Traumatic Brain Injury in a Paediatric Population

‘A thesis submitted to the University of Manchester for the degree of Doctor of Clinical Psychology in the Faculty of Medical and Human Sciences’

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Abstract

Traumatic Brain Injury in a Paediatric Population
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This thesis examined neuropsychological and psychological outcomes following paediatric traumatic brain injury (TBI). The introductory chapter provides an overview of the paediatric TBI literature, giving definitions of key terms and concepts and providing a description of the epidemiology of childhood head injury. Key models relevant to paediatric TBI are introduced, including developmental neurological, cognitive and psychological perspectives. This is followed by a discussion of factors pertinent to outcome after TBI, followed by a description of outcomes relating to cognitive, behavioural, psychological, adaptive and family functioning domains. Existing research demonstrates that poor outcomes are frequently observed in paediatric TBI populations across these domains and difficulties are persistent over time, particularly where children have sustained severe head injury. Thus, research has turned its focus to the prediction of outcomes which can assist clinicians in the identification of those individuals who will require rehabilitation in order to promote their long-term recovery. Whilst the literature has identified injury and demographic factors that can assist in this process, little attention has been given to the potential utility of psychological screening assessment.

Given the prevalence of neuropsychological and psychosocial problems after paediatric TBI and lack of empirical data considering factors predictive of difficulty at the post-acute phase, this research aimed to consider the clinical utility of completing a pre-discharge screening assessment in children and adolescents with TBI. Specific areas of consideration included the potential impact of injury severity on neuropsychological functioning, psychosocial impairment and return to full-time schooling. The study design comprised a prospective case series of 11 children and adolescents with TBI (aged 7-15 years), who were assessed both pre- and post-discharge (3-6 month follow-up). Domains of intellectual, emotional, behavioural, and adaptive functioning, health-related quality of life and parenting stress were assessed at both time-points. Clinically significant findings were demonstrated in domains of neuropsychological and psychosocial functioning, particularly for those with a severe TBI. Specifically, ratings of self-reported emotional distress, and parental perceptions of child health-related quality of life were found to be within clinical ranges at pre- and post-discharge for more than half of the participants. The majority of participants with severe injury required further neuropsychological assessment and interventions relating to emotional and/or behavioural management.

The post-discharge functioning of this cohort provided preliminary evidence for the clinical utility of cognitive and psychosocial screening after paediatric TBI. The observed level of clinical need, particularly in the severely-injured group indicated that screening was a useful tool for early identification of difficulties, and provided an opportunity for timely intervention. Without screening, children and adolescents with TBI may be discharged to the community without appropriate support in place; raising long-term concerns for the child, family, and the wider social and economic systems. Despite this, further research which explicates these findings within larger samples is required. The discussion chapter reviews these findings in relation to the wider literature, followed by consideration of this study’s limitations. The thesis concludes with a description of the clinical implications of the findings and suggested future directions.
Declaration

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Finally, another big thank you to my fellow trainees who have been there throughout the past three years.
This chapter provides an introduction to the area of paediatric traumatic brain injury (TBI) and to this thesis study. In Part One, a broad overview of TBI occurring in childhood is described including definitions, epidemiology and the measurement of injury severity. Part Two provides an introduction to theories and models underpinning the understanding of paediatric TBI and Part Three outlines the various factors that influence outcome after head injury. The sequelae and assessment of such are presented in Parts Four and Five respectively. Finally, the rationale and hypotheses for this thesis study are presented.

**Part One – Defining, epidemiology and severity of traumatic brain injury in childhood**

**1.1 Defining traumatic brain injury**

TBI describes an injury to the brain caused by a trauma to the head, including blunt, penetrating or blast injuries, that can lead to an altered state of consciousness (British Medical Journal, 2011; Headway, 2012). It is the alteration to an individual’s conscious state which distinguishes TBI from minor head injuries (Anderson, Northam, Hendy, & Wrennall, 2001). The causes of TBI are wide-ranging, but most commonly occur as a result of road traffic accidents (40.9%), falls (36.9%) non-accidental injury (1.9%) or sporting injury (0.2%, Bayreuther et al., 2009). As such, there are varying degrees and mechanisms of insult on the underlying physiology of the brain.

Neurophysiological damage to the brain as a result of TBI can be classified according to primary impact and secondary injuries (Anderson et al., 2001). Primary impact injuries are directly caused by the physical force on the brain, such as fractures, contusions (bruising), lacerations and diffuse axonal damage (widespread lesions of the brain’s white matter). Secondary injuries are a consequence of primary impact injuries, and include haemorrhage, raised intracranial pressure, oedema (swelling), hypoxia (deprivation of oxygen), infection and metabolic abnormalities. There are also two classifications of TBI; penetrating (open) or closed head injury, with the characteristics of each again differing due to the underlying mechanism of injury on the brain (Anderson et al., 2001).

Penetrating head injury generally results in a focal injury to the brain, but is fairly infrequent in paediatric populations. The majority of TBIs sustained in childhood are
classified as closed head injuries, when injury is caused by forceful movement of the brain (backwards, forwards and rotation within the skull). This is also known as ‘coup contrecoup’ injury, where the movement leads to multiple injury sites and diffuse axonal injury. This form of injury is commonly observed following head injuries sustained in road traffic accidents (Anderson et al., 2001).

1.2 Epidemiology of TBI

TBI is one of the most common causes of acquired disability during childhood, and can result in global health, social and economic problems (Robertson, Joffe, Moore, & Watt, 2002). Annual prevalence rates for paediatric TBI are estimated to be in the region of 250 per 100,000 of the population (Anderson et al., 2001). A recent study investigating UK trauma patterns and mortality rates used data collected by the Trauma Audit and Research Network (TARN, Bayreuther et al., 2009). Sixty percent of trauma-receiving hospitals in England and Wales participate in the TARN. Paediatric trauma cases are eligible to be recorded on this database if they are admitted to hospital for 72 hours or more, where individuals are admitted to a high dependency or intensive care unit, if inter-hospital transfer takes place, or where the trauma results in death. Between 1990 and 2005, the TARN database identified that head injury accounted for 24.6% of all paediatric trauma, with this classification associated with the highest mortality rates (Bayreuther at el., 2009). It is approximated that 83% of paediatric head injuries are classified as ‘mild’, 9% as ‘moderate’, 6% as ‘severe’, whilst 1% will likely result in death (Hawley, Ward, Long, Owen & Magnay, 2003). It is reported that many children presenting at hospital following TBI are discharged within 24 hours, and there are likely many more who do not seek medical attention (Anderson & Catroppa, 2006). Therefore, it is probable that these prevalence rates underestimate the true occurrence of paediatric TBIs.

The incidence, cause and nature of childhood head injury appears to vary with respect to the age, gender, race and psychosocial context of the child (Anderson et al., 2001). Children less than three years of age are most likely to sustain head injury as a result of falls or non-accidental injury, whilst children of school-age (4-16 years) are more likely to sustain head trauma as a result of a sporting, cycling or road traffic accident (Anderson et al., 2001). In the case of severe injuries, mortality rates are highest (50%) in those children less than two years old, with better survival rates associated with increasing age (Bayreuther et al., 2009; Michaud, Rivara, Grady & Reay, 1992). It is also widely documented that males are at increased risk of sustaining head injury, with figures
suggesting that they are more than twice as likely as their female peers to experience a TBI (Anderson et al., 2001; Hawley et al., 2003; Michaud et al., 1992). Research completed in the USA has also indicated that incidence of TBI varies according to race, with mortality and hospitalisation rates following road traffic accidents significantly higher for children of Black ethnic origin than those of White ethnic origin (Langlois, Rutland-Brown & Thomas, 2005). Finally, increased prevalence of TBI has been associated with psychosocial factors including social deprivation (Hawley et al, 2003; Parslow, Morris, Tasker, Forsyth & Hawley, 2005) and where children have pre-existing behavioural or emotional disorders (Brown, Chadwick, Shaffer, Rutter & Traub, 1981).

1.3 Severity of TBI

In the acute stages of TBI, healthcare practitioners employ methods of assessing injury severity in order to best manage the needs of the patient, and prevent further complications or secondary injury that may arise as a result of the initial trauma (Jennett, 1976). Currently, measures that assess impaired consciousness or duration of post-traumatic amnesia, and neuroimaging techniques are routinely used to assess severity of TBI (Anderson et al., 2001).

1.3.1 Impaired consciousness

As has been identified above, alteration to an individual’s conscious state is one factor which separates TBI from more minor head injury (Anderson et al., 2001). One widely employed measure which indicates level of consciousness is the Glasgow Coma Scale (GCS; Teasdale & Jennett, 1974). This tool was designed for use by a range of professionals, without the need for specialist training. It aims to gauge deterioration or improvement in the acute stages of brain injury, as well as providing an indication of the degree and duration of impaired consciousness. The GCS assesses three aspects of behaviour: motor responsiveness, verbal performance, and eye-opening. It is suitable for use with individuals who are over the age of five years, where a score of 13-15 is indicative of mild TBI, a score of 9-12 reflecting moderate TBI and a score of 8 or less defining severe TBI (Teasdale & Jennett, 1974).

In order to accommodate infants and young children, whose developmental level prevents them from performing on several items within the motor and verbal sub-scales of the GCS, a modified version of the scale was later developed; the Paediatric Coma Scale (Reilly, Simpson, Sprod & Thomas, 1988). Table 1.1 below compares the adult and child versions
of these scales. As Table 1.1 illustrates, the score and severity rating obtained will depend on the age of the child, with children over the age of five able to score a maximum of 15, and those younger than six months only able to achieve a maximum score of nine. Although the adult and paediatric versions of these scales are commonly used within clinical settings, there are several limitations worth acknowledging; the reliability of the scale is dependent upon the experience and interpretation of the rating clinician, monitoring of GCS is disrupted following administration of sedatives, and there is a lack of consensus regarding the optimal time to assess using these scales (Anderson et al., 2001).

The predictive utility of the GCS score as a determinant of outcome has been investigated. Chung et al. (2006) collected various assessment data from paediatric TBI cases including GCS score, injury details, information relating to surgical procedures, computed tomography brain imaging, and the Glasgow Outcome Scale (GOS; Jennett & Bond, 1975). The GOS was designed to compliment the GCS, in order to assist practitioners in predicting outcome. The scale assesses severity of disability, according to both duration and intensity, from which individuals are assigned to one of five categories (‘death’, ‘persistent vegetative state’, ‘severe disability’, ‘moderate disability’ or ‘good recovery’). Of the data collected by Chung et al. (2006), the most effective predictor of outcome, as measured by the GOS was the GCS score. Furthermore, through ROC analysis it was established that in order to maximise sensitivity for paediatric populations, the predictive critical score of the GCS should be set at five, rather than eight as is set for adult populations. Another study investigating predictors of survival and severity of disability after severe TBI in childhood drew similar conclusions (Michaud et al., 1992). Of the factors analysed, GCS score 72 hours post-injury, and more specifically the motor responses score, was the most significant predictor of subsequent disability.
<table>
<thead>
<tr>
<th>Glasgow Coma Scale</th>
<th>Paediatric Coma Scale</th>
<th>Age-related best possible response</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Eyes open</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spontaneously</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>In response to speech</td>
<td>3</td>
<td>As for adults</td>
</tr>
<tr>
<td>In response to pain</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Does not open eyes</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Best verbal response</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oriented, converses normally</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Confused, disoriented</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Inappropriate words</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Incomprehensible sounds</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Makes no sound</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Best motor response</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Obeys commands</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Localises painful stimuli</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Flexion/withdrawal to pain</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Abnormal flexion to pain</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Extension to painful stimuli</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Makes no movement</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>
1.3.2 Duration of impaired consciousness

An alternative indicator of injury severity is length of post-traumatic amnesia (PTA). In relation to head injury, PTA refers to the period of confusion or disorientation following a trauma. One early study demonstrated that duration of PTA correlated with other clinical features of severe injury including signs of brain damage, occurrence of secondary complications, degree of ultimate physical and mental recovery, and time to return to normal activity (Jennett, 1976). Estimations of PTA are advantageous over other measures of injury severity, as they can be made by a healthcare practitioner seeing the patient for the first time since the injury, although once again, the reliability of measuring PTA is influenced by sedation. Length of PTA is estimated within the broad categories illustrated in Table 1.2.

<table>
<thead>
<tr>
<th>Post-traumatic amnesia classifications</th>
<th>Injury severity classifications</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 5 minutes</td>
<td>Very mild</td>
</tr>
<tr>
<td>&lt; 1 hour</td>
<td>Mild</td>
</tr>
<tr>
<td>1-24 hours</td>
<td>Moderate</td>
</tr>
<tr>
<td>1-7 days</td>
<td>Severe</td>
</tr>
<tr>
<td>&gt; 7 days</td>
<td>Very severe</td>
</tr>
<tr>
<td>&gt; 4 weeks</td>
<td>Extremely severe</td>
</tr>
</tbody>
</table>

More recently, several standardised measures of PTA have been developed for use with paediatric populations, namely the Children’s Orientation and Amnesia Test (COAT, Ewing-Cobbs, Levin, Fletcher, Miner & Eisenberg, 1990) and the Westmead Post-Traumatic Amnesia Scale (Westmead P.T.A, Shores, 1989). Both measures require the child or young person to answer questions relating to personal details, assess their orientation to time, and include simple memory tasks. They are administered in the days following TBI, until the patient reaches a level of functioning when they are no longer deemed to be within PTA. When injury severity is defined by structured measures such as the COAT or Westmead P.T.A, it has been argued that PTA is the most reliable indicator of functional outcome after TBI (Anderson et al., 2001).

1.3.3 Structural imaging techniques

With technological advances, the use of neuroimaging in the management of TBI has become increasingly important. Computed Tomography (CT) and Magnetic Resonance (MR) imaging can both provide valuable information regarding the type, location and severity of intracranial injuries. This information can prove crucial to the acute management of head injury, indicating where neurosurgical procedures are required. Issues
such as radiation risk in CT, and the associated cost of neuroimaging means that not all children admitted following TBI are routinely scanned (Martin & Falcone, 2008). Medical teams use guidelines issued by the National Institute for Clinical Excellence (NICE, 2007) when making decisions regarding whether individuals require neuroimaging procedures. NICE guidelines (2007) for the management of head injury in children and young people under the age of 16 indicate that CT should be completed where:

- Witnessed loss of consciousness lasting > 5 minutes
- Amnesia (anterograde or retrograde) lasting > 5 minutes
- Abnormal drowsiness
- Three or more discrete episodes of vomiting
- Clinical suspicion of non-accidental injury
- Post-traumatic seizure, without history of epilepsy
- Age > 1 year: GCS < 14 on assessment in the emergency department
- Age < 1 year: GCS (paediatric) < 15 on assessment in the emergency department
- Suspicion of open or depressed skull injury or tense fontanelle
- Signs of basal skull fracture (haemotympanum, ‘panda’ eyes, cerebrospinal fluid leakage from ears or nose, Battle’s sign)
- Focal neurological deficit
- Age < 1 year: presence of bruise, swelling or laceration > 5 cm on the head
- Dangerous mechanism of injury (high-speed road traffic accident either as pedestrian, cyclist or vehicle occupant, fall from > 3 metres, high-speed injury from a projectile or an object)

With the development of MR techniques there have been increasingly powerful means of identifying the structural correlates of impaired cerebral function (Gadian, 2002). MR imaging uses strong magnetic fields and radio waves (NHS Choices, 2011), and is advantageous as the individual is not exposed to radiation, as is the case with CT imaging. Through MR imaging, volumetric measurements of brain structures can be obtained and radiological diagnoses can be made based on visual inspection of the obtained images (Gadian, 2002). For more detailed information relating to MR techniques, the reader is directed to (Gadian, 2002).
In summary, TBI is a common cause of disability and death in childhood, but is prevalent to varying degrees according to demographic characteristics. Severity of injury is generally rated according to measures of impaired consciousness, PTA and neuroimaging findings, that assist clinicians in the management of paediatric TBI.

Part Two – Foundations of paediatric TBI

Current developmental neuropsychology is largely built upon knowledge of adult neuropsychology and neuroscience, developmental neurology, cognitive psychology and animal models. Traditionally, researchers investigating paediatric TBI used models of adult neuropsychology to inform their understanding of the impact of brain insult in childhood, including knowledge of cerebral localisation and integrated brain systems (Anderson et al., 2001). However, over time it has become clear to researchers and clinicians that understanding the impact of insult on the developing brain requires much more than pre-existing knowledge relating to cerebral pathology observed in adults. The developing brain is dynamic in nature, rapidly evolving and maturing. Therefore, although adult neuropsychological models can provide some understanding of the functioning of the young brain after insult, it is imperative that developmental neurological, cognitive and psychological perspectives are also considered, to account for the dynamic nature of the paediatric brain.

1.4 Developmental neurology

Maturation of the central nervous system begins early in gestation and continues throughout infancy, childhood and into early adolescence. Post-natal processes such as dendritic aborisation, myelination and synaptogenesis occur in a hierarchical fashion, with the anterior or ‘frontal’ regions of the brain maturing last, during puberty (Anderson, 1998). There is also evidence to suggest that this elaboration occurs in a stepwise manner, with spurts in growth occurring in early infancy, between 7-10 years of age and once again during adolescence (Anderson, 1998; Thatcher, 1991; 1992). These stepwise neurological changes have been linked to increments in the cognitive abilities of children (Anderson et al., 2001), highlighting the inseparable relationship between brain development and observable behaviour.

Numerous events occurring during childhood can impact on the normal developmental trajectory of the central nervous system including head injury, infection, malnutrition, severe sensory deprivation and exposure to environmental toxins. Our understanding of the
influence of such occurrences on the developing brain dates back to the 1800s and has evolved over time. Initial theorists suggested that the young brain had greater ‘plasticity’ than the mature brain, that it was more flexible in its neural circuitry, allowing for transfer of function from damaged to undamaged areas (Anderson, Spencer-Smith & Wood, 2011). The earliest observations of such were reported by Broca, who studied a patient with a congenital absence of their left frontal lobe, a region known for its role in speech function, yet they exhibited language which suggested their right hemisphere had subsumed speech function (Broca, 1861; 1863).

Research completed in the 1930s investigated the impact of lesions to the motor and premotor areas in infant and adult monkeys (Kennard, 1936). Following these lesions, adult monkeys demonstrated a slower and lesser degree of recovery than infant monkeys. Despite lesions to the brain regions usually associated with voluntary purposeful movement, these abilities were not lost in the young animals, and were subsumed by other areas of the brain. Some decades later in the 1960s and 1970s, further research demonstrated early plasticity of the language and visual systems and the malleability of these structures in relation to environmental stimulation (Hubel & Wiesel, 1965; 1970; Lenneberg, 1967).

