

## Requirements for Rehabilitation Services for Children after Severe Acquired Brain Injury

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### Abstract

#### **Aim**

Acquired brain injury (ABI) is a common cause of acquired disability in children. Rehabilitation services are known to be underdeveloped in Ireland. We aimed to estimate the incidence of severe ABI in young people in Ireland.

#### **Methods**

The National Quality Assurance and Information System (NQAIS) database was analysed to identify patients aged 1-16 years who had suffered a "probable severe acquired brain injury requiring rehabilitation" (PSABIR) from 2016 – 2019. PSABIR is defined as the co-occurrence of a medical condition likely to cause ABI with a length of hospital admission longer than 28 days.

#### **Results**

187 young people in Ireland had PSABIRs from 2016-2019, accounting for 21.4% of all prolonged admissions (incidence 4.55 per 100,000 per year). Median length of stay was 46 days (IQR 35- 80 days). Two children (1%) were discharged directly to specialist rehabilitation; 132 (70.6%) were discharged directly home.

#### **Conclusion**

Severe ABI accounts for a significant proportion of prolonged paediatric admissions, with an average of 47 such events per year. Most young people spend the acute and subacute phases of recovery in a tertiary acute hospital, before being discharged directly home. Rehabilitation services need to be developed in all settings to address unmet need.

## Introduction

Acquired Brain Injury (ABI) is one of the most common causes of death and disability in young people.<sup>1-3</sup> It includes any injury to the brain after a period of normal development and can be caused by trauma, anoxia, stroke, malignancy, inflammation, or infection.<sup>3</sup>

Rehabilitation aims to improve functioning and enhance participation via an interdisciplinary approach tailored to each individual, mindful of specific medical issues, child and family goals, and environmental context.<sup>4,5</sup> Provision of acute, subacute and chronic rehabilitation is the mainstay of treatment for young people following ABI.<sup>4-7</sup> In most countries, increasing survival rates have not been met with an increase in rehabilitation provision.<sup>3,5</sup> A recent WHO study has estimated that, far from being a niche area, rehabilitation services are needed by up to one third of all people during their lifetime.<sup>5</sup> Alongside morbidity and mortality, functioning is a critical “third indicator” of health and is integral to rehabilitation.<sup>8</sup>

Research into ABI incidence and outcomes has been historically hampered by practical issues.<sup>1</sup> Survivors of ABI are heterogeneous in terms of age and developmental status at the time of injury, and their injuries can vary widely in type and severity. This an impediment to comparison.<sup>1,7</sup> The ICD-10 does not provide a specific diagnostic code for ABI which is a barrier to estimating incidence. Rehabilitation may be provided by different systems which is likely to affect outcomes.<sup>7,9</sup> Discrepancies in rehabilitation research and provision in children compared to adults leaves children at risk of receiving suboptimal care.<sup>10,11</sup> In the context of these challenges, reporting on the need for rehabilitation is a matter of public health importance.<sup>5,12</sup>

A recent report on major trauma in Ireland found that from 2014-2019, only 1% of children involved in major trauma were discharged directly to specialist rehabilitation; 83% were discharged directly home.<sup>13</sup> Specialist paediatric rehabilitation in Ireland is under-resourced in comparison to adult rehabilitation, and in comparison, to paediatric services abroad.<sup>14,15</sup>

There is little data on the incidence of severe ABI in young people in Ireland. A recent UK study<sup>3</sup> estimated an incidence of PSABIR of 3.6 per 100,000 young people aged 1- 16 years per annum in the UK; this number is “the tip of the iceberg” with regards to identification of children who may benefit from rehabilitation.<sup>3</sup>

This study aims to estimate the incidence of severe ABI in children and young people in Ireland, so as to inform the need for provision of specialist rehabilitation.

## Methods

The National Quality Assurance and Information System (NQAIS) database was accessed to extract anonymised information pertaining to length of stay (LOS) and ICD-10 diagnostic codes for young people aged 1-16 years admitted to hospitals in Ireland from 2016 – 2019. Young people aged over 16 were excluded as they receive care via adult healthcare services.

