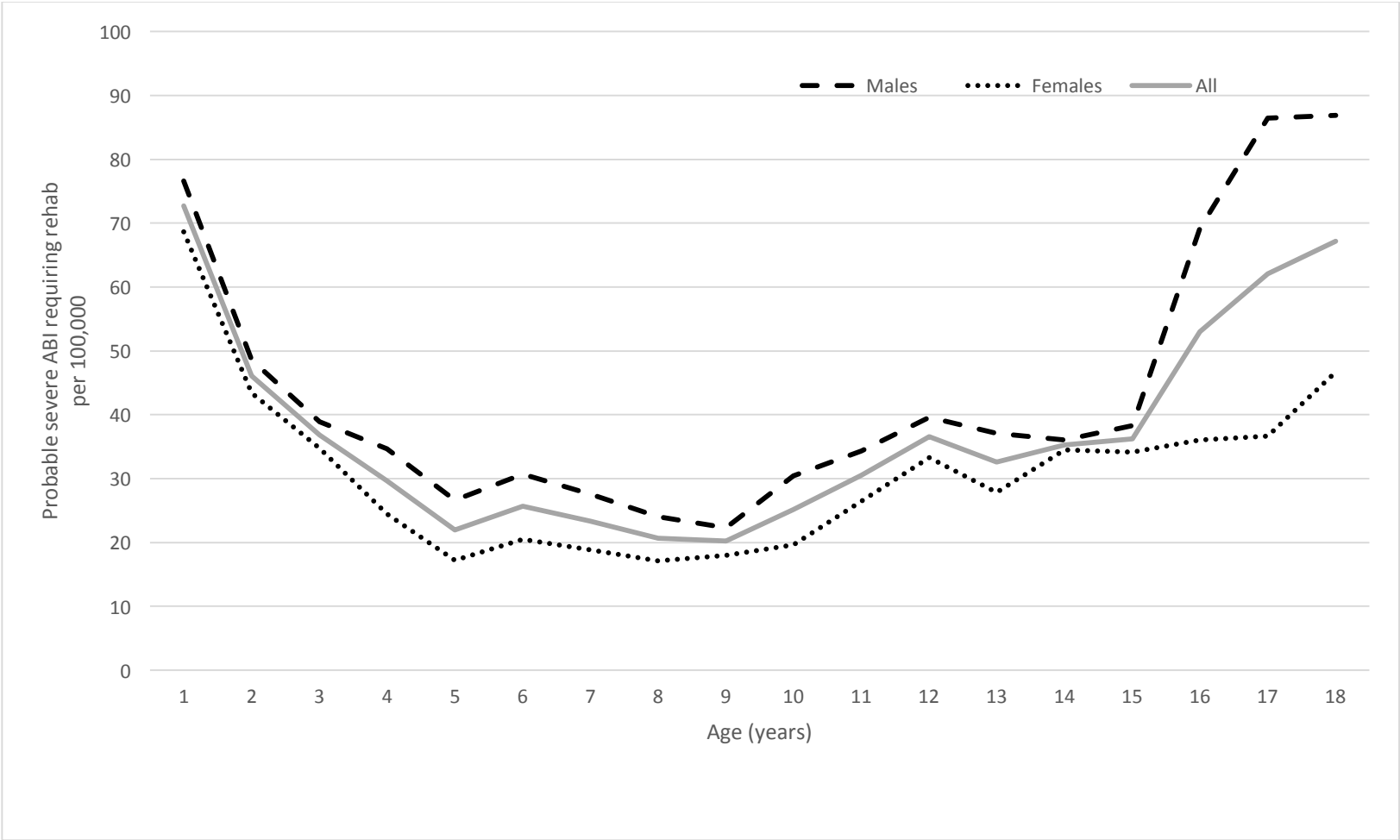

Table S1 Categories of International Classification of Diseases codes included.

Diagnoses	ICD-10 code
Trauma	S02, S06, S07, T06, T90
Brain tumour	C70, C71, C79, D32, D33, D42, D43
Anoxia	G41, G93.6, I46, R09, R57, T71, T75.1
Meningitis	A17, A32, A39, A87, A89, B01, G00, G01, G02, G03, G06, G07, GO8
Vascular insults	G46, I60, I61, I62, I63, I64, I68, G93.8, G93.9
Encephalitis	A81, A83, A85, A86, B00, B02, B05, B22, B50, B94, G04, G05, G09
Metabolic encephalopathy	E10, E11, E13, E14, E15, E51, G92
Toxicity	A48, T40, T42, T51, T56, T57, T58, T62, T64, T65
Other brain injury	G91, G93.1, G93.2, G93.4, G93.5, G99, R29, R40, R90, T75

Table S2. Summary of ABI diagnoses by year (1 April 2003 to 31 March 2012)

	2003-4		2004-5		2005-6		2006-7		2007-8		2008-9		2009-10		2010-11		2011-12		**All**	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Trauma	165	(27.6)	174	(34.4)	187	(31.9)	195	(34.2)	187	(36.2)	129	(28.2)	133	(26.8)	100	(22.4)	93	(27.8)	**1363**	(30.2)
Brain tumour	153	(25.6)	86	(17.0)	121	(20.6)	87	(15.3)	79	(15.3)	74	(16.2)	101	(20.4)	96	(21.5)	69	(20.7)	**866**	(19.2)
Anoxia	107	(17.9)	83	(16.4)	100	(17.1)	94	(16.5)	95	(18.4)	98	(21.4)	97	(19.6)	87	(19.5)	65	(19.5)	**826**	(18.3)
Meningitis	74	(12.4)	65	(12.8)	75	(12.8)	81	(14.2)	59	(11.4)	69	(15.1)	64	(12.9)	74	(16.6)	41	(12.3)	**602**	(13.4)
Vascular insults	28	(4.7)	41	(8.1)	35	(6.0)	51	(8.9)	35	(6.8)	42	(9.2)	44	(8.9)	49	(11.0)	32	(9.6)	**357**	(7.9)
Encephalitis	25	(4.2)	26	(5.1)	35	(6.0)	31	(5.4)	25	(4.8)	30	(6.6)	30	(6.0)	21	(4.7)	18	(5.4)	**241**	(5.3)
Metabolic encephalopathy	18	(3.0)	8	(1.6)	5	(0.9)	8	(1.4)	4	(0.8)	5	(1.1)	4	(0.8)	3	(0.7)	3	(0.9)	**58**	(1.3)
Other brain injury	19	(3.2)	19	(3.8)	25	(4.3)	15	(2.6)	23	(4.5)	6	(1.3)	18	(3.6)	12	(2.7)	10	(3.0)	**147**	(3.3)
Toxicity	8	(1.3)	4	(0.8)	3	(0.5)	8	(1.4)	9	(1.7)	4	(0.9)	5	(1.0)	4	(0.9)	3	(0.9)	**48**	(1.1)
Total	**597**		**506**		**586**		**570**		**516**		**457**		**496**		**446**		**334**		**4508**	