In contrast, research completed since the 1980s has challenged the notion of ‘early plasticity’, deeming it too simple and optimistic considering the complexity of the human brain. Research using human rather than animal subjects, has put forward an opposing concept of ‘early vulnerability’, which has suggested that the plasticity of the developing brain may not necessarily be adaptive, but may come at a cost. Researchers argued that transfer of function can lead to depletion of neural resources, and disruption of predetermined normal developmental processes, including the acquisition of new skills (Anderson et al., 2011; Bond-Chapman & McKinnon, 2000). Such disruption to normal neurological and cognitive developmental trajectories is likely to result in an ever-increasing gap between the brain-injured child and their demographically-matched peers. This is particularly so when the child has sustained a severe injury, leading to the hypothesised ‘double-hazard’ model, whereby severe TBI in early childhood, or moderate TBI in infancy, place children at greatest risk for post-injury impairments in functioning (Anderson, Catroppa, Morse, Haritou, & Rosenfeld, 2005a).
The use of contemporary neuroimaging techniques has allowed for the development of our understanding of the mechanisms involved in transfer of function. Accordingly, where injury to the central nervous system occurs in the prenatal period, it appears that functional transfer does not take place, but that skills are maintained ineffectively within damaged areas, generally leading to developmental delays (Anderson et al., 2001). Where injury occurs in the post-natal period, transfer may occur, however outcomes remain suboptimal due to “crowding” of skills within those subsumed areas, leading to a general depression in neuropsychological function (Anderson et al., 2001).

To summarise, plasticity processes following brain insult appear to be much more complicated than researchers originally believed, and are still far from being fully understood. The most recent review of the debate relating to the ‘early plasticity’ and ‘early vulnerability’ hypotheses has argued that these contradictory perspectives may in fact reflect opposite ends of a recovery continuum (Anderson et al., 2011). This model suggests that a child’s ultimate outcome will depend on numerous mediating factors, which form part of the discussion found within Part Three of this chapter.

1.5 Cognitive development

1.5.1 Models of cognitive development

As well as the rapidly changing neurological developments occurring during infancy, childhood and adolescence, cognitive processes are also becoming increasingly more sophisticated throughout these periods. One of the earliest conceptual models of cognitive development was proposed by the developmental psychologist Piaget, who argued that an infants’ knowledge is acquired through exploration and interaction with their environment, and it is this learning which guides neural development (Andrade & May, 2004). Piaget proposed a model within which infants and children sequentially pass through developmental stages, indicating the acquisition of increasingly complex cognitive abilities (Piaget, 1952). These stages are briefly described in Table 1.3.
Table 1.3. Piaget’s stages of cognitive development (1952), adapted from Cole & Cole (2001).

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth to 2</td>
<td>Sensorimotor</td>
<td>Coordination of sensory perceptions and simple motor behaviours. Development of object permanence. Early understanding of causality. The emergence of symbolic thought, or representation (imagination, pretend play and imitation).</td>
</tr>
<tr>
<td>2 to 6</td>
<td>Preoperational</td>
<td>Ability to represent reality through symbols, images, words and gesture. Children will fail to distinguish their own point of view from that of others, become easily captured by surface appearances, and are confused about causal relationships.</td>
</tr>
<tr>
<td>6 to 12</td>
<td>Concrete Operational</td>
<td>Operational thinking allows children to mentally combine, separate, order, and transform objects and actions in a logical manner.</td>
</tr>
<tr>
<td>12 to 19</td>
<td>Formal Operational</td>
<td>Ability to think systematically about all logical relations within a problem. Interest in abstract ideas and the process of thinking itself.</td>
</tr>
</tbody>
</table>

An alternative theory of cognitive development was proposed by Vygotsky, who emphasised the importance of the child’s interaction with their environment, and in particular, social interaction. He argued that children learn about how to behave through observing and conversing with others, that they internalise this knowledge, imagine themselves behaving in the same way, and will then test this behaviour out themselves (Andrade & May, 2004). Another key concept put forward by Vygotsky was the notion of the zone of proximal development. Actions that a child is currently capable of demonstrating fall within their established level of performance, and actions that they have not yet learned fall at their upper limit of competence. In between are actions that the child is capable of, if they are first able to observe someone else, and are then encouraged to imitate (Andrade & May, 2004). In contrast to Piaget, who suggested that cognitive development occurred in a stepwise framework, Vygotsky’s theory suggested that as successful learning impacts on both the child’s level of performance and competence, their zone of proximal development simultaneously progressed in a continuous manner.
Piaget and Vygotsky’s theories of cognitive development relate to typical or normal development, which in the case of paediatric TBI become disrupted. An alternative model that gives consideration to the functioning of the underlying neuronal system is the neural efficiency model (Schafer, 1982). The neural efficiency model states that efficient and adaptable brain processing correlates with higher intellectual abilities. Schafer (1982) suggested that a brain that was able to function efficiently will inhibit its response to insignificant stimuli, and attend robustly to crucial stimuli. He stated that this functioning reflected an individual who had the ability to adapt to their environment more intelligently. However, where TBI has occurred, varying degrees of neuronal damage will be detrimental to an individual’s efficient and adaptable neural processing, and therefore on the basis of this model, a decline in cognitive abilities would be expected.

1.5.2 Intelligence

Regardless of the different mechanisms of learning which are proposed by theories of cognitive development, all theories broadly assume that children develop in an ordered and progressive manner, however the rate at which an individual achieves developmental gains varies from one child to the next (Anderson et al., 2001). Interest in the assessment of such variation in the cognitive abilities or ‘intelligence’ of children has existed since the end of the nineteenth century. At this time, Binet and his colleagues developed tasks that aimed to evaluate the developmental status of children, in order to distinguish those who would not benefit from standard academic schooling (Binet & Simon, 1905). In contrast to previous tests of intelligence, such as the sensori-motor tasks developed by Galton (Kaufman, 2000), Binet’s tests were language-based, and involved tests of judgment, memory, comprehension and reasoning (Flanagan & Kaufman, 2009). Binet’s tests have been hugely successful, and subjected to numerous revisions and language adaptations, the most recent being the Stanford-Binet Intelligence Scales – Fifth Edition (Roid, 2003).

Another prominent figure within the field of intelligence testing was Wechsler, who gained considerable experience of administering such tests to army recruits during World War One. In the 1930s Wechsler began developing his own intelligence tests, beginning with the Wechsler-Bellevue Intelligence Scale (Wechsler, 1939). Subsequently, the Wechsler Intelligence Scale for Children (WISC, Wechsler, 1949) was developed, with a later downward extension for younger children, the Wechsler Preschool and Primary Scale of Intelligence (WPPSI; Wechsler, 1967). By the 1960s, intellectual assessment had an important contribution within the education system, with the introduction of laws which
stated that all children with intellectual disabilities in the US should be provided with an individualised education program (Flanagan & Kaufman, 2009). These programs required each child’s level of cognitive functioning to be evaluated, and thus the development of standardised intelligence tests continued.

The Wechsler, Standford-Binet and other measures of cognitive functioning have been the subject of numerous revisions to date, with the most recent editions reflecting a greater alliance with the theory upon which they are based. It is beyond the scope of this thesis to provide a detailed discussion of contemporary intelligence tests and their theoretical underpinnings, and for this, the reader is directed to Flanagan, Genshaft & Harrison (2005). However, a brief description of the ‘four waves’ of test interpretation is detailed below.

Initially, the quantification of general level classified individuals into groups according to their abilities. This approach was heavily influenced by Spearman’s ‘g’ theory of intelligence, which suggested a universal unity of intellect, with all cognitive tasks having in common one underlying function (Spearman, 1904). The main focus of quantification of general level was to classify individuals according to the global entity of an IQ score. According to Wechsler (1939), intelligence could be defined as “the aggregate or global capacity of the individual to act purposefully, to think rationally, and to deal effectively with his environment”, and that it “avoids singling out any ability, however esteemed, as crucial or overwhelmingly important” (p. 3). The distributions of IQ scores in any age group have a mean of 100 and a standard deviation of 15, and as they are normally distributed, can be converted into percentile ranks (Beaumont, Kenealy & Rogers, 2001).

The second wave; Clinical Profile Analysis, expanded on global IQ with interpretation focused on more specific aspects of cognition and the analysis of patterns on sub-test scaled scores (Kamphaus et al., cited in Flanagan et al., 2005). Sub-test scaled scores are standardised, with a mean of 10 and a standard deviation of 3 (range 1-19). This approach to the interpretation of intellectual functioning conceptualised it as a collection of mental abilities, with sub-test interpretation measuring discrete cognitive skills (Flanagan & Kaufman, 2009). Both the Wechsler-Bellevue Intelligence Scale and WISC grouped sub-tests according to a dichotomy of verbal and non-verbal abilities, and yielded composite scores including Full-Scale IQ (FSIQ), Verbal IQ (VIQ) and Performance IQ (PIQ). At this
time, it was considered that patterns within an individual’s sub-test profile could provide indications of diagnostic considerations.

The third wave; Psychometric Profile Analysis, was borne out of factor-analytic procedures which revealed that tests such as the WISC and Wechsler Adult Intelligence Scale (WAIS; Wechsler, 1955), rather than holding a dichotomous structure, in fact appeared to hold a three-factor structure (Flanagan & Kaufman, 2009). The three factors were titled Verbal Comprehension, Perceptual Organisation, and Freedom from Distractibility, and these were adopted in subsequent revisions of both the WISC and WAIS.

Lastly, building upon Psychometric Profile Analysis, came the fourth wave; Application of Theory. This approach to test interpretation emphasised the need to integrate theory and research, highlighting the weaknesses of previous approaches that lacked a theoretical base upon which the process of interpretation could be guided (Flanagan & Kaufman, 2009). This approach saw a move towards reorganising subtests according to clusters, established by theories of cognitive ability, and interpreting performance at the cluster rather than subtest level. One such theory is the Cattell-Horn-Carroll (CHC) theory, a comprehensive framework which describes cognitive abilities and processes at a broad and narrow level (Flanagan & Kaufman, 2009). Table 1.4 illustrates the broad ability classifications suggested by CHC theory.

Table 1.4 Broad ability classifications as indicated by CHC theory (Flanagan & Kaufman, 2009).

<table>
<thead>
<tr>
<th>Broad ability classification</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fluid intelligence (Gf)</td>
<td>Mental operations used when facing a novel task that cannot be performed automatically. Includes: forming and recognising concepts, perceiving relationships among patterns, drawing inferences, comprehending implications, problem-solving, extrapolating, and reorganising or transforming information. Narrow-ability indicators of Gf include: inductive and deductive reasoning.</td>
</tr>
<tr>
<td>Crystallised intelligence (Gc)</td>
<td>Breadth and depth of a person’s acquired knowledge, and the effective application of such. Includes both declarative (long-term) and procedural knowledge (reasoning from previously learned concepts).</td>
</tr>
</tbody>
</table>
Quantitative knowledge (Gq)  
An individual’s store of acquired quantitative, declarative and procedural knowledge. Ability to use quantitative information and manipulate numeric symbols.

Short-term memory (Gsm)  
Ability to apprehend and hold information in immediate awareness and use it within a few seconds.

Visual processing (Gv)  
Ability to generate, perceive, analyse, synthesise, store, retrieve, manipulate, transform, and think with visual patterns and stimuli. Requires the perception and manipulation of visual shapes and forms, usually of a figural or geometric nature.

Auditory processing (Ga)  
Ability to perceive, analyse, and synthesise patterns among auditory stimuli and discriminate subtle nuances in patterns of sound and speech when presented under distorted conditions.

Long-term storage & retrieval (Glr)  
Ability to store information in and fluently retrieve new or previously acquired information from long-term memory. Glr is the efficiency by which information is initially stored in and later retrieved from long-term memory.

Processing speed (Gs)  
Mental quickness. Ability to fluently and automatically perform cognitive tasks, especially when under pressure to maintain attention and concentration.

In summary, IQ scores are considered to provide an indication of ‘intelligence’, and are good predictor’s of school performance (Lezak, Howieson & Loring, 2004). However, the concept of ‘intelligence’ itself has been subject to much critique within the literature. As outlined above, neuropsychological assessment has developed significantly over time, and it has been suggested that testing instruments do not assess a unitary construct, but that they measure discrete cognitive abilities (Lezak et al., 2004). It is considered that these specific processes work together, to produce an efficient and integrated cognitive system (Schafer, 1982). Therefore, although IQ scores provide the best estimate of general ability, due to the diversity of functions measured by test batteries such as the Wechsler scales, IQ scores in fact characterise a ‘composite’ of performance (Lezak et al., 2004). It is beyond the scope of this thesis to also provide a detailed overview of the discrete areas of cognitive functioning such as memory, attention or executive function. For a more detailed account of these neuropsychological functions, the reader is directed to Anderson et al., (2001), Baron (2004) and Lezak et al. (2004).
Part Three – Factors affecting outcome following traumatic brain injury

Outcomes following paediatric head injury are highly variable, with numerous factors implicated within the literature as predictors of recovery or outcome. A review of this literature has identified the most commonly reported factors, which can be found in Table 1.5 (Anderson & Catroppa, 2006). The paragraphs which follow focus on a discussion of injury and developmental factors, and their relationship with paediatric TBI. Finally, a model illustrating the factors implicated within long-term outcome of paediatric TBI is presented.

Table 1.5 Factors contributing to outcome after childhood brain injury

<table>
<thead>
<tr>
<th>Domain</th>
<th>Predictor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Injury factors</td>
<td>Severity (mild, moderate, severe)</td>
</tr>
<tr>
<td></td>
<td>Nature and location of injury (diffuse or focal)</td>
</tr>
<tr>
<td></td>
<td>Subsequent disability (post-traumatic epilepsy, speech or physical disability)</td>
</tr>
<tr>
<td>Developmental factors</td>
<td>Age at injury</td>
</tr>
<tr>
<td></td>
<td>Developmental stage</td>
</tr>
<tr>
<td>Pre-injury factors</td>
<td>Pre-injury functioning (cognitive ability, personality)</td>
</tr>
<tr>
<td></td>
<td>Family factors (family functioning, parent mental health)</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
</tr>
<tr>
<td>Environmental factors</td>
<td>Socioeconomic status</td>
</tr>
<tr>
<td></td>
<td>Access to resources (educational, rehabilitation)</td>
</tr>
</tbody>
</table>

1.6 Injury factors

As is found following TBI sustained in adulthood, the nature and severity of the cerebral insult is hugely important in determining outcomes for children and young people. Examination of the literature reveals that the dose-response relationships observed in adult populations are also evident in paediatrics, with greater cerebral insult indicative of greater disruption to normal functioning (Ewing-Cobbs, Milner, Fletcher, & Levin, 1989). Severe TBI has been frequently associated with poorer outcomes within cognitive, physical, behavioural, adaptive, and academic domains (Anderson et al., 2005a; 2005b; Anderson et al., 2006; Catroppa, Anderson, Morse, Haritou, & Rosenfeld, 2008; Fay et al., 2009), in addition to increased levels of family burden (Anderson, Catroppa, Haritou, Morse & Rosenfeld, 2005b).

Severe injury also places children and young people at greater risk of experiencing multiple deficits, as has been demonstrated by two research groups who have utilised longitudinal study designs to investigate outcomes in ‘functional’ domains (Anderson et
al., 2005b; Fay et al., 2009). Within these studies, functional deficits encompassed a degree of impairment within the domains of physical, intellectual, memory, attention, behavioural or family functioning (Anderson et al., 2005b) and neuropsychological, behavioural, adaptive or academic functioning (Fay et al., 2009). Fay and colleagues (2009) demonstrated that when a TBI group and orthopaedic injury controls were compared, whilst nearly 60% of the severe TBI group evidenced at least one functional deficit at 12-months post-injury, a much lower rate of 25% was observed in the orthopaedic group. This discrepancy remained evident at the four year follow-up, with 40% of the severe TBI group continuing to demonstrate deficits in two or more domains, as opposed to less than 20% in the orthopaedic group. Similar results were observed by Anderson and colleagues (2005b).

Orthopaedic injury groups are commonly used as controls within studies investigating outcome post-TBI. Use of orthopaedic controls provides a comparative sample that have also experienced the stress associated with a traumatic injury and hospitalisation, and allows researchers to control for the risk factors that may predispose children to injury (Levin, Hanten & Li, 2009; Wade et al., 2004; Yeates et al., 2001). An additional advantage of using orthopaedic comparison groups within studies investigating psychological disorder; is that they allow researchers to control for emotional distress that is influenced by somatic complaints, such as pain or fatigue that may be experienced by both patients with TBI or orthopaedic injury (Luis & Mittenberg, 2002).

The ‘dose-response’ relationship between injury severity and outcome has been widely supported within research in paediatric TBI (Johnson, DeMatt, & Salorio, 2009; Taylor et al., 2002; Yeates et al., 2002), and has been demonstrated up to five years post-injury (Anderson, Catroppa, Morse, Haritou & Rosenfeld, 2009; Catroppa et al., 2008). It has been hypothesised that children sustaining severe injury may not only demonstrate persistent and multiple impairments, but these difficulties may increase over time as a result of disruption to normal developmental processes (Anderson & Catroppa, 2006; Anderson et al., 2009).

The nature of the brain injury itself also leads to differential outcomes. Focal injuries such as stroke or brain tumour occur more commonly in adulthood and generally lead to specific difficulties including aphasias (impairment in language function) and apraxias (loss of the ability to perform initiated movement). These focal injuries and subsequent impairments
are less commonly seen in children and young people, who tend to be affected by more
generalised insults such as TBI. Acquired injuries such as TBI, hydrocephalus or infection
have a more widespread impact on the brain, leading to greater disruption of cognitive
skills (Anderson et al., 2001). One review paper has identified that children sustaining
open head injuries, multiple fractures and non-accidental injury fair worse in relation to
post-injury physical and cognitive functioning (Johnson et al., 2009). Another commonly
identified result of moderate and severe TBI is diffuse axonal injury, consisting of
numerous lesions that are disruptive to the brain’s neural circuitry. Such neurological
damage is important as these circuits are crucial for mediating a variety of cognitive
functions, and as such, greater diffuse axonal injury is also predictive of poor outcome
(Johnson et al., 2009).

Lesion site has also been the focus of research investigating outcome following paediatric
TBI, with functional specialisation of the brain’s hemispheres. Generally, the left
hemisphere is considered responsible for the processing of verbal, mathematical and motor
sequences, with the right hemisphere more adept at the processing of stimuli that is hard to
verbalise (Lezak et al., 2004, p. 55). The left hemisphere is also reportedly superior in
processing of familiar material, and in obtaining the detail within stimuli, whilst the right is
more suited to the processing of novel material, and obtaining the global entity of a
concept (Lezak et al., 2004, p. 55). In young children, it had been suggested that either
hemisphere was capable of subsuming language function, but that the left hemisphere
naturally took on a greater role in this domain throughout normal child development
(Lenneberg, 1967). Lenneberg (1967) argued that if damage occurred during the ‘critical
period’ (2-5 years of age), there was potential for transfer of function. However, more
recent studies employing neuroimaging techniques have failed to support this theory,
suggesting that even with early lesions there is evidence of language impairment
(Anderson et al., 2001). With regards to IQ scores, it appears that insult occurring after 12
months of age within the left hemisphere may not result in any verbal or performance IQ
deficits, in contrast to the decreased verbal performance that is generally seen in adult
populations, yet that with lesions occurring in the right hemisphere, a decrease in
performance IQ has been noted, in keeping with the pattern observed in adults (Anderson
et al., 2001).