Consistent with methods used by other authors<sup>3</sup> we identified young people aged 1-16 years who had suffered a “probable severe ABI requiring rehabilitation (PSABIR) event.” This is defined as the occurrence of a medical condition from a predetermined list of conditions (Appendix 1) which are potential causes of ABI, in the context of an inpatient length of stay of 28 days or longer.<sup>3</sup>

Discharge ICD codes were searched for relevant diagnoses including trauma, brain tumour, anoxia, meningitis, vascular insults and other causes of brain injury (Appendix 1). Results were manually reviewed and those patients for whom the relevant ICD code was not the reason for the prolonged admission were excluded.

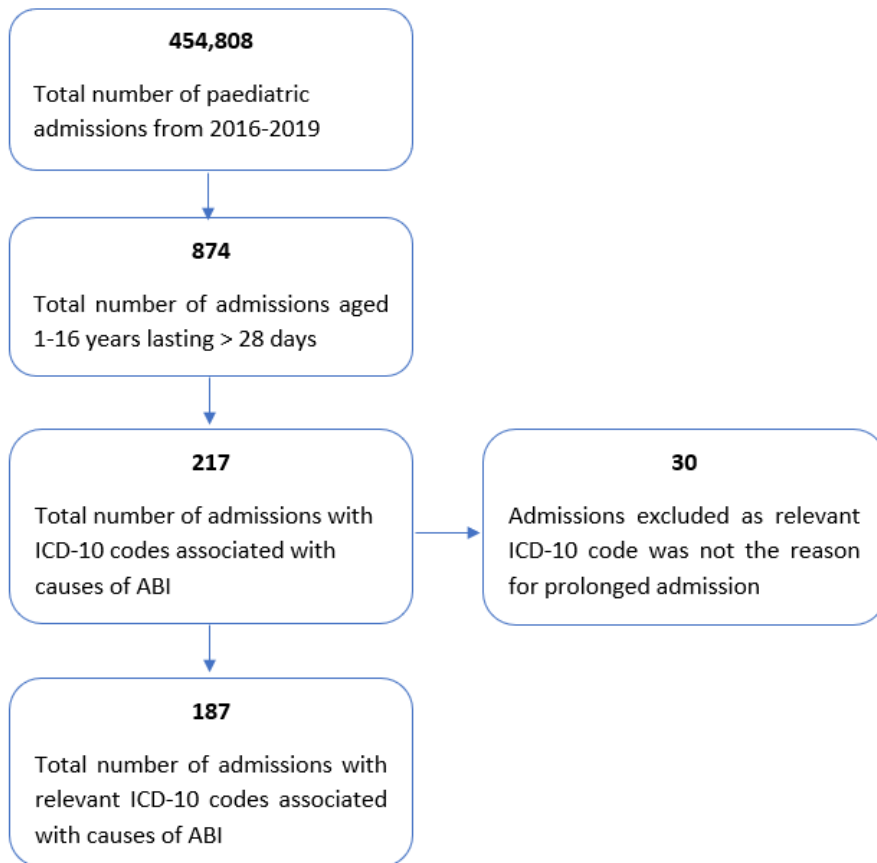
Further data was gathered for each patient including age, gender, requirement for intensive care, palliative care involvement, death, and discharge destination. Data was analysed using Stata/IC 14.0.

Ethical approval for the study granted by the Department of Research at Children’s Health Ireland (CHI) at Temple Street, and permission to access NQAIS data was granted by the National Office for Clinical Audit (NOCA).

## Results

There was a total of 454,808 discharges of young people aged 1-16 years in Ireland from 2016 – 2019 inclusive; 874 had a LOS of 28 days or longer. Review of ICD codes identified 217 admissions associated with causes of ABI; 30 were excluded as the ICD code pertaining to ABI was not the reason for the prolonged admission. 187 admissions met criteria for a PSABIR event (Figure 1). This accounts for 21.4% of all admissions of young people in Ireland with LOS of 28 days or longer, with an incidence of 4.55 per 100,000 per year based on Census figures.<sup>16</sup>

**Figure 1: Study Flow.**



Demographic and aetiological data is shown in Table 1. Anoxia was the most common cause (20.8% of cases), followed by meningitis (17.5%) and brain tumour (12.3%). 33 patients (17.6%) were discharged in 2016, 40 (21.4%) in 2017, 63 (33.7%) in 2018 and 51 (27.3%) in 2019.