With regards to specific cerebral areas, temporal lesions have been associated with poor
memory function and learning (Di Stefano et al., 2000; Salorio et al., 2005), parietal
injuries with somatosensory, perceptual and motor deficits (Kolb & Whishaw, 1990, p. 418-429), and frontal insults with reduced empathy (Shamey-Tsory, Tomer, Berger, & Aharon-Peretz, 2003), poor verbal fluency and learning (Kolb & Whishaw, 1990, p. 469) and widespread difficulties in executive function (Fontaine, Azouvi, Remy, Bussel & Samson, 1999). Specific lesion sites have also been linked to a range of psychological disorders. Post-injury anxiety has been associated with lesions to the superior prefrontal gyrus (Max et al., 2011) and mesial prefrontal and temporal lobe lesions specifically associated with post-injury obsessive-compulsive symptoms (Grados et al., 2008).

Depressive disorder and personality change have been associated with insult to the frontal lobes (Max et al., 2005c; 2006; Max et al., 2012). Although some studies have made initial claims linking specific lesion locality to post-injury symptoms, one recent review of the literature has concluded that findings tend to be inconsistent, and that as such, there is currently little evidence to suggest relationships between lesion location and psychosocial outcome (Anderson et al., 2011).

1.7 Developmental factors

The literature suggests that the age at which a child sustains brain insult will influence the development of their neurobehavioural skills (behaviour resulting from neurological function), although it is acknowledged that this relationship is not simple in nature (Anderson et al., 2011). One review of the literature concluded that research supports the hypothesis that development is more adversely affected the younger the child is at the time of brain insult, and that there was little evidence to suggest that deficits resolve with age (Taylor & Alden, 1997). Elsewhere, Bond-Chapman & McKinnon (2000) highlight that whilst some impairments in young children increase in severity over time, others may only emerge at later stages after injury, thus age at injury acts not as a predictor, but a moderator of outcome.

Anderson and Moore (1995) examined the relationship between age at injury and cognitive outcome by assessing children injured before and after the age of seven years. Their results indicated that children who had sustained a TBI prior to seven years of age performed more poorly than did those children injured at or after the age of seven. Recovery trajectories were also found to be associated with age at injury. Whilst younger children demonstrated a stable performance from four months to two years post-injury, older children demonstrated increases in their abilities across the follow-up period. The recovery seen in older children is more consistent with recovery profiles observed following TBI.
sustained in adulthood. Similarly, research which focused upon intellectual outcome in preschoolers indicated that those with severe TBI were at risk for persistent and global deficits up to five years post-injury (Anderson et al., 2009). However, the site of the lesion also appears to be implicated within the relationship between age at insult and outcome, with children sustaining early frontal injuries appearing to ‘grow into their deficits’ (Bond-Chapman & McKinnon, 2000). Where young children have sustained frontal injury, they may initially appear to function normally, until they reach a maturational and cognitive level when executive skills tend to become more apparent. Thus, plasticity appears less advantageous for younger children who have not yet acquired certain skills, such as those maintained within frontal areas.

1.8 A model of developmental brain plasticity
Numerous studies have investigated the factors that influence outcome after paediatric TBI. Dennis (2000) argues that neurobehavioural outcome is determined by the biological risk associated with a medical condition and is moderated by age and developmental stage, the time since onset of the condition, and the resources available within the child, family, school, and community. In summary of the research evidence, and drawing upon Dennis’ framework, Bond-Chapman & McKinnon (2000) have proposed a model illustrating how biopsychosocial factors influence developmental recovery after childhood brain insult. This model can be found in Figure 1.1.

Bond-Chapman & McKinnon’s model asserts that plasticity of the injured brain is associated with the severity, size and location of the insult. This is moderated by the maturational stage of the brain and the integrity of surrounding neuronal circuits. The framework also acknowledges that the maturational stage of the brain is closely related to an individual’s cognitive developmental stage, with early neurological injury leading to increased difficulty in acquiring those cognitive stages that are naturally developed during adolescence. Finally, Bond-Chapman & McKinnon (2000) highlight the influence of exogenous factors on the adaptability of the brain, including family, school, social and community support. Should these external influences have a positive impact, this may alleviate stress levels and have a beneficial effect on the individual, whereas post-injury anxiety or depression could complicate recovery processes (Bond-Chapman & McKinnon, 2000).
Part Four - Sequelae of paediatric TBI

Over the years, research in relation to paediatric TBI has challenged the notion that children can be viewed as ‘little adults’, or that the developing brain is capable of adaptation which would be advantageous to an individual’s ultimate outcome (Anderson et al., 2001). As this literature has become more prevalent, interest in investigating outcomes after paediatric TBI has increased. Initially, research focused on cognitive and physical outcomes, with more recent research focusing upon psychosocial domains of functioning. This section aims to describe research which has investigated outcomes within cognitive and psychosocial domains.

1.9 Cognitive outcomes

Studies investigating the cognitive impact of paediatric TBI have documented significant and on-going impairment, with particular deficits in information processing, attention, memory and learning reported (Anderson et al., 2001). A recent meta-analysis reviewed the literature regarding neurocognitive recovery after paediatric TBIs across the injury
spectrum (Babikian, & Asarnow, 2009). The reviewers were interested in the domains of general intellectual functioning, attention, executive functions, memory and visual perceptual or motor skills. Results indicated that children who sustained mild injuries (GCS 13-15) demonstrated few, if any impairments across a two year follow-up period. In contrast, children with moderate injuries (GCS 9-12) demonstrated a reasonable recovery in intellectual functioning, but exhibited particular deficits in executive skills, processing speed, attention, fluency, inhibition and problem-solving by two years post-injury. This group did not appear to successfully regain levels of cognitive functioning in line with their demographically-matched peers. Finally, children with severe injuries (GCS 3-8) demonstrated significant impairments across cognitive domains at the two year follow-up. This group appeared to fall further behind their demographically-matched peers over time, as their impairments prevented them from achieving developmental age-appropriate milestones (Babikian & Asarnow, 2009).

Babikian and Asarnow’s review supported the hypothesised ‘dose-response’ relationship between injury severity and neurocognitive outcome, where those children who sustain the greatest cerebral insult demonstrate greatest neuropsychological impairment (Ewing-Cobbs et al., 1989). Although research has indicated that injury severity accounts for a proportion of the variance in outcome following childhood head injury, particularly in relation to the cognitive domain, this variable alone does not fully explain degree of impairment. As Figure 1.1 illustrates, pre-morbid deficits in learning or behaviour, psychosocial factors, age at injury and time since injury have also been investigated in relation to their role in determining outcomes (Anderson et al., 2001; Bond-Chapman & McKinnon, 2000).

1.10 Psychosocial
The umbrella term ‘psychosocial’ has been widely used within health research (Martikainen, Bartley, & Lahelma, 2002), including that which has investigated outcome following paediatric TBI. The Oxford Dictionaries (2013) define ‘psychosocial’ as: “relating to, or the interrelation of social factors and individual thought and behaviour”. In relation to paediatric TBI, research has demonstrated that psychosocial difficulties are common following TBI, and are often viewed by parents and teachers as the most concerning of all post-injury symptoms (Levin, 1987). Whilst some difficulties such as irritability, impulsivity and emotional lability may occur as a direct result of brain insult, other difficulties such as depression, low self-esteem or ineffective social integration may result from secondary adjustment problems, pre-morbid functioning or family factors.
(Anderson et al, 2001; Semrud-Cliekman, 2001). One review has highlighted that common psychosocial difficulties include disinhibition, apathy, inattention, behavioural immaturity, increased anger and aggression, impulsivity, social awkwardness and withdrawal, hyperactivity, anxiety and depression (Noggle & Pierson, 2010).

In contrast to the widely accepted relationship between severity of injury and poor outcomes in relation to cognitive and physical functioning, the presentation of psychosocial difficulties do not always demonstrate the same linear relationship (Anderson et al., 2005b; Noggle & Pierson, 2010). The risk of psychiatric, behavioural and social disturbance following paediatric TBI appears to be related to the presence of pre-morbid psychosocial difficulties (Anderson et al., 2001; Anderson et al., 2005b, Brown et al., 1981). Age at injury has also been implicated in determining the types of presentations observed, where young children tend to present with internalising problems, with age, externalising difficulties appear to increase (Poggi et al., 2003). The domains of psychosocial functioning that have been considered in relation to paediatric TBI will now be discussed in turn. This discussion will include consideration of behavioural, psychological, adaptive and family functioning.

1.10.1 Behavioural functioning

Research which has investigated behavioural difficulties after childhood head injury has considered the broad concepts of behavioural functioning or adjustment, or the prevalence of specific disorders including ADHD, disruptive behaviour disorders and aggression. Where TBI groups have been compared with non-injury or orthopaedic injury groups, children with head injuries consistently demonstrate poorer post-injury behavioural functioning (Andrews, Rose & Johnson, 1998; Light et al., 1998; Taylor et al., 1999). Identified behavioural difficulties have included impulsivity and hyperactivity (Knights et al., 1991), poor competence (Donders & Ballard, 1996; Taylor et al., 1999), maladaptive behaviour, aggression and anti-social behaviour (Andrews et al., 1998). However, the literature is not entirely consistent, with some papers concluding that levels of behavioural disturbance post-TBI were low, tending not to exceed the ‘normal’ range (Barker-Collo, 2007; Hayman-Abello, Rourke & Fuerst, 2003; Ponsford et al., 1999). The variation in reported outcome is likely due to the variation in research methodologies employed within these studies.
Much of the literature investigating behavioural functioning also considers the frequency of reported difficulties in relation to injury severity classifications. To date, this research has produced mixed findings. Whilst several studies found no direct relationship between behavioural impairment and injury severity (Andrews et al., 1998; Hayman-Abello et al., 2003; Ponsford et al., 1999), other studies employing analysis of variance methods demonstrated that the presence and degree of behavioural disturbance was associated with injury severity, with children sustaining severe injury faring worse than those with mild or moderate injuries (Kinsella, Ong, Murtagh, Prior & Sawyer, 1999; Knights et al., 1991; Taylor et al., 1999). Other studies have employed regression analysis to investigate factors that were predictive of behavioural difficulties. They identified that injury severity (Kinsella et al., 1999), pre-morbid functioning (Donders & Ballard, 1996), familial and environmental factors (Kinsella et al., 1999; Taylor et al., 1999) all influence post-injury behavioural disturbance.

With regard to specific disorders which have been associated with behavioural dysfunction post-TBI, research has investigated the prevalence of Attention-Deficit Hyperactivity Disorder (ADHD), Oppositional Defiance Disorder (ODD) and conduct disorder (CD). ADHD is defined as a disorder most prominently characterised by deficits in behavioural inhibition; including hyperactivity, impulsivity and inattention (Gerring et al., 1998). ODD and CD are disruptive behaviour disorders, the criteria for which range in severity from non-compliance to physical aggression (Gerring et al., 2009).

Prevalence rates of ADHD in TBI groups have been found to be higher than in community samples, both pre-morbidly and post-injury (Gerring et al., 1998), leading the authors to suggested that a diagnosis of ADHD may place children at greater risk of sustaining head injury. Risk factors that have been associated with the onset of ADHD following childhood head injury include sustaining an injury of greater severity, poorer family functioning, lower socio-economic status (SES), greater psychosocial adversity and poorer pre-injury adaptive functioning (Max et al., 1998a; Max et al., 2005a; Max et al., 2005b). Post-injury ADHD has also been associated with the onset of other behavioural and psychological disorders including personality change, ODD and CD (Max et al., 2005a; Max et al., 2005b).

Fewer studies have considered the epidemiology of post-TBI ODD and CD, and the conclusions drawn from this research are inconclusive to date. One study indicated that
prevalence of ODD symptoms tends to increase in the initial 12-months post-injury, then declines over the second year, yet remains elevated in comparison to pre-injury levels (Max et al., 1998b). Contrastingly, Gerring et al. (2009) did not observe the same increase in ODD, yet did observe an increase in CD. This paper also identified that new-onset ODD/CD were commonly present with other behavioural difficulties, including new-onset ADHD. Finally, other research which investigated post-injury aggression, concluded that significantly higher levels of aggression were demonstrated in the year following head injury, including verbal aggression, physical aggression towards objects and against others (Cole et al., 2008). These authors also found that pre-injury aggression, pre-injury child and family functioning and injury factors were significant predictors of post-injury aggression.

1.10.2 Psychological functioning

Another large body of research investigating outcomes after childhood head injury focuses upon psychological or psychiatric disorders. Within this area, studies have employed various terms to describe emotional distress, including psychiatric, neurobehavioural or psychological dysfunction. Alternatively, studies have investigated the prevalence of specific mental health difficulties including posttraumatic stress disorder (PTSD), depression, anxiety disorders and personality change.

Research that has focused upon ‘psychiatric disturbance’ has found that at 12-months post-injury, children who sustained severe head trauma present with psychiatric diagnoses at a rate twice that seen in an orthopaedic injury group (Brown et al., 1981). Post-injury psychiatric disorders were also more common where children had experienced pre-injury psychiatric disturbance. Longitudinal research has studied ‘new-onset’ psychiatric disorder following paediatric TBI at 3-, 6-, 12- and 24-months post-injury. At 3-months, 46% of children were diagnosed with a new-onset psychiatric disorder (Max et al., 1997a). Respective rates at the 6-, 12- and 24-month follow-up assessments were 24% (Max et al., 1997b), 37% (Max et al., 1998c) and 36% (Max et al., 1997c). The authors also investigated which factors predicted new-onset psychiatric disorder. Whilst the individual predictors changed across the follow-up, by 24-months post-injury, severity of injury, family functioning and lifetime psychiatric disorder all significantly contributed to the development of a new disorder (Max et al., 1997c).
Another concept which has been used within the literature to describe emotional dysfunction following childhood head injury is ‘psychological disorder’. Using the Child Behavior Checklist (Achenbach, 1991), Poggi et al. (2005) identified that whilst psychological disorders were observed in 57.1% of a TBI group, a far lower rate of 26.7% was observed in a brain tumour control group. This again reflects the distinctly higher rates of emotional dysfunction in TBI groups, as opposed to other paediatric populations.

As for behavioural disorders, prevalence of specific psychiatric disorders post-TBI has also been investigated. PTSD is one such disorder which has received attention within the literature. One longitudinal study concluded that incidence of PTSD was in fact rare, with only two participants within a cohort of 50 meeting full diagnostic criteria (Max et al., 1998d). Within this study, even when full criteria had been met, this had resolved by the 3-month follow-up. Experience of individual trauma symptoms was more common, with the most frequently reported symptom being intense psychological distress at exposure to events that resembled the trauma. Generally, symptoms appeared to increase in the first three months post-head injury, with a subsequent and gradual decline up to 24-months (Max et al., 1998d). It is possible that the reportedly low prevalence of PTSD after TBI is associated with PTA, and the fact that many children and young people simply do not recall the events leading up to and during the traumatic event.

A further study investigating the incidence of PTSD post-TBI and orthopaedic injury, employed both parent and child informants (Levi, Drotar, Yeates & Taylor, 1999). Parent-report revealed that there were significant group differences, with parents of children with TBI reporting more symptoms at 6- and 12-months post-injury. In contrast, no significant group differences were detected in the child-report at 6-months, yet by the 12-month follow-up, children with severe head injuries were reporting more symptoms of PTSD. A similar lack of parent-child agreement regarding PTSD symptoms was also observed by Gerring et al. (2002). In their group of severe TBI participants, 13% were reported to develop PTSD, yet in only two cases were symptoms substantiated by parent- and child-report. These studies also utilised regression analysis to identify predictors of PTSD symptomatology and full incidence of the disorder. Predictors commonly identified included pre-injury or early post-injury symptoms of internalising disorders (Gerring et al., 2002; Max et al., 1998d), injury severity (Gerring et al., 2002; Levi et al., 1999; Max et al., 1998d) and social disadvantage (Levi et al., 1999; Max et al., 1998d).
Prevalence of depression after head injury has also received attention within the literature. This research has indicated that TBI groups consistently demonstrate significantly higher levels of depressive symptoms than orthopaedic injury groups (Kirkwood et al., 2000; Luis & Mittenberg, 2002). Risk factors for the development of clinically significant depression are reported to include lower SES and sustaining an injury of greater severity (Kirkwood et al., 2000). Luis and Mittenberg (2002) assessed for both mood and anxiety disorders, and found that 46% of TBI participants demonstrated a new-onset mood disorder, compared to 14% within an orthopaedic comparison sample. In contrast, a much lower prevalence rate was identified by Max et al. (2012), who found that at six months post-injury, 11% of children had definite/sub-clinical depression. Furthermore, these authors did not identify a relationship between injury severity and depressive symptoms, but did identify that increasing age at injury was an important variable, with the rate of depressive disorder increasing five-fold from nine to twelve years of age.

Other research has investigated post-injury anxiety disorders. Vasa et al. (2002) calculated anxiety aggregate scores for a sample of children with severe head-injury, and observed a significant increase in mean anxiety aggregate scores from pre- to post-injury. The greatest increase in symptoms was associated with OCD, separation anxiety and simple phobia. In another study, new-onset definite/sub-clinical anxiety disorders after head injury were identified in 8.5% and 17% respectively (Max et al., 2011). Disorders included PTSD, separation anxiety, simple phobia, GAD, adjustment disorder, social phobia and panic. Younger age at injury has been consistently associated with increases in post-injury anxiety (Max et al., 2011; Vasa et al., 2002). More specifically, Grados et al. (2008) investigated OCD post-TBI. In a sample of 72 children with severe head-injury, 21 (29%) presented with new-onset obsessions or compulsions (12 obsessions, 13 compulsions, 4 both). Factors associated with new-onset OCD included being female, greater psychosocial adversity and co-morbid psychiatric disorder.

Finally, longitudinal research has investigated personality change in a cohort of TBI participants across a 24-month follow-up (Max et al., 2005c; Max et al., 2006). In the initial 6-months post-injury, personality change was reported to occur in 22% participants (Max et al., 2005c), with respective rates at 12- and 24-months of 13% and 12% (Max et al., 2006). At all time-points, personality change was associated with other new-onset disorders including ADHD, ODD and CD, and was significantly predicted by greater injury severity (Max et al., 2005c; Max et al., 2006).
1.10.3 Adaptive functioning

Research has also considered the impact of childhood head injury upon adaptive functioning, although this area has received less attention than the domains of behavioural or emotional functioning. Adaptive behaviour can be defined as “the performance of daily activities required for personal and social sufficiency” (Sparrow, Cicchetti & Balla, 2005, p. 6). Adaptive behaviour is age-dependent, generally increasing in complexity with age; it is defined by the expectations of others, is modifiable and is based on typical performance, rather than absolute ability (Sparrow et al., 2005). Studies focusing upon adaptive or social functioning have commonly employed the Vineland Adaptive Behavior Scales (Sparrow, Balla & Cicchetti, 1984) and/or the Child Behavior Checklist (Achenbach, 1991), and have generally demonstrated consistent results.

Children sustaining head injury appear to achieve lower scores on measures of adaptive functioning than children with orthopaedic injury (Levin et al., 2009; Poggi et al., 2005; Yeates et al., 2004). Where studies have utilised the Vineland Adaptive Behavior Scales, the communication and socialisation domains in particular appeared to be areas in which TBI participants fared poorly (Levin et al., 2009). Injury severity also appeared related to the degree of adaptive impairment, with children sustaining injuries of greater severity demonstrating worse outcomes (Arroyos-Jurado, Paulsen, Merrall, Lindgren & Max, 2000; Yeates et al., 2004). Poorer adaptive functioning has also been associated with family dysfunction, lower SES, and poor pre-morbid functioning (Yeates et al., 2004). Prigatano and Gupta (2006) investigated whether parental ratings of the number of their child’s close friends differed amongst groups of children who had sustained TBI or orthopaedic injury. Whilst 75% of parents in the orthopaedic group reported their children to have four or more close friends, in the TBI group, this percentage decreased as a function of injury severity: 38.9% in the mild group, 20% in the moderate group and 14.3% for the severe group.

1.10.4 Family functioning

Finally, research has considered the impact of paediatric TBI on parents and families, including family functioning, burden, or adaptation and caregiver coping, stress, distress or concerns. In relation to perceived family burden, where TBI and orthopaedic injury groups have been compared, parents of children with TBI consistently report higher levels of family burden (Ganesalingham et al., 2008; Wade, Taylor, Drotar, Stancin, & Yeates, 1998). Whilst levels of burden in both groups reportedly declined over the post-injury period, the orthopaedic injury group demonstrated the greatest reduction in burden scores.
Several papers have also indicated that levels of parental psychological distress tend to be higher in parents of children who had sustained TBIs of greater severity (Prigatano, & Gray, 2007; Wade et al., 1998). Whilst parents of children with severe injuries have reported clinically significant levels of psychological distress (Wade et al., 1998), parents of children with mild injuries scored within the non-clinical range (Ganesalingham et al., 2008).

Factors which have been associated with poor post-injury family functioning include poor pre-injury functioning and the child developing a new-onset psychiatric disorder (Max et al., 1998c). Furthermore, greater resources in the form of friends or partners, and lower levels of family- or partner-associated stress appeared to predict lower levels of parent distress (Wade et al., 2004). This relationship was present regardless of the nature of the child’s injury (TBI/orthopaedic injury) however; the association was strongest in the context of the greater adversity associated with severe TBI.

1.11 Summarising outcomes

Neuropsychological impairment post-TBI has been documented across cognitive domains for moderately-injured children in relation to their executive skills, processing speed, attention, fluency, inhibition and problem-solving, within additional intellectual impairment for those with severe injuries (Babikian & Asarnow, 2009). These children and young people do not appear to successfully regain levels of cognitive functioning in line with their demographically-matched peers, and particularly in the case of those with severe injuries, fall further behind over time as their impairments prevent them from achieving developmental age-appropriate gains. Such findings support the need for neuropsychological screening of all children who have sustained moderate/severe TBI, in order that their continued recovery takes into account new-onset difficulties which may otherwise hinder their onward development.

With regard to psychosocial functioning after paediatric head injury, the literature is continuing to grow, however to date, the focus has largely been on post-injury behavioural and psychological outcomes. The research investigating behavioural functioning appears to be the least consistent, with some papers arguing for increased behavioural disturbance after childhood head injury, whilst others argue the contrary. These inconsistent findings are likely due to differences in methodologies employed, the length of time since injury, varying degrees of injury severity, the age-range of the participants under study, and the
psychometric measures utilised to quantify outcome. However, one behavioural difficulty which does appear to be consistently associated with TBI both pre- and post-injury is ADHD (Gerring et al., 1998).

Findings relating to psychological and adaptive outcomes appear to be more consistent, with paediatric TBI groups fairing worse when compared with other paediatric populations. TBI occurring during childhood appears to increase the risk of experiencing post-injury emotional disturbance (Brown et al., 1981; Max et al., 1997c; Poggi et al., 2005). Specifically, whilst diagnoses of PTSD have been found to be rare, new-onset symptoms of depression and anxiety have been frequently associated with paediatric TBI (Grados et al., 2008; Kirkwood et al., 2000; Luis & Mittenberg, 2002; Max et al., 2011; Max et al., 2012). Whilst post-injury symptoms of depression are associated with greater injury severity (Kirkwood et al., 2000), anxiety appears to be related to age at injury, with younger children more commonly presenting with such difficulties (Max et al., 2011; Vasa et al., 2002). Finally, poorer adaptive functioning also appears to be associated with paediatric TBI, with particular impairment in communication and socialisation domains (Levin et al., 2009; Poggi et al., 2005; Prigatano and Gupta, 2006; Yeates et al., 2004).

It is of worthy note that many of the studies reporting on the presence of behavioural difficulties or emotional distress do so in terms of categories found within diagnostic manual such as the DSM-IV (American Psychiatric Association, 1994) or ICD-10 (World Health Organisation, 1992). The short-coming of describing psychosocial impairment according to such diagnostic concepts, is that the validity of such have been debated. A comprehensive review paper by Wakefield (1997) criticises the DSM-IV for the over-inclusive nature of its diagnostic criteria, which he argues fail to accurately distinguish between true mental health disorders and ‘problems of living’. Wakefield suggests that the criteria allow ‘normal’ but rowdy children to be diagnosed with ADHD, and those who are difficult to manage diagnosed with ODD. He further argues that young people are wrongly diagnosed with CD, when they present with antisocial behaviour as a result of peer pressure, threats, or abuse within the home. A further review argues that there is little evidence that widely recognised and utilised mental health diagnoses are separated by natural boundaries, and that in fact, symptoms occur along a continuum which does not fit with the current categorical system (Kendell & Jablensky, 2003). It is beyond the scope of this thesis to provide further discussion relating to the validity of diagnostic concepts, and
for further detail the reader is directed to Kendell & Jablensky (2003), Spitzer & Wakefield (1999) and Wakefield (1997).

Significantly, studies suggest that families and teachers perceive psychosocial difficulties to be more problematic than neuropsychological deficits, with reportedly higher levels of parent distress and poorer family functioning after TBI than in other paediatric groups (Ganesalingham et al., 2008; Prigatano, & Gray, 2007; Wade et al., 1998). Several factors appear to be associated with an increased risk of psychosocial difficulty after paediatric TBI, including presence of pre-morbid sub-clinical/clinical symptoms, greater injury severity, psychosocial adversity, lower socio-economic status and poor family functioning. It is not uncommon that children and young people will experience multiple psychosocial difficulties after head injury within behavioural, psychological and social domains. As has been identified within this chapter, the prevalence and intensity of the sequelae of paediatric TBI result from a complex interaction between numerous factors. These relationships are still far from being fully understood, but the reader is once again directed to Bond-Chapman & McKinnon’s (2000) framework, as a guide to the factors which require consideration from researchers and clinicians working with survivors of paediatric TBI.

**Part Five - Assessment after paediatric TBI**

“The child neuropsychologist might function as an independent provider or participate as a multidisciplinary team member, but he or she always brings a unique medical-psychological perspective to the multi-factorial assessment of a child’s neurocognitive functioning” (Baron, 2004, p. 3).

**1.12 Timing of assessment**

A number of time-related variables have been identified as important to the reliable assessment of the sequelae of brain injury sustained in childhood (Taylor & Alden, 1997). As previously discussed within this thesis, age at injury is an important factor in determining recovery and subsequent development of the child. Time since insult is also an important consideration when completing neuropsychological assessment due to: i) the rapid recovery that occurs in the post-acute period; and ii) evidence which indicates that young children may fall developmentally further behind their peers over time, as a result of the sequelae of their injury (Anderson et al., 2011). Assessment completed in the post-acute period may highlight short-term impairments that will recover with time (delayed
development), or may fail to indicate those impairments which are yet to develop (emerging deficits). Such assessment needs to be distinguished from that completed in the long-term recovery period. Finally, age at testing is also important when assessing outcome as it will determine the range of cognitive abilities which can be reliably measured, and in turn, will dictate test selection (Anderson et al., 2011; Baron, 2004). For example, impairment in simple language skills, such as picture naming, may be apparent even in the preschool years, whilst higher-order language or executive skills may not emerge until later in development.

As Baron (1995) indicates, medical and behavioural symptoms can prevent comprehensive neuropsychological assessment in the post-injury period, whilst other children are often ‘lost’ to early discharge. She recommends that clinicians administer a brief test battery prior to a child’s discharge from hospital, that can capture baseline functioning. Baseline neuropsychological evaluation obtained early after injury, aids the identification of and monitoring of deficits over time (Baron, 2004). Early identification is essential for the implementation of interventions in a timely and effective manner. This enables areas of concern to be identified early, and be compared with later performance when more extensive assessment is appropriate. It is recommended that such follow-up assessment should occur between three and six months post-injury (Lezak et al., 2004).

**1.13 Assessment measures**

Assessment for ‘impairment’ assumes that there is an ‘ideal’ or previous standard of functioning against which an individual’s performance is measured (Lezak et al., 2004). Where an individual has sustained a TBI, assessment can provide indications about recovery, in relation to pre-morbid functioning. Neuropsychology makes use of two standards of comparison; normative and individual standards. Normative data is derived from an appropriate population, and an individual’s performance can be compared against such. Where children are the subject of assessment, measurement is concerned with abilities which change with age; in essence, it is assessment of a ‘moving target’. In these circumstances, the normative standard may be the average age at which a cognitive function develops. Further, due to the differential rates of cognitive development in girls and boys, separate normative data is typically provided for each gender. Individual comparison standards involve looking at the rate of change, which can also be particularly useful with children, where rate of development can be measured (Lezak et al., 2004).
In summary, neuropsychological assessment provides standardised, objective, and reliable measures of diverse aspects of human behaviour, which allow neuropsychologists to specify and make interpretations regarding individual unique cognitive profiles (Baron, 2004). Where paediatric assessment is required, the neuropsychologist must use their knowledge of normal child development to aid their clinical impression of an individual’s performance based on their developmental stage.

**Part Six - Rationale for the current study**
Largely, the available evidence indicates that paediatric TBI can lead to significant and enduring impairment across neuropsychological and psychosocial domains. As such, research has turned its focus to the prediction of outcomes which can assist clinicians in the identification of those individuals who will require rehabilitation in order to promote their long-term recovery. Currently, there is available literature which looks to injury and demographic factors in the prediction of long-term outcome. However, little attention has been given to neuropsychological screening assessments completed in the post-acute phase, and the potential utility of such measures in identifying those most at risk of future impairment in behavioural and psychosocial domains. Early prediction of outcome is essential for the identification of targeted interventions which can assist a child’s recovery, continued learning, and adaptation to disability (Johnson et al., 2009). Standard clinical practice following paediatric TBI does not always include assessment of neuropsychological deficit, particularly in the weeks and months which follow the injury. For those children not referred until many months or years post-injury, there is a lost opportunity for recommended early treatment, raising concerns for the child, their family, and the wider social and economic systems (Robertson et al., 2002).

The research presented within this thesis aims to investigate whether a brief assessment of cognitive functioning completed at pre-discharge is related to psychosocial outcomes at a follow-up assessment completed several months post-injury. Should a cognitive assessment prove clinically useful in identifying those children most at risk of later psychosocial impairment, this would provide evidence towards the use of cognitive screening to engage those children and young people performing most poorly, who could otherwise potentially be ‘lost’ to discharge (Baron, 2004). Individuals who are not assessed prior to their discharge may be entirely missed by neuropsychological services, despite evidence to suggest that difficulties can emerge later, even where children have seemingly made good recoveries (Department of Health, 2004). In such instances, children may not
be referred to services until difficulties become entrenched, and given the later onset of
such problems, may not be referred to services which are most appropriate for their needs.

This research is particularly timely given the recent reorganisation of UK paediatric trauma
networks, following a national service review that highlighted variability in service
structure, resource and skills across the UK (Steers & Stower, 2010). This report indicated
that there was a need for high quality and effective multi-disciplinary teams, and a focus on
rehabilitation services as a priority for the future. In response to this review, ‘Safe and
Sustainable’, within the National Specialised Commissioning Team recommended the
development of ‘Children’s Neuroscience Networks’ (NHS Specialised Services, 2012).
The Safe and Sustainable approach aims to ensure that all parts of the care system work
together, and ensures accessibility to specialist expertise in a standardised fashion. Thus,
the aims of this study were considered to be valuable in the development of local trauma
services within the North West of England.

1.14 Hypotheses
The proposed project aimed to investigate whether a pre-discharge assessment of cognitive
functioning is predictive of psychosocial outcomes (paediatric-related parenting stress,
self-reported psychological distress, health-related quality of life, behavioural difficulty,
and adaptive functioning) at follow-up, in a paediatric TBI population.

In line with previous research, it was hypothesised that performance on a brief measure of
intellectual functioning would be significantly related to psychosocial outcomes, such that
children who performed most poorly on the cognitive screening assessment pre-discharge,
would demonstrate higher levels of paediatric-parenting stress and behavioural
disturbance, elevated levels of self-reported psychological distress, poorer health-related
quality of life and adaptive functioning at a follow-up assessment completed post-
discharge (Andrews et al., 1998; Babikian & Asarnow, 2009; Ganesalingham et al., 2008;
Levin et al., 2009; Poggi et al., 2005; Prigatano & Gray, 2007).
CHAPTER II: METHODOLOGY

This chapter outlines the methodology and design of this thesis study. Due to slower than anticipated recruitment, the study design was adapted from that which was originally planned. Part One of this chapter describes the initial study design in brief, with Part Two focusing upon the final study design.

**Part One – Original study**

**2.1 Design**

A within-groups, repeated measures design was planned in order to evaluate the relationship between pre-discharge screening scores and psychosocial outcome at follow-up. At the pre-discharge phase, participants would complete a screening assessment comprising of brief cognitive testing and completion of five questionnaires that measured various aspects of psychosocial functioning. Each participant would then be assessed once more for a follow-up assessment, completed between three and six months post-discharge, at which time the five psychosocial questionnaires would be re-administered.

A power calculation, as recommended by Field (2009) was used to calculate the number of participants required to demonstrate statistical significance (p≤0.05) using this study design. Field’s calculation indicated that 15 participants were required for each predictor variable entered into the regression equation. Thus, this calculation indicated that a minimum of 75 participants would need to complete this study, to satisfy this recommendation.

Clinical experience of the field supervisor indicated that at the main research site approximately 60-80 cases of moderate and severe TBIs had been admitted within the 12-months prior to study commencement. Given that this research project intended to recruit participants with varying degrees of injury severity (mild, moderate and severe), from three major paediatric neurology sites across the North of England, it was felt that obtaining 75 participants was an ambitious yet achievable target.

**2.2 Analysis**

Initially, the normal distribution of the five outcome measures (Vineland-II ABC, PIP total score, PedsQL-4.0 total score, SDQ total difficulties score and PI-ED) were to be assessed through exploratory statistics and graphical representations.
Assuming normality of distributions, the principal aim of this study; to determine whether a pre-discharge measure of cognitive functioning was predictive of psychosocial outcomes between three-six months post-discharge, was due to be investigated using a series of hierarchical multiple regression analyses. These were to be performed to identify the variance in adaptive functioning, paediatric-related parenting stress, health-related quality of life, behavioural difficulties and emotional distress, accounted for by demographic, injury, and cognitive variables.

Demographic (age, gender, socio-economic status) and injury (GCS score) variables (p≤0.1) were planned to be entered at Step 1 using forced entry, whilst Full-Scale IQ was planned to be entered at Step 2 (Field, 2009). Therefore the final regression models were due to differ by the outcome measured, due to possible differences in covariate models. In order to minimise Type I error, a Bonferroni correction to the analysis of the outcome variables was planned (0.05/5= 0.01, Tabachnick & Fidell, 2007), as five outcome variables were planned to be analysed (ABC, PIP total score, PedsQL-4.0 total score, SDQ total difficulties and PI-ED).

2.3 Challenges

During the initial recruitment stage of this study, fewer potential participants (n= 9) were identified than was anticipated and all were recruited through the main research site. Several factors appeared to have influenced slower than anticipated recruitment; including seemingly fewer TBI admissions than was expected. A smaller population of children and young people with TBI presenting at hospital limited the number of potential participants that the research team were able to approach. At the main research site, key members of the medical team were approached, briefed on the project and were regularly contacted to enquire about new TBI admissions. Furthermore, posters promoting the study had been placed in the accident and emergency department, in order to maximise staff and patient awareness of the study. It was intended that these posters would aid in the recruitment of those individuals with mild injuries who might not receive formal admission to a hospital ward.

Despite these attempts, within the first few months of the study, recruitment was sporadic. Healthcare teams naturally focus on patients’ physical recovery, therefore promoting patient and family involvement in a psychosocial research project was unlikely to feature
highly within their priority of care. Services also face many pressures, including bed-management and are encouraged to discharge patients without unduly delay. Notably, the mode length of hospital stay for paediatric head traumas at the main research centre is <72 hours (S. Rust, personal communication, June 27, 2012). Taken together, these factors were likely to have hindered communication with the research team, and as such, presented a huge challenge to the recruitment of potential participants. It is likely that many children and young people who had been admitted with TBIs were missed, particularly those who spent only a short time in hospital.

Although preparations had been made to enrol participants at two additional research sites, recruitment through these hospitals presented further challenges. It appeared that not having the research team based on site meant that communication with frontline staff regarding potential participations was further impeded. Greater responsibility was placed on the field supervisors based within these research sites, and given their primary role was clinical, they appeared to have less resource available to seek out potential participants.

Given the repeated-measures design of this study, requiring a period of at least three months between pre- and post-discharge assessments, the time-frame available for recruitment was limited (to seven months). As recruitment progressed slowly, it was necessary to alter the study design. It was considered that it would be more feasible, given the time constraints of completing a clinical psychology doctoral research project, that the study design should be altered to a case series, describing in detail the post-acute functioning of a small cohort of children and adolescents following TBI. As such, from this point forwards, recruitment focused solely on the main research site, and collecting substantial, meaningful data which would allow for comprehensive discussion of participants’ functioning in the period immediately after injury, and in the months that followed. This revised study was largely similar to that intended for the original study design, and is described in detail below.

**Part Two – Revised study**

2.4 Aims and research questions

This case series aimed to consider the clinical utility of completing a neuropsychological and psychological screening assessment in children and adolescents with TBI. Completion of a follow-up assessment aimed to provide a comparative data set that could indicate the outcomes of this cohort over time.
The following research questions were considered:

- Do children and adolescents with severe injury demonstrate greater difficulty in returning to full-time schooling after TBI than their mildly- or moderately-injured counterparts?
- Do children and adolescents with severe TBI demonstrate greater impairment in neuropsychological and psychosocial domains following TBI than those with mild or moderate injuries?
- Do parents of children and adolescents with TBI describe changes in their child’s personality post-injury?