**Table 1: Demographics and aetiology of PSABIR events.**

<b>Age (years)</b>	Female (%)	Male (%)	Total (%)
Pre-school (1-4)	23 (26.1)	37 (37.4)	60 (32)
Primary school (5-11)	34 (38.7)	36 (36.4)	70 (37.5)
Secondary school (12-16)	31 (35.2)	26 (26.2)	57 (30.5)
Total	88	99	187 (100)
<b>Aetiology</b>			
Anoxia	14 (15.9)	25 (25.3)	39 (20.8)
Brain tumour	12 (13.6)	11 (11.1)	23 (12.3)
Meningitis	16 (18.2)	17 (17.2)	33 (17.5)
Encephalitis	21 (23.8)	5 (5.1)	26 (13.9)
Trauma	3 (3.4)	17 (17.2)	20 (10.6)
Vascular insults	7 (8)	10 (10.1)	17 (9.6)
Other brain injury	6 (6.8)	9 (9)	15 (8)
Metabolic encephalopathy	7 (8)	2 (2)	9 (4.7)
Toxicity	2 (2.3)	3 (3)	5 (2.6)
Total	88	99	187 (100)

The incidence of PSABIR events was similar in males (4.73 per 100,000 95% CI 3.86 – 5.78) and females (4.39 per 100,000, 95% CI 3.54 – 5.38). TBI accounted for 17.2% of PSABIR in males and 3.4% in females. Rates of PSABIR increased from 3.55 per 100,000 (2.79- 4.48) 2016-2017 to 5.7 per 100,000 (4.58 – 6.68) in 2018-2019.

Median length of stay (LOS) was 46 days (IQR 35 – 80 days), with LOS ranging from 28 - 1998 days. 115 (61.5%) patients required ICU care. Median PICU LOS was 11 days (IQR range 4 – 21 days), ranging from 1 – 213 days.

Most patients were admitted to a tertiary paediatric hospital (152, 81.3%) or an adult hospital with a paediatric neurosurgical ward (24, 12.8%); 169 of the 187 (90.4%) were admitted to hospitals in Dublin.

Only 2 children (1%) were discharged from acute hospitals to the National Rehabilitation Hospital. The majority of children were discharged directly home (132, 70.6%), or to a regional hospital (38, 20.3%). Three children were discharged to hospice care (1.6%), and 11 (5.8%) died in hospital.

## **Discussion**

This study estimates the incidence of PSABIR in young people in Ireland aged 1-16 years at 4.55 per 100,000 per annum, as compared to 3.6 per 100,000 in the UK.<sup>3</sup> An average of 47 young people in Ireland experience PSABIR every year, spending 46 days in hospital on average, accounting for 2,162 bed days per annum and likely needing significant ongoing care. A small number of patients had longer admissions, increasing the mean LOS of all patients to 95 days.

The methodology used has some limitations; mainly that it detects only the children with the most significant physical disability and therefore likely significantly underestimates the total burden of disability caused by ABI in children. Many young people with ABI (including many with severe injuries) spend less than 28 days in hospital and are therefore excluded by the methodology used here. The methodology used likely captures patients with the most significant acquired physical disability; it does not capture the significantly larger number of young people with ABI who do not experience chronic physical disability, but who are at risk of “invisible disability” and whose difficulties related to ABI are known to be at risk of being misattributed or missed.<sup>3,17</sup>

Beyond physical disability (which prolongs admissions), there is a significant burden of cognitive, behavioural and mental health difficulties in young people who experience mild-moderate ABI, who are typically discharged home after shorter hospital stays and whose experiences are not captured here. Such difficulties often only become apparent long after the injury occurs,<sup>7</sup> emerging as a young person fails to keep pace with their peers due to the increasing complexity of the demands placed on them by their social and educational environments.<sup>3</sup> Disability of this nature is under-attributed to ABI due to a lack of appreciation of the potential sequelae of mild-moderate ABI and the time lag in difficulties emerging, as well as the fact that it occurs in children without physical disability who may appear outwardly unaffected by their brain injury.<sup>17</sup>

One in every 20 paediatric emergency department attendances in Dublin is with head injury, most of which are mild.<sup>18</sup> UK studies suggest an incidence of TBI of approximately 450 per 100,000, 10% of whom will sustain a moderate to severe brain injury with temporary or lasting neurological sequelae.<sup>19</sup> A comparable incidence of TBI in Ireland would imply 450-500 young people each year would suffer TBI with neurocognitive sequelae. This does not include non-traumatic ABI and so represents an underestimate of the total burden of ABI morbidity. The cumulative incidence of children who acquire significant new neurological morbidity due to ABI is comparable to that of cerebral palsy.<sup>20</sup>