Based on the literature to date, it was anticipated that individuals with severe injuries would demonstrate poorer outcomes, and that changes in the injured child’s personality post-TBI would be reported (Anderson et al., 2005a; 2005b; 2006; Babikian & Asarnow, 2009; Catroppa et al., 2008; Fay et al., 2009; Max et al., 2005c).

2.5 Ethical considerations

Ethical approval for the study was sought and obtained from the Liverpool East NHS Research Ethics Committee (REC reference: 11/NW0324). Subsequently, local Research and Development approval was sought from the NHS trust responsible for the main research site Trust (PIN: R01608). The amendment to the study design was approved in December 2011.

2.6 Consent

For those families who agreed to take part in the research, parents of children aged 6-15 years were asked to provide written consent (Appendix 1). Whilst formal consent was obtained from parents, children and young people under 16 years of age were also asked to indicate their agreement to take part, via the age-appropriate assent form (Appendices 2-3). Young people aged between 16 and 17 years were deemed able to provide their own formal consent to participate (Appendix 4).

2.7 Confidentiality

Participants were informed that all personal and identifiable data would remain confidential. Paper records were kept in locked filing cabinets within the paediatric psychology department of the research site. All research data was anonymised by
providing each participant with an individual alphanumerical code, known only to the research team. This information was stored in a separate locked filing cabinet. Once anonymised, all participant data was entered into a password-protected electronic database to allow for analysis.

2.8 Design
The revised study adopted a case series design in which participants’ neuropsychological and psychosocial functioning at the pre- and post-discharge stages were assessed and described in detail. The timings and content of the assessment batteries completed at the pre- and post-discharge stage were similar to that described above, with the addition of re-administering cognitive assessment measures at the post-discharge stage.

2.9 Recruitment of participants
Participants were recruited from paediatric neuroscience wards within a children’s hospital within the North West of England. All children and adolescents who had been admitted as a result of a TBI were invited to participate.

2.9.1 Inclusion and exclusion criteria
Children and young people between the ages of 6 to 17 years who had sustained a TBI of any nature or severity were eligible to participate. Given that the assessment measures employed were standardised on English speaking populations, non-English speaking individuals were not eligible to participate.

2.10 Procedure
Children who had been recently admitted to hospital following a TBI were approached and invited to participate by a member of the research team (the thesis author or field supervisor). Additionally, recruitment posters were placed within the paediatric accident and emergency department of the main research site to promote recruitment.

During recruitment, families were provided with a verbal description of the study, in addition to a written information sheet outlining the research (Appendices 5-8). Wherever possible, families were offered at least 24 hours to consider their participation, however where an individual’s discharge from hospital was imminent, provision of this period of time was not always possible. Where families indicated their agreement to take part in the study, a member of the research team collected written informed consent/assent from
children, young people and their parents. Prior to each participant’s discharge from hospital, demographic and injury data was collected, a brief cognitive screening assessment was completed and measures of psychosocial functioning were administered to both the participant and their parent/caregiver. Details of the assessment measures used are described below in section 2.11.

Between three and six months post-discharge, participants were invited to attend a follow-up appointment, either at their local paediatric psychology department, within their school or at home. During this session, cognitive assessment was repeated and psychosocial questionnaire measures were administered to each participant and their parent/caregiver. For clarity, Table 2.1 below illustrates the assessment measures completed at both the pre- and post-discharge stages.

Table 2.1 Overview of assessment measures completed at the pre- and post-discharge phase within the revised study

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre-discharge</th>
<th>Post-discharge</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Neuropsychological assessment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wechsler Abbreviated Scale of Intelligence</td>
<td>✓*</td>
<td></td>
</tr>
<tr>
<td>Wechsler Individual Attainment Test – 2nd UK Edition</td>
<td>✓*</td>
<td>✓*</td>
</tr>
<tr>
<td>Wechsler Intelligence Scale for Children – 4th UK Edition</td>
<td>✓*</td>
<td></td>
</tr>
<tr>
<td><strong>Psychosocial assessment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vineland Adaptive Behavior Scales – Version 2</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Pediatric Inventory for Parents</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Pediatric Quality of Life Inventory – Fourth Edition</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Strengths and Difficulties Questionnaire</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Paediatric Index of Emotional Distress</td>
<td>✓*</td>
<td>✓*</td>
</tr>
</tbody>
</table>

* denotes child assessment

Following both the pre- and post-discharge assessments, a brief feedback report outlining the child or young person’s current functioning was written by the thesis author, and disseminated to families and relevant professionals. Where assessment highlighted that there was a clinical need, for example further neuropsychological assessment or mental health problems including low mood or anxiety, onward referrals to appropriate services were placed by the research team.

**2.11 Measures**

The following section outlines the data collected within this study and the psychometric properties of the assessment measures employed. Cognitive and psychometric tests were selected on the basis of their utility within the clinical setting where this study took place.
Measures are described within the categories of injury data, cognitive functioning and psychosocial functioning.

2.11.1 Demographic and injury data
2.11.1.1 Socioeconomic classification
Demographic data including information pertaining to each participant’s socio-economic status (SES) classification was collected by a questionnaire completed by parents/caregivers (Appendix 9). SES classifications were determined using the National Statistics Socio-economic Classifications (NS-SEC) self-coded method (Office for National Statistics, 2010). The NS-SEC illustrated within Table 2.2 were derived from the responses to five questions relating to occupation and employment status information.

Table 2.2 Five classifications derived from the self-coded NS-SEC method (Office for National Statistics, 2010)

<table>
<thead>
<tr>
<th>Class</th>
<th>Label</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Managerial, administrative and professional occupations</td>
</tr>
<tr>
<td>2</td>
<td>Intermediate occupations</td>
</tr>
<tr>
<td>3</td>
<td>Small employers and own account workers</td>
</tr>
<tr>
<td>4</td>
<td>Lower supervisory and technical occupations</td>
</tr>
<tr>
<td>5</td>
<td>Semi-routine and routine occupations</td>
</tr>
</tbody>
</table>

2.11.1.2 Injury severity
Injury severity classification was assigned based on participants’ lowest recorded GCS score (Jennett & Teasdale, 1974). For a description of the GCS, the reader is directed to Section 1.3.1. The pre-determined categories of injury severity were adopted, thus mild injuries were indicated by GCS scores of 13-15, moderate injuries where GCS scores were 9-12, and severe injuries of GCS scores of 8 or less. Each participant’s GCS score was retrospectively obtained from a review of their medical records, and according to these scores, each participant was classified as having sustained a mild, moderate or severe TBI.

2.11.1.3 Neuroimaging data
Of those participants undergoing neuroimaging procedures, radiologists’ reports were retrospectively consulted to ascertain injury site and underlying neurological damage resulting from the TBI. Participants underwent both CT and MRI scans, and in some instances had repeated scans dependant on clinical need.
2.11.2 Cognitive functioning

2.11.2.1 Intellectual functioning (pre-discharge) - The Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999) was developed as a brief and reliable measure of intelligence. It is suitable for use with individuals aged 6-89 years. It is a standardised measure, yielding performance T-scores, which are transformed into three composite scores; namely the Verbal, Performance, and Full-Scale IQ scores (mean= 100, standard deviation= 15). It is suggested that IQ scores provide an indication of an individual’s ability across a range of cognitive functions, and that they are good predictors of academic performance (Lezak et al., 2004).

The WASI consists of four sub-tests: Vocabulary, Block Design, Similarities, and Matrix Reasoning. These subtests are similar to their counterpart versions within the lengthier WAIS and WISC assessment batteries, and are the tasks with the highest loadings on g, or general ability (Wechsler, 1999). Table 2.3 provides a brief description of each WASI sub-test.

Table 2.3 Content description of the WASI (Wechsler, 1999)

<table>
<thead>
<tr>
<th>Domains and Sub-tests</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>VIQ Vocabulary</td>
<td>A 42-item task measuring expressive vocabulary and verbal knowledge. Vocabulary relies upon memory, learning and language development, reportedly assessing crystallised and general intelligence.</td>
</tr>
<tr>
<td>Similarities</td>
<td>A 26-item task in which two words are presented and the examinee is required to explain the similarity between the presented objects or concepts. This sub-test measures verbal concept formation, abstract verbal reasoning and general intelligence.</td>
</tr>
<tr>
<td>PIQ Block Design</td>
<td>Consists of 13 modelled or printed two-dimensional geometric patterns that the examinee replicates using two-colour cubes. This task measures visual-spatial ability, visual-motor coordination, and abstract conceptualisation.</td>
</tr>
<tr>
<td>Matrix Reasoning</td>
<td>A series of 35 incomplete patterns are presented, and the examinee completes the pattern by choosing the correct response from a choice of five. A task of non-verbal fluid reasoning and general intelligence.</td>
</tr>
</tbody>
</table>

The WASI assessment battery provides a means of estimating an individual’s verbal, non-verbal and general cognitive functioning within a 30 minute time-frame. As has been identified, brief and reliable assessment of cognitive functioning within the post-acute
period following TBI is recommended (Baron, 1995), and can assist in rehabilitation planning. These baseline assessments also prove beneficial when later, more comprehensive assessment is completed. Employment of the WASI in this study was particularly useful at the pre-discharge stage, when assessment was required to be time-limited due to potential fatigue of the participants.

One test review of the WASI identified that at the sub-test and scale score level, reliability coefficients indicated a high level of internal consistency (Garland, 2005). This review also indicated that the WASI had adequate test-retest reliability and strong inter-rater reliability coefficients. With regards to its validity, the WASI is reported to have good content, convergent and discriminant validity (Garland, 2005). This review concluded that the WASI meets the general validity and reliability requirements for a brief test of intellectual functioning.

2.11.2.2 Intellectual functioning (post-discharge) – The Wechsler Intelligence Scale for Children, Fourth UK Edition (WISC-IV; Wechsler, 2004) was selected for administration at the post-discharge assessment as an alternative and comprehensive measure of intellectual functioning. An alternative measure of general ability was selected for the follow-up assessment, given that the recommended retest period required for these measures exceeded the follow-up period adopted by this study (Wechsler, 1999). The WISC-IV is comprised of 10 core sub-tests that yield five index scores: Verbal Comprehension (VCI), Perceptual Reasoning (PRI), Working Memory (WMI), Processing Speed (PSI) and FSIQ (mean= 100, standard deviation= 15). The sub-tests that contribute to each of these indices are presented in Table 2.4.

The WISC-IV was standardised on a stratified sample of 2,200 children aged 6-16 years, and has demonstrated excellent internal consistency (Cronbach’s $\alpha = 0.92-0.94$) and good validity (Wechsler, 2003). Further studies that have investigated the validity of the WISC-IV have concluded that FSIQ is a robust predictor of academic achievement (Watkins, Glutting & Lei, 2007), and that the WISC-IV can provide helpful diagnostic indicators which have implications for educational interventions (Mayes & Calhoun, 2004). Additionally, the WISC-IV has been administered to samples of children from special groups including those with TBI (n= 43). Two TBI groups; including 16 children with a history of moderate or severe open head injury (FSIQ mean= 92.4, standard deviation= 17.8), and 27 children with a history of moderate or severe closed head injury (FSIQ
mean = 90.0, standard deviation = 12.2) were assessed (Wechsler, 2003). Other research that has examined the performance of children with TBI on the WISC-IV has indicated specific deficits in processing speed (Allen, Thaler, Donohue & Mayfield, 2010; Donders & Janke, 2008; Prigatano, Gray, & Gale 2008), and working memory functioning (Clonkin, Salorio & Slomine 2008).

In order to obtain a summary score that was less sensitive to the influence of working memory and processing speed, the General Ability Index (GAI) was calculated and substituted for the FSIQ score (Raiford, Weiss, Rolfhus, & Coalson, 2006). This allowed for more direct comparison of index scores provided by the WASI and WISC-IV. Correlations between the WASI and WISC-IV indicate that these measures produce consistent scores (VCI-VIQ r = .85, PRI-PIQ r = .78, Wechsler, 2003).

Table 2.4 Content and indices organisation of the WISC-IV (core sub-tests; Wechsler, 2003)

<table>
<thead>
<tr>
<th>Indices/Sub-tests</th>
<th>Description</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Verbal Comprehension Index (VCI)</strong></td>
<td>The Child is presented two words that represent common objects or concepts, and describes how they are similar.</td>
<td>Test of auditory comprehension, memory, distinction between nonessential and essential features and verbal expression.</td>
</tr>
<tr>
<td>Similarities</td>
<td>Vocabulary</td>
<td>The child names pictures and gives definitions for words that the examiner reads aloud.</td>
</tr>
<tr>
<td></td>
<td>Comprehension</td>
<td>The child answers questions based on their understanding of general principles and social situations.</td>
</tr>
<tr>
<td><strong>Perceptual Reasoning Index (PRI)</strong></td>
<td>The child views a constructed model or picture, and uses red-and-white blocks to recreate the design within a specified time limit.</td>
<td>Tests an ability to analyse and synthesise abstract visual information, nonverbal concept formation, visual perception and organisation, visual-motor coordination and learning.</td>
</tr>
<tr>
<td>Block Design</td>
<td>Picture Concepts</td>
<td>The child is presented with two/three rows of pictures, and chooses one picture from each row to form a group with a common characteristic.</td>
</tr>
</tbody>
</table>
Matrix Reasoning | The child looks at an incomplete matrix and selects the missing piece from five response options. | Measures fluid intelligence, visual information processing and abstract reasoning skills.

**Working Memory Index (WMI)**

| Digit Span (Forward and Backward) | Digit Span Forward requires the child to repeat numbers in the same order as verbally presented to them. Digit Span Backward requires the child to repeat the numbers in reverse order to that presented. | Measures auditory short-term memory, sequencing, attention and concentration. The shift between tasks also requires cognitive flexibility and mental alertness.

| Letter-Number Sequencing | The child is read a sequence of numbers and letters and recalls the numbers in ascending order and the letters in alphabetical order. | Assesses sequencing, mental manipulation, attention, short-term auditory memory, visuospatial imaging and processing speed.

**Processing Speed Index (PSI)**

| Coding | The child copies symbols that are paired with simple geometric shapes or numbers, within a specified time limit. | Test of processing speed, short-term visual memory, learning ability, visual perception, visual-motor coordination, visual scanning, cognitive flexibility and attention.

| Symbol Search | The child scans a search group and indicates whether a target symbol(s) matches any of the symbols in the search group, within a specified time limit. | Relies upon processing speed, short-term visual memory, visual-motor coordination, cognitive flexibility, visual discrimination and concentration.

---

2.11.2.3 Academic attainment – The Wechsler Individual Attainment Test, Second UK Edition (WIAT-II; Wechsler, 2005) consists of sub-tests that assess the achievement of children and young people aged 4-16 years, across the domains of reading, writing, mathematics and oral language. For each sub-test, raw scores are converted to standard scores (mean= 100, standard deviation= 15). The WIAT-II is often used where there are concerns over an individual’s educational progress, as it can provide meaningful information to assist with diagnostic, placement and intervention decisions (Wechsler, 2005).

Participants were administered the Word Reading sub-test, a brief assessment of phonological awareness, word recognition and decoding. Adult neuropsychological models use performance on word reading tasks as an indicator of pre-morbid ability (Crawford,
In childhood, this task provides an estimate of individual achievement, given that reading is an essential skill for academic attainment.

The WIAT-II has been standardised on a UK population using a stratified sampling plan, ensuring that representative proportions of children from each demographic group were included in the validation process. Word Reading was demonstrated to have strong internal consistency (Cronbach $\alpha = .97$), test-retest reliability ($r = .98$) and good content-, construct- and criterion-related validity (Lichtenberger & Smith, 2005). Furthermore, the construct validity of the measures of general ability and academic attainment employed within this study have been demonstrated by the strong correlation observed between the FSIQ of the WISC-IV and the Word Reading sub-test of the WIAT-II ($r = .74$, Wechsler, 2003).

2.11.3 Psychosocial functioning

2.11.3.1 Adaptive functioning – The Vineland Adaptive Behavior Scales, Version 2 (Vineland-II; Sparrow, Cicchetti & Balla, 2005) parent/caregiver rating form, was selected as a well-established and comprehensive measure of adaptive functioning. The Vineland-II assesses adaptive behaviour in the four broad domains of Communication, Daily Living Skills, Socialization and Motor Skills, and is applicable from birth through to 90 years of age. Table 2.5 below provides an overview of the skills measured within each of the four domains of adaptive functioning:

<table>
<thead>
<tr>
<th>Domains and sub-domains</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td></td>
</tr>
<tr>
<td>Receptive</td>
<td>How the individual listens, pays attention and what they understand</td>
</tr>
<tr>
<td>Expressive</td>
<td>What the individual says, and how they use words/sentences to gather and provide information</td>
</tr>
<tr>
<td>Written</td>
<td>What the individual understands about how letters make words, and what they read and write</td>
</tr>
<tr>
<td>Daily Living Skills</td>
<td></td>
</tr>
<tr>
<td>Personal</td>
<td>How the individual eats, dresses, and practices personal hygiene</td>
</tr>
<tr>
<td>Domestic</td>
<td>What contribution the individual has to household tasks</td>
</tr>
<tr>
<td>Community</td>
<td>How the individual uses their time, money, the telephone, computer and occupational skills</td>
</tr>
<tr>
<td>Socialization</td>
<td></td>
</tr>
<tr>
<td>Interpersonal relationships</td>
<td>How the individual interacts with others</td>
</tr>
<tr>
<td>Play and leisure time</td>
<td>How the individual plays and uses leisure time</td>
</tr>
</tbody>
</table>
Coping skills  
How the individual demonstrates responsibility and sensitivity to others

**Motor Skills**  
**Gross**  
How the individual uses their limbs for motor coordination

**Fine**  
How the individual uses their hands and fingers to manipulate objects

**ADAPTIVE BEHAVIOUR COMPOSITE**  
A composite of the Communication, Daily Living Skills, Socialization and Motor Skills domains

The number of items completed by the parent/caregiver varies according to the age of their child, with each item considered against a three-point Likert scale. For individuals up to the age of six years, the Vineland-II yields standard scores across the four aforementioned domains of adaptive functioning (Communication, Daily Living Skills, Socialization and Motor Skills), in addition to an Adaptive Behavior Composite (ABC) score. For those over the age of seven years, a score for Motor Skills is not obtained. Higher scores are indicative of better adaptive functioning.

The Vineland-II was standardised in the USA on a sample of 3,695 individuals from birth to 90 years of age. In relation to the age group of participants under investigation within this thesis, the Vineland-II standardisation sample comprised of 1,965 individuals aged 6-18 years. The Vineland-II has demonstrated high internal consistency across domains (Cronbach’s α = .87-.97), moderate to high test-retest reliability (.74-.91) and good validity (Sparrow et al., 2005).

2.11.3.2 *Paediatric parenting stress* – The Pediatric Inventory for Parents (PIP; Streisand, Braniecki, Tercyak, & Kazak, 2001) is a self-report questionnaire assessing parental stress related to caring for a child with an illness. This measure was selected over general measures of parenting stress, given that it provides items relevant to parenting children with health problems (Streisand et al., 2001). The PIP measures the frequency and degree of difficulty associated with 42 stressful events, within four domains relevant to caring for a child with physical health problems (medical care, communication, role function and emotional functioning). Each item is rated on a five-point Likert scale for both the frequency and difficulty associated with that event. Frequency and difficulty scores are summed to provide total frequency (PIP-F) and total difficulty (PIP-D) scores. Higher scores are indicative of greater frequency and difficulty associated with stressful events.
This measure was standardised on a sample of parents of children with cancer, during which the PIP demonstrated high internal consistency (Cronbach’s \( \alpha = .80-.96 \)) and good validity (Streisand et al., 2001).

2.11.3.3 Health-related quality of life – The Pediatric Quality of Life Inventory, Fourth Edition, Generic Core Scales (PedsQL 4.0; Varni, Seid, & Kurtin, 2001) were selected as a brief and well-established measure of health-related quality of life (HRQoL). The parent-proxy report version of PedsQL 4.0 is a 23-item questionnaire which assesses parental perceptions of child quality of life in relation to physical, emotional, social and school functioning. Each item is rated against a five-point Likert scale. Responses yield three scores; physical health, psychosocial health and a total score, with clinical cut-off scores provided for each; physical health= 62.28, psychosocial health= 64.38, and total score= 65.42 (Varni, Burwinkle, Seid, & Skarr, 2003). Where respondents score below the clinical cut-off, this is indicative of an individual who is deemed ‘at risk’ in terms of their HRQoL. Three parent-proxy versions relevant to the age-range of the participants were administered (‘young child’= 5-7 years, ‘child’= 8-12 years, and ‘adolescent’= 13-18 years).

The PedsQL 4.0 has been applied to paediatric populations, and more specifically to children and adolescents who have experienced TBI (McCarthy et al., 2005; Varni et al., 2003). McCarthy and colleagues (2005) confirmed that when the PedsQL 4.0 was administered to a TBI population, it demonstrated good internal consistency (Cronbach’s \( \alpha = .74-.93 \)) and good test-retest reliability (\( r = .75-.90 \)).

2.11.3.4 Behavioural functioning – The Strengths and Difficulties Questionnaire (SDQ; Goodman, 1999) parent-proxy version was selected as a 25-item behavioural screening questionnaire, with accompanying impact supplement. The SDQ assesses positive and negative psychological attributes, using a three-point Likert scale across five domains (emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems and pro-social behaviour). The SDQ is suitable for use with children and adolescents aged 3-16 years. Parent responses are used to obtain scale scores for five subscales, with item scores for the first four scales summed to generate a total difficulties score. Norms are available for the UK population (Youth in Mind, 2001).

In a British epidemiological sample of 5-15 year olds, the SDQ was demonstrated to hold adequate internal consistency across sub-scales (Cronbach’s \( \alpha = .63-.85 \)) and satisfactory
test-retest reliability (Goodman, 2001). Although the psychometric properties of the SDQ have not been evaluated within a TBI population specifically, research has demonstrated its efficacy in identifying emotional and behavioural difficulties in a paediatric setting (Glazebrook, Hollis, Heussler, Goodman, & Coates, 2003). Furthermore, a recent systematic review concluded that the parent-proxy version of the SDQ was an efficient psychiatric screening tool for use within clinical and community populations (Warnick, Bracken, & Kasl, 2008).

2.11.3.5 Emotional distress – The Paediatric Index of Emotional Distress (PI-ED; O’Connor, Carney, House, Ferguson, & O’Connor, 2010) is a brief self-report measure of emotional distress for use with children and adolescents aged 8-16 years. The PI-ED is a downward version of the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), a measure that is widely administered within adult populations. The PI-ED is a 14-item questionnaire, which requires individuals to choose the response that best describes their mood in the last seven days. Gender-specific cut-off scores are provided, which indicate clinically significant levels of emotional distress (boys= 10, girls= 11).

The PI-ED has been standardised on a large UK population in educational and clinical settings, and excludes somatic symptoms of distress that can be mistaken for the presentation of physical illness (O’Connor et al., 2010). Rather than indexing anxiety and depression scores separately, the PI-ED provides a total score which indicates emotional distress severity. Factor analyses performed on the PI-ED data suggested that this scale measures a higher-order construct (emotional distress), that has anxiety and depression as lower order, co-morbid factors (O’Connor et al., 2010). The authors of this measure suggest that terms such as cothymia, negative affectivity or internalising disorder are appropriate for describing this higher-order construct.

The psychometric properties of the PI-ED have been evaluated with a clinical sample consisting of children recruited from a general hospital paediatric outpatient department O’Connor et al., 2010). In relation to this population, the PI-ED was demonstrated to have good internal reliability (Cronbach’s α = .74-.86) and adequate test-retest stability (r=.71-.81).
2.11 Analysis

The demographic, injury, neuropsychological and psychosocial data collected for each participant was presented in individual case descriptions. For ease of reading and interpretation, mildly- and severely-injured cases have been grouped together.

The overall group cognitive and psychosocial outcome data has also been presented within tables, with scores of particular significance highlighted for the reader. Finally, in order to summarise outcomes as positive or negative within the group of participants under study, each case has been rated against four dichotomous variables relevant to psychosocial outcome: return to full-time schooling; no intervention with psychological services required; no intervention with social services required; parent perception of child’s personality was unchanged. In particular, on-going service involvement captures a wide-range of post-injury difficulties which may be neuropsychological and/or psychosocial in their origin. Again, for ease of interpretation, these ratings are grouped according to injury severity, in order that consideration could be given to the impact of severity on outcome.
CHAPTER III: RESULTS

This chapter provides the results of a case series of 11 children and young people who had experienced a TBI. Initially, case descriptions are presented, followed by a summary of outcomes according to the four dichotomous variables outlined in section 2.11.

3.0 Case descriptions
This section provides a case description for each of the 11 participants. Injury factors, neurological data, information relating to pre-injury functioning, neuropsychological outcomes, psychosocial outcomes and qualitative remarks are presented for each participant. For readability, participants who sustained ‘mild’ head injury (GCS score 13-15) are presented first, followed by those participants who sustained ‘severe’ head injury (GCS score ≤ 8). Demographic and injury data for all participants is presented in Table 3.1. Tables 3.2 and 3.3 present individual participant scores obtained on the cognitive and psychological measures respectively.

3.1 Participants with mild head injury
3.1.1 Case one

Pre-injury functioning
Case One was an 11 year old White British male. Parent report indicated that prior to his TBI, he was of average intelligence and well-liked amongst his peers. In terms of his interests, he described enjoying sports, particularly BMX biking.

Mechanism of injury
Case One sustained his head injury when in the company of friends. He fell approximately seven foot from a rope swing, and subsequently slipped into a stream.

Medical data/neurology
Those present at the scene described that after falling, Case One lost consciousness for several minutes. Upon the paramedic’s arrival, his Glasgow Coma Scale score (GCS) was assessed and recorded as 13/15. He was transported to the accident and emergency department (A&E) at his district general hospital, where upon his arrival his GCS score had increased to 15/15. He presented as drowsy, with vomiting and complaints of headache.
Table 3.1 Demographic and injury characteristics of participants (n=11)

<table>
<thead>
<tr>
<th>Case</th>
<th>Age (years)</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Handed-ness</th>
<th>SES Code</th>
<th>Injury</th>
<th>Injury to T1 (days)</th>
<th>T1 to T2 (days)</th>
<th>Injury severity score (GCS)</th>
<th>Injury severity classification</th>
<th>Pre-injury difficulties identified</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case 1</td>
<td>11.6</td>
<td>M</td>
<td>WB</td>
<td>R</td>
<td>1</td>
<td>Fall</td>
<td>10</td>
<td>104</td>
<td>13</td>
<td>M</td>
<td>N</td>
</tr>
<tr>
<td>Case 2</td>
<td>13.6</td>
<td>M</td>
<td>WB</td>
<td>R</td>
<td>1</td>
<td>Fall</td>
<td>58</td>
<td>95</td>
<td>15</td>
<td>M</td>
<td>N</td>
</tr>
<tr>
<td>Case 3</td>
<td>11.3</td>
<td>M</td>
<td>WB</td>
<td>R</td>
<td>3</td>
<td>Sport-related</td>
<td>13</td>
<td>159</td>
<td>15</td>
<td>M</td>
<td>N</td>
</tr>
<tr>
<td>Case 4</td>
<td>14.1</td>
<td>M</td>
<td>WB</td>
<td>L</td>
<td>1</td>
<td>RTA</td>
<td>3</td>
<td>126</td>
<td>15</td>
<td>M</td>
<td>N</td>
</tr>
<tr>
<td>Case 5</td>
<td>15.3</td>
<td>M</td>
<td>WB</td>
<td>L</td>
<td>2</td>
<td>Fall</td>
<td>7</td>
<td>105</td>
<td>13</td>
<td>M</td>
<td>Y</td>
</tr>
<tr>
<td>Case 6</td>
<td>8.3</td>
<td>F</td>
<td>WB</td>
<td>L</td>
<td>4</td>
<td>RTA</td>
<td>10</td>
<td>105</td>
<td>8</td>
<td>S</td>
<td>N</td>
</tr>
<tr>
<td>Case 7</td>
<td>9.1</td>
<td>M</td>
<td>WB</td>
<td>R</td>
<td>5</td>
<td>RTA</td>
<td>94</td>
<td>103</td>
<td>7</td>
<td>S</td>
<td>N</td>
</tr>
<tr>
<td>Case 8</td>
<td>10.9</td>
<td>M</td>
<td>WB</td>
<td>L</td>
<td>5</td>
<td>RTA</td>
<td>28</td>
<td>131</td>
<td>8</td>
<td>S</td>
<td>Y</td>
</tr>
<tr>
<td>Case 9</td>
<td>7.5</td>
<td>F</td>
<td>MR</td>
<td>L</td>
<td>4</td>
<td>Fall</td>
<td>7</td>
<td>93</td>
<td>3</td>
<td>S</td>
<td>N</td>
</tr>
<tr>
<td>Case 10</td>
<td>13.2</td>
<td>M</td>
<td>WB</td>
<td>R</td>
<td>5</td>
<td>RTA</td>
<td>42</td>
<td>164</td>
<td>4</td>
<td>S</td>
<td>N</td>
</tr>
<tr>
<td>Case 11</td>
<td>13.8</td>
<td>M</td>
<td>WB</td>
<td>L</td>
<td>1</td>
<td>RTA</td>
<td>8</td>
<td>124</td>
<td>6</td>
<td>S</td>
<td>Y</td>
</tr>
</tbody>
</table>

Key: F= female, M= male, WB= White British, MR= Mixed race, L= left, R= right, SES codes (1= managerial, administrative or professional, 2= intermediate occupations, 3= small employers and own account workers, 4= lower supervisory and technical, 5= semi-routine or routine), RTA= road traffic accident, T1= pre-discharge, T2= post-discharge, GCS= Glasgow Coma Scale, S= severe, M= mild, Y= yes, N= no.
Given this clinical presentation, he was transferred and admitted to the high dependency unit (HDU) at the regional trauma centre. Computerised tomography (CT) scanning revealed a small subdural/extradural bleed (between the arachnoid mater and the skull) and swelling in the right frontal-parietal region, with a right temporal skull fracture. Damage to the right frontal-parietal brain region has been associated with motor, somatosensory or perceptual deficits (Kolb & Whishaw, 1990, p. 418-429).

**Neuropsychological data**

Case One’s pre-discharge assessment was undertaken 10 days after he sustained his injury. He was observed to cope well with the tasks and was able to complete them in one session. He declined the offer of a break during administration of the WASI, but was clearly fatigued by the end of the assessment, returning to bed to sleep. The assessment of his general intellectual functioning revealed that he was performing at the upper end of the ‘average’ range, in terms of both his verbal and visuospatial abilities (VIQ/PIQ). His reading abilities also fell within the ‘average’ range.

At the post-discharge follow-up, completed 104 days (3.5 months) post-injury, whilst Case One’s visuospatial scores (PRI) were comparable to those achieved at pre-discharge (PIQ), his language skills (VCI) appeared less robust. During his initial assessment, he had achieved a Similarities scaled score falling at the upper end of the ‘high average’ range, however at follow-up, his obtained score was six scaled points lower, falling at the lower end of the ‘average’ range. This led to a reduction in his obtained verbal aggregate score (VCI).

It is not recommended that interpretation of neuropsychological function is made on the basis of individual sub-test scores, as overall trends of scores within specific domains are more reliable indicators of ability (Flanagan & Kaufman, 2009; Ryan-Morgan, 2012). Given that Case One’s abilities on other verbal tasks fell within average ranges, rather than the post-discharge assessment reflecting a decline in his verbal abilities, it was more probable that his high pre-discharge Similarities score was an anomaly. Furthermore, the potential decline in his verbal abilities was not in-keeping with Case One’s right-sided injury, where visuospatial deficits are more commonly observed (Lezak et al., 2004, p. 55). With regards to his performance on the working memory and processing speed tasks of the WISC-IV, Case One achieved scores that fell within the ‘average’ range. Finally, his
performance on the reading task at follow-up indicated that his abilities in this domain were equivalent to that observed at the pre-discharge assessment.

**Psychosocial functioning**

In relation to his psychosocial functioning, Case One’s self-reported emotional functioning improved over time, moving from the clinical to non-clinical range from pre-discharge to follow-up. Deficits in behavioural or adaptive functioning as measured by the SDQ and Vineland-II respectively were not observed at either the pre- or post-discharge assessments. However, parent-report did indicate a slight decline in their perception of child HRQoL, across both physical and psychosocial domains. Despite this decline, his scores did not fall below the clinical cut-offs at either assessment. Finally, a significant reduction in paediatric-related parenting stress was observed over time.

**Qualitative remarks**

During clinical interview, Case One’s mother noted that he seemed to be lacking in organisational skills and to be forgetful. However, she acknowledged that her concerns were in the context of a recent transition to secondary school, where there was an increased expectation of managing organisational demands. Occasionally, Case One had been observed to make word substitutions for common objects, such as naming a vacuum cleaner an “iron”. His level of insight regarding this was reportedly good, given that he was able to self-correct these mistakes immediately.

By the follow-up assessment Case One had returned to school full-time, but following the advice of the medical team was not yet participating in contact sports. He was reportedly finding this difficult, wanting to return to football and rugby. His mother also reported feeling somewhat anxious about allowing him to participate in BMX biking, due to worries that he may fall and injure himself further. In general, the family reported feeling that Case One’s recovery was going well, and did not feel that further involvement with psychological services was required. With regard to his mother’s minor concerns relating to his memory and organisation skills, they were advised to adopt a ‘watchful waiting’ strategy, and to approach the paediatric neuropsychology service, should these concerns persist. The paediatric neuropsychology service within which these participants were assessed operates an open access policy, and families are able to self-refer following the completion of an initial assessment, such as those undertaken within this study.
3.1.2 Case Two

Pre-injury functioning
Case Two was a 13 year old White British male. Pre-injury, Case Two was described by his parents as very sociable, with a large group of friends who he frequently spent time with after school. He was also reported to enjoy playing football, computer games and skiing holidays. Case Two was in the upper sets at school for all subjects, and was reportedly a bright individual who aspired to study medicine.

Mechanism of injury
Case Two was with friends when he sustained extensive injuries, including head trauma, after falling 20 feet from a tree.

Medical data/neurology
It was unknown whether Case Two lost consciousness for a period of time after his fall, however paramedics at the scene recorded his GCS score as 15/15. Initially, Case Two was taken to a district general hospital, where he presented as very pale and with irregular breathing. He was subsequently intubated whilst he underwent CT scanning, which revealed liver lacerations and bleeding, pancreatic bleeding, splenic injury and two rib fractures. He was immediately transported to the regional trauma centre for liver related surgery. After surgery, Case Two was admitted to the paediatric intensive care unit (PICU) where he stayed for a total of 35 days.

An MR scan later confirmed that Case Two had also sustained diffuse axonal injury and a contusion to his left occipital lobe. Lesions involving the visual association areas of the occipital lobes can result in visual agnosias or visual distortions, with left-sided lesions in particular leading to difficulties in the correct naming of familiar faces (Lezak et al., 2004, p. 66-68), however, no problems with Case Two’s functional visual system were reported, and the results of an ophthalmological assessment were consistent with this. During his neurorehabilitation, Case Two required nasogastric tube feeds and was supported by a multidisciplinary team including physiotherapists and speech and language therapists. He was discharged from hospital after 65 days in hospital.

Neuropsychological data
Case Two undertook the pre-discharge assessment 58 days post-injury, given that he was not deemed medically stable until this time. He engaged well with the assessment process,
appearing motivated and interested in his performance. He was able to complete the pre-discharge cognitive assessment in one session. On this occasion, Case Two obtained a FSIQ score falling within the ‘high average’ range, with a relative strength in his visuospatial skills (PIQ in the ‘high average’ range) when compared to his language abilities (VIQ in the ‘average’ range). The observed strength in his visual skills was pleasing given the occipital location of his TBI (Lezak et al., 2004, p.66-68). At this time, his reading abilities were observed to fall at the upper end of the ‘average’ range.

Case Two’s follow-up assessment was undertaken 95 days (3.2 months) after his initial assessment. Again, he appeared motivated and engaged in the assessment process. At this time, Case Two’s language skills (VCI) appeared to have been preserved, as he achieved a score within the ‘average’ range of functioning. Although his visuospatial composite score (PRI) was slightly lower at follow-up, he still achieved a score within the ‘average’ range. Inspection of Case Two’s performance on the individual tasks comprising the PRI (Block Design and Matrix Reasoning) revealed that on both tasks, he had obtained a scaled score at least one point lower than that which he had achieved pre-discharge. Additional data that was gained from administration of the WISC-IV indicated no concerns with regards to Case Two’s working memory abilities (‘average’ range); however his performance on the tasks of processing speed indicated that these skills were significantly weaker than his abilities in other domains (‘low average’). This is not an uncommon finding post-TBI, with processing speed having been identified as particularly vulnerable to the effects of paediatric TBI (Anderson et al., 2001). Finally, his performance on a task of word reading indicated that these skills were maintained at follow-up, achieving a score within the ‘high average’ range.

Psychosocial functioning
At both the pre- and post-discharge phase, self-reported emotional distress scores fell within the non-clinical range. However, this was in contrast to parent-report that indicated a slight increase in emotional symptoms over time, as measured by the SDQ. Of significant note, Case Two’s adaptive functioning skills appeared to decline over time, with the composite score falling from the ‘adequate’ to ‘low’ range. Whilst he had maintained his daily living skills, both his communication and socialisation scores had declined with time. At the pre-discharge assessment, parent-report indicated the perception that Case Two’s physical and psychosocial quality of life was poor, with scores falling below the clinical
cut-offs. Scores at follow-up reflected clinically significant improvement over time (Varni et al., 2003). Paediatric-related parenting stress appeared elevated across the assessment period.