Consistent with the findings of a recent audit of major trauma in Ireland,<sup>13</sup> 1% of children with PSABIR in this study were discharged directly to dedicated specialist rehabilitation services; the vast majority of children with PSABIR were discharged either directly home or to a regional hospital. This reflects the typical journey to specialist rehabilitation of children in Ireland, who are most often discharged directly home before being later admitted to the National Rehabilitation Hospital (NRH) in Dublin. The vast majority of children access the NRH do so after having been discharged home first. Improved access to rehabilitation in flexible programmes beyond the inpatient setting has the potential to shorten tertiary hospital admissions.

This pattern reflects resourcing; admission to dedicated specialist rehabilitation is delayed by capacity, and as a result children with PSABIR in Ireland typically spend the acute and subacute phases following their injuries in acute hospitals. It is therefore imperative that services are developed within these centres to meet the need for acute rehabilitation during this phase, as well as in the single national specialist centre and in the community to facilitate ongoing meaningful recovery. Development of dedicated paediatric rehabilitation structures in Ireland has lagged behind those for adults, which are themselves known to be under-resourced in comparison to the UK, Europe and Australia.<sup>14,15</sup> At present there are 1.25 WTE consultant positions covering paediatric rehabilitation services for Ireland.

Recent restructuring of disability services in Ireland aims at a more equitable provision of services.<sup>21</sup> Services are designed predominantly for children with congenital causes of disability and developmental problems (e.g. cerebral palsy, autism). The needs of children with ABI are often overlooked in the design of services,<sup>22</sup> despite the significant burden of disability.<sup>23</sup> The therapy needs of young people with brain injuries are known to be different from those of young people with other causes of disability.<sup>24</sup> Recovery after ABI follows a sigmoidal pattern, with an early period of rapid recovery eventually followed by a phase of slowing recovery and eventual plateau.<sup>6</sup> The period following ABI is a window for recovery, provided services are configured to provide structured specialist rehabilitation to young people who need it; in the absence of such services, the opportunity for recovery may be lost.<sup>3,6,7</sup> Neuroplasticity is not inherently “good” and must be harnessed by practice of meaningful tasks to improve recovery.<sup>25</sup>

Length of stay has weaknesses as a proxy marker of ABI severity- chiefly, it underestimates the total burden of morbidity as outlined above. It is affected by factors unmeasured by this study, such as resource provision and patient factors. Young children with severe ABI may be discharged more readily due to the increased ease of meeting their care needs as compared to (larger) older children and are likely under-represented by this methodology. Length of stay is most likely to be prolonged by acquired physical disability rather than impairments in cognition and communication which are significant contributors to a child's experience of disability.

Length of stay may also be prolonged by the need for prolonged oncology treatment. However, in contrast to the methodology used by Hayes et al,<sup>3</sup> due to differences in data recording methods between Ireland and the UK we did not include and consolidate "spells" where admissions (e.g. for chemotherapy) were interrupted by brief periods at home; as a result, such visits home do not result in a single admission erroneously appearing on records as multiple brief stays. Our method, therefore, did not include such admissions as PSABIR events.

This study examines severe ABI in children in Ireland from the perspective of acute healthcare provision. Future studies reporting on patient outcomes using measures of functioning and quality of life, as well as qualitative methodologies, would further improve our understanding of the lived experiences of young people with acquired brain injury in Ireland, which are not currently well described.<sup>12</sup> High quality epidemiological research on ABI in children in Ireland is needed so as to accurately determine how many young people in Ireland are living with the sequelae of ABI, as well as to identify any shortfalls of provision of rehabilitation services; in the absence of a national paediatric rehabilitation strategy or a dedicated pathway for children with ABI separate to generic disability services, it is likely that these shortfalls are currently significant. Rehabilitation services for young people in Ireland are in urgent need of review and expansion so as to address unmet need, and to facilitate more flexible provision of services beyond an inpatient setting.

**Declaration of Conflicts of Interest:**

No conflicts of interest to declare.

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