**Qualitative remarks**

At the post-discharge assessment, Case Two was only able to attend school for one or two hours a day due to fatigue. Both he and his mother reported that the return to school had been a challenging and overwhelming experience for him. In order to supplement his learning, Case Two was receiving five hours of home tuition per week. It was envisaged that he would continue with a phased return to school over the following weeks and months.

During clinical interview at follow-up, it was also reported that subsequent to his discharge from hospital, Case Two was experiencing separation anxiety and difficulties sleeping alone. He described feeling safer when in his mother’s company. On this basis, Case Two was offered and provided with on-going psychological support addressing his post-trauma anxiety and confidence.

### 3.1.3 Case Three

**Pre-injury functioning**

Case Three was an 11 year old, White British male. He was reported by his parents to excel at school, and to have a competitive nature with other pupils. He was also reported to enjoy sport, and playing computer games.

**Mechanism of injury**

Case Three sustained his TBI when on a golf course. A golf ball inadvertently struck him on the forehead, from a distance of approximately 40 yards.

**Medical data/neurology**

No loss of consciousness was recorded at the scene or later in hospital; however Case Three did describe “feeling funny”, possibly an indication of concussion. His GCS score was consistently recorded as 15/15. Post-injury, Case Three attended A&E at his district general hospital, where his head wound was ‘glued’, prior to him being sent home. Overnight, Case Three developed vomiting and was subsequently brought back to A&E. A CT scan was completed, which indicated a depressed fracture of the right frontal bone, in
addition to a right frontal lobe contusion and oedema. He was therefore transferred to the regional trauma centre.

An MR scan completed four days post-injury revealed that Case Three had extensive oedema and swelling of the right frontal cortex, and slight midline shift to the left. Midline shift occurs when the brain shifts past its centre line, and identification of such is important as this shift is an indicator for raised intracranial pressure (ICP) and diffuse injury (Maas, Stocchetti & Bullock, 2008). Case Three underwent a right frontal craniotomy, during which a small extradural haemorrhage was noted and subsequently evacuated. Right frontal injuries have been associated with decreased empathic responses (Shamey-Tsorry, Tomer, Berger, & Aharon-Peretz, 2003), reduced block construction and design copying performance (Kolb & Whishaw, 1990; p. 469).

Neuropsychological data

Case Three undertook the initial screening assessment 13 days after sustaining his TBI. He was entirely cooperative with the testing and maintained good engagement throughout, not requiring any breaks to rest. Case Three obtained a pre-discharge FSIQ falling at the upper end of the ‘average’ range, however his verbal score (VIQ) was relatively stronger, falling with the ‘high average’ range. His reading abilities also fell within the ‘average’ range of functioning.

The follow-up assessment was completed 159 days (5.3 months) post-injury. On the measure of general ability, Case Three’s pattern of scores were comparable to that obtained at pre-discharge, with a relative strength in the language domain. A slight increase in both his VCI and PRI composite scores had also led to his overall ability score (GAI) moving into the ‘high average’ range of functioning, as was his Word Reading score at follow-up. Given that Case Three’s scores were improved at follow-up, going against the notion of regression towards the mean (Davis, 2008), this suggested that Case Three may have evidenced a degree of recovery in function during the post-acute period.

There were no concerns with regard to his working memory functioning or processing speed, which fell within the ‘average’ and ‘high average’ ranges respectively. In general, the measures of general ability and word reading skills did not highlight any specific concerns relating to Case Three’s cognitive functioning.
Psychosocial functioning
Across psychosocial measures and over time, Case Three’s scores fell within non-clinical ranges, indicating that emotional, behavioural and adaptive functioning were without concern. Furthermore, parental perception of child HRQoL was perceived to be good, falling above the clinical cut-offs. In contrast, parenting stress scores appeared to increase over time. This may be attributed to the difference in the informant, given that pre-discharge data was based on paternal-report, whereas post-discharge data was based on maternal-report.

Qualitative remarks
By the post-discharge assessment, Case Three had returned to full-time schooling. His mother considered that his recent move to secondary school had been positive, and that he had settled in well. She did not feel that further involvement from psychological services was required at the time, but was advised to contact services should she have any concerns regarding future neuropsychological impairment.

3.1.4 Case Four
Pre-injury functioning
Case Four was a 14 year old White British male. His parents described him as being good at ‘academic subjects’; and this was reflected in his placement within the highest achieving sets at school. Case Four was also reported to be of an anxious predisposition, to have a small but close group of friends and to enjoy going to the cinema.

Mechanism of injury
Case Four sustained his head injury during a pedestrian versus car road traffic accident, with a vehicle travelling at approximately 25 mph. He was hit on his left side, with the left-hand side of his head striking the car’s windscreen.

Medical data/neurology
Case Four experienced no loss of consciousness following his accident, and his GCS score remained 15/15 throughout. From the scene, he was transported to his district general hospital, where a CT scan revealed that he had sustained a left parietal fracture and an extra axial haematoma (bleeding within the skull, but outside of the brain’s tissue), with a degree of midline shift. With damage to the left parietal lobe, it was possible that Case Four would experience some perceptual deficits, specifically related to his controlling of
movement (Kolb & Whishaw, 1990, p. 421). Given the neuroimaging results, Case Four was transported to the regional trauma centre, where he was treated conservatively with repeat head scans. He was discharged from hospital eight days subsequent to his TBI.

Neuropsychological data
Case Four undertook the pre-discharge assessment three days after sustaining his TBI. Due to his experience of headache and significant fatigue, he required three sessions on sequential days in order to complete the WASI and word reading task. Despite these symptoms, he was entirely cooperative with the assessment and appeared to demonstrate good effort throughout testing. In terms of his intellectual functioning at pre-discharge, Case Four obtained a FSIQ within the ‘average’ range. Inspection of his individual composite scores revealed that he demonstrated a relative strength in his verbal skills, obtaining a VIQ within the ‘high average’ range, with a particularly high score on the Vocabulary task (‘superior’ range). His word reading abilities also fell within the ‘high average’ range. In contrast, Case Four’s PIQ fell at the lower end of the ‘average’ range.

At follow-up, completed 126 days (4.2 months) post-injury, Case Four demonstrated good engagement with the assessment. Post-discharge, the scores achieved on the cognitive assessment were wholly comparable to those obtained at pre-discharge, with his GAI falling within the ‘average’ range. Furthermore, the relative strength in verbal tasks (VCI) had been maintained and his word reading abilities remained within the ‘high average’ range. In relation to the additional subtests included within the WISC-IV, Case Four obtained a WMI score at the upper end of the ‘low average’ range, and a PSI score within the ‘average’ range. Despite sustaining a left-sided head trauma that has been associated with verbal deficits (Lezak et al., 2004, p.55), Case Four consistently demonstrated strengths in the verbal domain, likely reflecting a pre-injury strength within this domain.

Psychosocial functioning
Case Four’s self-reported emotional distress was stable over time, remaining just within the clinical range at both assessments. He reported symptoms of worry, getting easily annoyed and being restless or fidgety. In contrast, Case Four’s parents did not report any concerns with regards to his emotional well-being, nor did they highlight any difficulties with adaptive or behavioural functioning at either assessment stage. Furthermore, parental perceptions of his HRQoL improved from the pre- to post-discharge phase. Of most
significance, his physical HRQoL scores had moved from the clinical to non-clinical ranges over time, reflecting clinically significant improvement (Varni et al., 2003). Finally, parent-report indicated a decline in parenting stress over time.

**Qualitative remarks**

At follow-up Case Four had returned to full-time schooling but was still experiencing occasional headaches. His reported progress following his transition back to school initially suggested that his academic performance had declined. However, by the follow-up assessment he had managed to regain his previous levels of ability. His mother reported some minor concerns with regard to him seeming forgetful, but acknowledged that “he had never seemed to have a good memory”. However, she generally perceived that he was doing well and such did not feel further involvement with psychological services was required at that time. His mother was advised to monitor Case Four’s memory functioning over time, and to contact services should she become more concerned at a later date.

### 3.1.5 Case Five

**Pre-injury functioning**

Case Five was a 14 year old White British male. Pre-injury, this participant was reported to have had behavioural difficulties and he had been expelled from mainstream school the previous year. At the time of the injury, Case Five was attending a short-stay school for a few hours each week, as a long-term educational placement had not yet been identified. Case Five’s mother had a history of substance abuse, and was a regular attendee of Narcotics Anonymous.

**Mechanism of injury**

Case Five sustained his TBI when he jumped from a moving taxi, hitting his head against a concrete bollard as he fell. He was reportedly following the actions of his friends, who jumped from the vehicle without injury.

**Medical data/neurology**

Case Five was taken from the scene by paramedics to his district general hospital.Whilst in the A&E department, he experienced a generalised tonic-clonic seizure that resolved without medication. An immediate CT scan revealed that Case Five had sustained a left-sided frontal contusion, swelling in the left frontal and right parieto-occipital areas, and thus he was immediately transferred to the regional trauma centre. Damage to these regions
has been associated with deficits in verbal fluency and learning (Kolb & Whishaw, 1990, 469), perceptual or somatosensory disorders (Kolb & Whishaw, 1990, p. 418-429) and visual agnosias or distortions (Lezak et al., 2004, p. 66-68). Case Five’s medical notes recorded his lowest GCS score to have been 13/15.

Neuropsychological data
Pre-discharge neuropsychological assessment took place seven days post-injury. Case Five was difficult to engage during the assessment, requiring much encouragement to continue with sub-tests to their discontinue rule. Due to low motivation, the assessment was completed in two sessions, during the second of which Case Five demonstrated a greater degree of willingness to participate. On this occasion, Case Five obtained a FSIQ score falling within the ‘borderline’ range, with somewhat better verbal (‘low average’) than non-verbal (‘borderline’) skills. His word reading ability also fell at the upper end of the ‘low average’ range, suggesting a relative strength in his language skills.

Follow-up assessment was completed 105 days (3.5 months) subsequent to Case Five’s injury. Again, Case Five demonstrated some reluctance to engage with the assessor, but with encouragement managed to complete the assessment in its entirety. At follow-up, Case Five’s level of general ability had fallen from the ‘borderline’ to ‘extremely low’ range of functioning, suggestive of potential decline in his intellectual abilities, in relation to his age-matched peers. With regard to his performance on the verbal and non-verbal tasks, his composite scores indicated a decline across both domains, with his scores falling by one category range, into the ‘borderline’ and ‘extremely low’ ranges respectively. He also performed poorly on tasks of working memory and those assessing processing speed, again achieving scores within the borderline and extremely low ranges of ability. In contrast, Case Five did obtain a similar score on the word reading task to that which he had achieved at pre-discharge, on this occasion falling just within the ‘average’ range of functioning.

Whilst Case Five demonstrated a decline in his cognitive functioning over time, his engagement with the assessments had to be taken into consideration, as it is possible that his lack of willingness to participate resulted in an under-estimation of his true abilities. Case Five consistently evidenced significant difficulties when faced with tasks reliant upon visuospatial skills, possibly reflecting a pre-existing problem in this area that may have
been exacerbated by the right-sided parieto-occipital injury sustained during his accident (Kolb & Whishaw, 1990; Lezak et al., 2004).

**Psychosocial functioning**

With regard to Case Five’s psychosocial functioning, his self-reported emotional distress scores fell within the clinical range at both time-points, but did decline over time. Specifically, Case Five’s responses indicated that he felt panicky, easily annoyed, and only described feeling happy or good about himself ‘sometimes’. The SDQ highlighted difficulties relating to behaviour, hyperactivity/inattention and peer relationships at both time-points, with adaptive behaviour also consistently rated in the ‘moderately low’ range. Parent-report also indicated that perceptions of their child’s psychosocial HRQoL fell below the clinical cut-off at both assessments, however physical HRQoL was perceived to improve over time. Paediatric-related parenting stress levels were reported to decline across the follow-up period.

**Qualitative remarks**

By the follow-up assessment, Case Five had not been placed back within mainstream education and his short stay schooling was also no longer available. He was receiving a minimal amount of formal academic input; one hour of home tuition per week. His mother reported continuing difficulties with regards to Case Five’s behaviour and ‘mood swings’. Furthermore, it was reported that he was being assessed by local services for suspected autistic spectrum disorder (ASD) and for a statement of educational need. A diagnosis of ASD was later discounted, but he continued to receive the support of local community psychological and psychiatric services.

### 3.2 Participants with severe head injury

#### 3.2.1 Case Six

**Pre-injury functioning**

Case Six was an eight year old, White British female. Prior to her injury, parental report indicated that she was a bright individual who was academically very able. Furthermore, she was described as a sociable and confident girl with many interests including ballet dancing, Brownies and getting involved with extra-curricular events at school.
Mechanism of injury
Case Six sustained her head injury when, as a pedestrian, she was hit by a car travelling between 20-30 mph.

Medical data/neurology
Upon arrival at the scene, paramedics recorded a GCS score of 10/15 which had declined to 8/15 (severe injury) upon arrival at accident and emergency department. She was intubated and ventilated and was initially transported to a general district general hospital, prior to her transfer to the PICU at the regional trauma centre. On PICU, neuroprotective measures were undertaken to maintain a stable ICP. This included being treated in a 30 degree head up position, adjusting her ventilation and being cooled to 35 degrees. Raised ICP is a secondary injury that can result from brain trauma, where there is an increase in cerebral blood flow volume (Lezak et al., 2004, p. 167-168). ICP can lead to intracranial bleeds, tissue damage, restriction of blood flow or the shifting of brain structures. Post-injury CT imaging revealed that Case Six had sustained right-sided parietal and temporal lobe contusions (bruising), a right-sided parietal skull fracture and a small contusion in the left anterior frontal region. Right-sided parietal insult can lead to deficits in perceptual and somatosensory ability (Kolb & Whishaw, 1990, p. 418-429), and damage to the right temporal lobe has been associated with deficits in non-verbal memory, processing speech sounds and interpretation of facial expression (Kolb & Whishaw, 1990, p. 445). Finally, insult to the left anterior frontal lobe can lead to difficulties in controlling movement related to language, verbal fluency and verbal learning (Kolb & Whishaw, 1990, p. 469).

Neuropsychological data
Pre-discharge neuropsychological assessment was undertaken 10 days after Case Six’s injury. She tolerated the assessment extremely well, managing to complete the assessment battery in its entirety within one session. She appeared attentive and motivated to take part in the assessment, however during administration of the final subtest, she began to display signs of fatigue, including decreased attention. On this occasion, Case Six obtained a VIQ score falling within the ‘very superior’ range, and a PIQ score within the ‘average’ range. This discrepancy in cognitive abilities was a pattern expected given the site of her head injury, as lesions to the right-side, particularly involving the posterior regions such as parietal lobes, are commonly associated with impairments in visuospatial abilities (Fisher & Loring, 2004). At this time, Case Six evidenced reading skills which placed her within the ‘average’ range of functioning when compared with her peer group.
At the post-discharge assessment, undertaken 105 days (3.5 months) after her injury, a consistent pattern of results was observed. Case Six continued to demonstrate a relative strength in the verbal domain; however at follow-up, this was to a lesser degree than observed at the initial assessment. Her scaled scores for those sub-tests found within both the WASI and WISC-IV test batteries had all decreased by at least one point, leading to decreases in her obtained VCI and PRI composites. The general decrease in her obtained scores at follow-up may be somewhat explained by regression towards the mean (Davis, 2008). With regards to her reading skills, these were maintained at the follow-up assessment, indicating no decline in her abilities within this domain. In summary, although strengths in her language relative to visuospatial abilities were consistently observed, abilities across cognitive domains appeared to have declined during the post-acute phase.

**Psychosocial functioning**

Case Six’s self-reported emotional distress scores declined over time, reflecting a reduction in her levels of distress, however her score remained within the ‘clinical’ range at follow-up. In contrast, parent-report of emotional symptoms on the SDQ indicated an increase in these difficulties over time. Furthermore, her behavioural and total difficulties scores on the SDQ moved from the ‘average’ to ‘clinical’ range across the follow-up period. At the post-discharge assessment, parent-report indicated an improvement in the perceptions of their child’s physical HRQoL, relative to the initial assessment. However, the psychosocial HRQoL score remained relatively stable over time, reflecting no improvement in her parent’s perception of her quality of life relating to emotional, social or school functioning. The Vineland-II was reportedly completed at the pre-discharge stage, but unfortunately was not returned to the research team. At follow-up; parent-report on this measure indicated no concerns in relation to Case Six’s communication, daily living or socialisation skills and a decline in parenting stress was observed from the pre- to post-discharge assessments.

**Qualitative remarks**

At the follow-up assessment, Case Six’s mother reported significant behavioural and personality change, including labile mood, reduced confidence, and difficulties in managing relationships both within the school and home environment. She was described to be regularly ‘falling out’ with her friends and younger sibling, due to a reduced tolerance for others and seemingly a lack of understanding of others’ emotions. Furthermore, Case Six was no longer expressing the same interest in social activities or
those hobbies which she had previously enjoyed. Case Six herself did not seem to hold the same level of insight into these difficulties as her parents, however she did describe feeling isolated from her peers as a result of the restrictions placed on her, such as not being allowed to participate in P.E. She also acknowledged feeling frustrated that she was finding learning at school more difficult than she had previously.

At the post-discharge assessment, Case Six was undergoing a phased return to school. She was attending full-time hours for three days a week, and half-time hours for the remaining two days. This was proving a challenge for her, and she was reportedly very fatigued from the transition back to school. At school, she was noted to be struggling with aspects of new learning, requiring much repetition and teacher support. Given her less robust performance on cognitive assessment at follow-up, combined with the reported difficulties at school, this participant was referred to psychology services for more detailed neuropsychological evaluation, and for support relating to her emotional and behavioural management.

3.2.2 Case Seven

Pre-injury functioning
Case Seven was a nine year old White British Male. Pre-injury, there were no specific concerns with regard to his cognitive or psychosocial functioning; however there was a history of familial psychosocial adversity, including domestic violence in the family home. In terms of his academic attainment, he was described as being of average ability.

Mechanism of injury
Case Seven sustained his TBI during a pedestrian versus van road traffic accident whilst he was outside playing with friends. The van was reported to be travelling at approximately 15 mph.

Medical data/neurology
At the scene, Case Seven’s GCS sore was recorded as 8/15 and he was immediately taken to his district general hospital. On arrival at A&E, his GCS score had dropped to 7/15 and he was intubated and ventilated prior to being transferred to PICU at the regional trauma centre. In addition to his head injury, Case Seven had also sustained an open fracture of his right tibia. Case Seven was ventilated for 17 days, and experienced extended posttraumatic amnesia (approximately seven days). Completion of CT and MR scanning revealed a fracture of Case Seven’s left parietofrontal bone, mild midline shift, and contusions to the
right frontotemporal and parietal region. As described above, insult to the right-sided temporal and parietal areas can result in deficits in non-verbal memory, processing speech sounds, interpretation of facial expression or perceptual skills (Kolb & Whishaw, 1990, p. 418-429, p. 445). Frontal damage has also been associated with memory deficits, executive dysfunction and attentional problems (Fontaine et al., 1999). Case Seven was discharged after three months in hospital, with multi-disciplinary follow-up within the community.

Neuropsychological data
Case Seven undertook his pre-discharge cognitive assessment 94 days post-injury, given that he was not deemed medically stable until this time. During the post-discharge assessment he was observed to struggle with concentration and ‘staying on task’. Case Seven achieved a FSIQ falling within the ‘low average’ range, with a relative strength in his language (‘average’ range) over visuospatial skills (‘low average’ range). He also obtained a Word Reading score within the ‘average’ range. The observed relative strength in Case Seven’s language abilities was in-keeping with the impairments associated with his right-sided TBI (Lezak et al., 2004, p. 55).

The post-discharge follow-up assessment was completed 103 days (3.4 months) following his initial assessment. Case Seven engaged well with the assessment process and appeared to apply a consistent level of effort. On this occasion, he achieved a GAI score within the ‘average’ range, suggesting some recovery of function within the intellectual domain. This was particularly relevant given that regression towards the mean would generally result in lower scores on repeated administration of cognitive assessment (Davis, 2008). Inspection of his individual composite scores revealed that the relative strength in the language domain was no longer apparent, with both his VCI and PRI scores falling within the ‘average’ range of functioning. Assessment of Case Seven’s word reading skills revealed a slight reduction in his obtained score, which at follow-up fell within the ‘low average’ range. Finally, in relation to his working memory and processing speed, Case Seven obtained scores that fell within the ‘average’ and ‘low average’ ranges respectively.

Psychosocial functioning
At the pre-discharge stage, difficulties were observed across all the domains of psychosocial functioning assessed, including clinically significant levels of self-reported emotional distress, behavioural difficulties, and poor adaptive functioning. By the follow-up assessment, measure responses were consistent, indicating persisting and increasing
deficits across domains. Parental perceptions of child HRQoL fell below the clinical cut-offs at both assessments, with no improvement in such over time. Furthermore, paediatric-related parenting stress was not reported to improve over time.

*Qualitative remarks*

At the follow-up assessment, Case Seven was attending school for half-days. Post-injury, his parents reported significant difficulties with regards to his mood, behaviour and sleep. Specifically, increasing levels of aggression, usually directed towards his siblings was identified. Given these difficulties, this participant was referred for further neuropsychological assessment and behavioural management support. As time progressed, it emerged that Case Seven had begun demonstrating socially inappropriate and sexualised behaviour in the presence of a younger sibling, and for this reason, a referral to Social Care was initiated.

3.2.3 Case Eight

*Pre-injury functioning*

Case Eight was a 10 year old White British male. Teacher-report indicated that Case Eight had always been a ‘low average’ pupil, yet had a strength in sporting activity. This participant had experienced a road traffic accident once previously, at eight years of age, in which he had sustained orthopaedic injuries. A noticeable decline in Case Eight’s learning trajectory had been observed following his initial road traffic accident, and he was also noted to have a speech impediment (stammer).

*Mechanism of injury*

Case Eight sustained his second TBI during a pedestrian versus car road traffic accident. He was reportedly crossing a road, when he was struck by a car that was travelling at approximately 30 mph that had driven through a red light.

*Medical data/neurology*

It is unknown whether Case Eight lost conscious following his accident, however due to his head and lower limb injuries; he was immediately transported via ambulance to his district general hospital. In A&E, his GCS score was recorded as 8/15, and he presented as agitated. As such, he required intubation and ventilation, prior to a CT scan which revealed a left temporal bone fracture, extra-axial haematoma in the right temporal lobe and contusions to the right temporal-parietal lobes. Left temporal lesions have been associated
with auditory deficits and difficulties in word retrieval (Lezak et al., 2004, p. 74-75). Damage to the right parietal and temporal lobes has been related to perceptual and somatosensory deficits (Kolb & Whishaw, 1990, p. 418-429), and impairments in non-verbal memory, processing speech sounds and interpretation of facial expression (Kolb & Whishaw, 1990, p. 445) respectively. Following insertion of an ICP monitor, Case Eight was transferred to the PICU at the regional trauma centre, where he was ventilated for eight days. Case Eight’s admission lasted 34 days, and after discharge he continued to receive multi-disciplinary rehabilitation in the community.

*Neuropsychological data*

Pre-discharge assessment was undertaken 28 days subsequent to Case Eight sustaining his injury. He engaged well with the assessment, but due to fatigue, the assessment was completed in two sessions. At this time, Case Eight obtained a FSIQ score at the lower end of the ‘average’ range, with strengths in visuospatial (‘average’) relative to language (low average’) skills. On this occasion he also achieved a word reading score within the ‘low average’ range.

The post-discharge follow-up assessment was completed 131 days (4.4 months) post-injury. He was re-assessed at school, where he was entirely cooperative with the assessment, although on tasks that he perceived to be difficult, his confidence appeared to reduce. On this occasion, Case Eight demonstrated the same pattern of results; however his language abilities appeared to have declined, moving to the ‘borderline’ range of functioning, whilst his visuospatial skills remained relatively static, within the ‘average’ range. A clinically significant decline in his word reading abilities was also observed, moving from the ‘low average’ to ‘borderline’ range. The observed decline in Case Eight’s language skills might be expected given that a degree of his injuries were left-sided, and this hemisphere’s dominance in language-based tasks (Lezak et al., 2004, p. 55). With regard to the additional composite scores obtained on the WISC-IV, Case Eight obtained a working memory score that fell within the ‘extremely low’ range and a processing speed score within the ‘low average’ range. Whilst a lower processing speed might be expected post-head injury, his working memory functioning was an area of significant concern.

*Psychosocial functioning*

With regard to Case Eight’s levels of emotional distress, his self-report scores fell below the clinical cut-off at both assessments. Parent-report indicated stability in Case Eight’s
adaptive functioning over time, however these scores generally reflected his poor communication, daily living and socialisation skills, with scores falling across ‘low’ to ‘moderately low’ ranges. At follow-up, elevated score on the SDQ indicated concerns regarding behavioural difficulties, hyperactivity/inattention and problems getting along with others, all of which fell within the clinical range. In addition, parental perception of child HRQoL declined over time across physical and psychosocial domains, also falling below the clinical cut-offs at follow-up. Paediatric-related parenting stress was reported to improve over time.

*Qualitative remarks*
By the follow-up assessment, Case Eight was attending school full-time; however areas of clinical concern included increased aggression and frustration in the home, and poor academic attainment, particularly with regard to new learning. Given that Case Eight had experienced two road traffic accidents, his mother was expressing significant concern relating to his road safety awareness, and the possibility that he may sustain further injury. Given the difficulties highlighted within the cognitive assessment at follow-up, and the qualitative report from both Case Eight’s mother and teacher, he was referred for supplementary neuropsychological assessment and intervention relating to behavioural management. At the time of completing the follow-up assessment, Case Eight had also been referred for a statement of educational need, prior to his upcoming move to secondary school.

### 3.2.4 Case Nine

*Pre-injury functioning*
Case Nine was a seven year old female of mixed race. Pre-injury, she was described by her parents as a shy and anxious child, although no concerns regarding to her learning or behaviour were reported.

*Mechanism of injury*
Case Nine sustained her TBI when she fell from a height of approximately four foot from a climbing frame in her school playground. She fell onto a concrete surface, hitting the left side of her head. The incident was witnessed by her mother, other school children and members of school staff.
Initially post-injury, Case Nine did not experience any loss of consciousness and she was reported to be walking and talking as normal. However, whilst still in the school playground, she subsequently vomited and presented with rapid neurological deterioration. On arrival at the scene, paramedics assessed and recorded her GCS score as 3/15. She was immediately taken to the A&E department of her district general hospital, where her GCS score was recorded as fluctuating between 4-6/15. Case Nine was intubated and ventilated prior to undergoing a CT scan, which indicated she had sustained a left-sided subdural haemorrhage (gathering of blood within the outermost meningeal layer). With left-sided injury, associated deficits in verbal abilities have been observed (Lezak et al., 2004, p. 55-57). She was subsequently transferred to the regional trauma centre, where she immediately underwent a craniotomy, evacuation of the haematoma and insertion of an ICP monitor. Post-operatively, she was nursed on PICU and was managed with neuroprotective measures (nursed head up and sedated) which maintained a stable ICP. She was extubated the following day and was transferred to the ward after two days on PICU. Case Nine was discharged after a total of 11 days in hospital.

Neuropsychological data
Pre-discharge assessment was undertaken six days subsequent to Case Nine’s injury. She was observed to have labile mood and to lack confidence, quickly becoming tearful. At pre-discharge, Case Nine obtained a FSIQ score falling at the upper end of the ‘average’ range, with strengths in language (‘superior’ range) relative to visuospatial (‘average’ range) skills. On the word reading task, Case Nine achieved a score that fell at the upper end of the ‘low average’ range. Given her left-sided injury, deficits in verbal skills may have been expected (Lezak et al., 2004, p. 55-57). However, given her performance on the language tasks at the pre-discharge assessment, it could be assumed that Case Nine had a pre-existing strength in verbal abilities.

The follow-up neuropsychological assessment was completed 93 days (3.1 months) after Case Nine’s TBI had occurred. Significant emotional distress was observed throughout the testing process, and this was likely to have had a detrimental impact on her ability to perform to her maximum potential. Despite this, Case Nine’s GAI score was comparable to the initial FSIQ score, falling within the ‘average’ range. However, her language skills appeared to have significantly declined, from the ‘superior’ (VIQ) to ‘average’ (VCI) range. Contrastingly, her performance on the word reading task at follow-up was better.
than had been observed during the pre-discharge screening, moving into the ‘average’ range of functioning. Regression towards the mean (Davis, 2008), in addition to her levels of distress and engagement with the assessment likely contributed to a reduction in her performance at the post-discharge assessment. However, given her left-sided injury, the potential impact of brain insult on language skills was of worthy note. With regards to her performance on tasks of working memory and processing speed, Case Nine obtained scores falling within the ‘low average’ range.

*Psychosocial functioning*

Both self- and parent-report indicated emotional distress within the clinical range at the pre- and post-discharge assessments, with distress increasing over time. Behavioural difficulties, hyperactivity/inattention and total difficulties scores on the SDQ were also elevated at the follow-up. No concerns were highlighted regarding adaptive functioning, at either time-point, with the exception of her socialisation skills which were reported to have declined by the follow-up. Parental perception of Case Nine’s HRQoL declined falling below the clinical cut-offs with regards to her physical and psychosocial functioning. Finally, paediatric-related parenting stress scores appeared to increase with time.

*Qualitative remarks*

The high levels of emotional distress observed during the cognitive assessments were reported by her parents and school staff to have become a general difficulty in Case Nine’s day-to-day functioning. Her re-integration to school was particularly challenging, due to significant anxiety when she was required to separate from her parents. At the post-discharge follow-up, she was attending school for mornings only, and was not completing lessons with her peers, requiring one-to-one support from a Learning Support Mentor. Given these difficulties, Case Nine was provided with on-going support in relation to her emotional and behavioural functioning. Due to the difficulties encountered in completing the cognitive assessment, the reliability of the results were questionable, and likely reflected an under-estimation of her abilities. As such, her school were advised to carefully monitor Case Nine’s progress, and to request further assessment at a later date, should cognitive concerns be raised.
3.2.5 Case Ten

Pre-injury functioning
Case Ten was a 13 year old White British male. Pre-injury, school reports indicated that there had been no concerns regarding Case Ten’s cognitive or psychosocial functioning. However there was a documented history of maternal mental health difficulties.

Mechanism of injury
Case Ten sustained his head injury when he was hit by a police car travelling at high speed whilst he was out on his scooter.

Medical data/neurology
Upon arrival of the paramedics at the scene of the accident, Case Ten was noted to have a GCS score of 4/15, and he immediately taken to the A&E department of his district general hospital. In A&E, his GCS was again assessed and recorded as 4/15, and he was intubated and ventilated. A CT scan revealed that Case Ten had sustained a right-sided parietal fracture and contusion, in addition to a left-sided frontal lobe contusion with cerebral oedema. Injury to the right parietal area has been linked to perceptual difficulties, whilst left frontal insult has been associated with verbal fluency and learning problems (Kolb & Whishaw, 1990, p. 418–429, p. 469). More generally, damage to the frontal lobes has been associated with deficits in memory, executive and attentional functioning (Fontaine et al., 1999). Abdominal imaging also indicated that Case Ten had sustained right kidney laceration. Due to the severity of his injuries, Case Ten was transported to the regional trauma centre.

Case Ten was operated on the day following his accident, and this included insertion of an ICP monitor. He was subsequently treated with neuroprotective measures for 48 hours (treated in a 30 degree head up position, adjusting her ventilation and being cooled to 35 degrees), which when subsequently relaxed led to spikes in his ICP. After a further CT scan, Case Ten underwent a frontal external ventricular drain. He was extubated 16 days post-injury, spending a total of 19 days on PICU. Case ten was discharged back to the community with a package of on-going multi-disciplinary care.

Neuropsychological data
The pre-discharge assessment was undertaken 42 days post-injury. Case Ten was entirely cooperative with the assessment, but appeared to hold little insight with regards to his
performance. On the assessment of general ability, Case Ten obtained composite scores falling within the ‘borderline’ range, yet his word reading score fell within the ‘average’ range of ability. In adults reading abilities are generally preserved following brain insult, and are therefore thought to provide an estimate of an individuals’ pre-morbid/pre-injury functioning (Crawford, 2003). Therefore, observed discrepancy between Case Ten’s assessment of general ability (‘borderline’), and reading skills (‘average’) at the pre-discharge assessment was potentially indicative of a decline in his cognitive abilities, resulting from his TBI.

The post-discharge follow-up was completed 164 days (5.4 days) after injury. Due to difficulties in engaging with this family, Case Ten completed his post-discharge assessment at school. On this occasion, his general ability composite score fell within the ‘low average’ range, with both the verbal and non-verbal composites also falling within the same range. Across the Vocabulary, Block Design, Similarities and Matrix Reasoning sub-tests, Case Ten had demonstrated an increase in his obtained scaled scores (range= 1-5). In summary, Case Ten’s performance at post-discharge was indicative of recovery of function in relation to his language and visuospatial abilities. At the follow-up, Case Ten’s word reading skills had been maintained within the ‘average’ range of functioning, his working memory abilities fell within the ‘average’ range, whilst his processing speed was somewhat lower, falling within the ‘low average’ range of functioning.

*Psychosocial functioning*

Despite indications of cognitive recovery, self-reported emotional distress increased across the follow-up period, moving well into the clinical range. Parent-report on the SDQ indicated agreement regarding Case Ten’s emotional functioning, with other elevations on behavioural, attention/hyperactivity sub-scales noted at the follow-up. With regards to adaptive functioning, both communication and socialisation scores declined over time; however his daily living skills were perceived to have been maintained. Despite this, parent-report indicated that they perceived child HRQoL to have improved across psychosocial and physical domains, with increases in score indicative of clinically significant improvement (Varni et al., 2003). Furthermore, levels of parenting stress were also reported to decrease over time.
Qualitative remarks
In clinical interview, concerns raised by the parents relating to Case Ten’s post-injury functioning included an increase in aggression, truanting from school, and expressed thoughts of deliberate self-harm/suicide. Whilst this participant had returned to full-time schooling, he was requiring full-time academic support from a teaching assistant, and had been referred to local educational psychology service. Due to the aforementioned concerns, Case Ten was offered further neuropsychological assessment and referrals were made to Social Care and Psychiatry in light of the risk issues.

3.2.6 Case Eleven
Pre-injury functioning
Case Eleven was a 13 year old White British male. This participant had pre-morbidly been the victim of sexual abuse and had also received a diagnosis of obsessive-compulsive disorder. He was under the care of local psychiatry and psychology services at the time of his TBI, and was prescribed Sertraline 50mg daily. However, he was described by his parents as a placid young man and an average pupil.

Mechanism of injury
Case Eleven sustained his TBI during a road traffic accident in which he was struck by a car, whilst he was out with friends.

Medical data/neurology
Medical records suggest that Case Eleven lost consciousness following his accident for an unknown period, however his GCS score improved to 15/15 upon his arrival at the A&E department of his district general hospital. Due to concerns relating to queried abdominal injuries, Case Eleven was transferred to the regional trauma centre. The following day, Case Eleven experienced an acute deterioration, caused by an evolving extradural haematoma (build-up of blood between the tough outer membrane of the central nervous system, and the skull). CT imaging revealed a large right-sided haematoma extending across the temporal and parietal lobes, a skull fracture extending across the right parietal and temporal bones, and a right-sided frontal depressed fracture. His GCS score had reduced to 6/15 and he required a surgical evacuation of the bleed. He subsequently spent two days on PICU, later being discharged after a total of 11 days in hospital. With damage to the right parietal, temporal and frontal regions, deficits in relation to perception, non-verbal memory, interpretation of facial expression, decreased empathic responses, attention
and executive skills may have been anticipated (Fontaine et al., 1999; Kolb & Whishaw, 1990, p. 418-429, p. 445; Shamey-Tsorry et al., 2003).

Neuropsychological data
Case Eleven undertook the initial cognitive assessment eight days post-injury. He was entirely cooperative with the assessment, and appeared to demonstrate a good level of engagement with tasks, however he demonstrated some perseveration, frequently asking repetitious questions of the assessor. On this occasion, Case Eleven’s WASI composite scores all fell within the ‘low average’ range, with a word reading score within the ‘average’ range of functioning.

At follow-up, a considerably different and discrepant cognitive profile was obtained, with the language score falling within the ‘average’ range, but a visuospatial score in the ‘extremely low’ range, indicating a clinically significant decline in his non-verbal abilities. Given his right-sided head injury, the observed discrepancy in his cognitive abilities was in the direction expected with impairment in visuospatial skills (Lezak et al., 2004, p.55). His word reading ability had however remained stable over time, remaining within the ‘average’ range of functioning. Case Eleven also demonstrated difficulties in relation to his working memory function and processing speed, again obtaining scores within the ‘extremely low’ range of ability.

Psychosocial functioning
Both self- and parent-reported emotional distress scores consistently fell within clinical ranges, and became more elevated over time. Scores on the hyperactivity/inattention and total difficulties sub-scales of the SDQ were also consistently elevated at pre- and post-discharge, with increasing behavioural difficulties over time. Adaptive functioning across domains declined over time, moving towards the ‘low’ range of functioning. Parent perception of child HRQoL also fell below the clinical cut-offs at both assessments, however, whilst Case Eleven’s psychosocial health was reported to decline across the follow-up, his physical HRQoL demonstrated clinically significant improvement (Varni et al., 2003). Paediatric-related parenting stress scores were observed to have only decreased slightly at follow-up.
Qualitative remarks

At the follow-up assessment, Case Eleven was attending school for half-days only due to significant fatigue. He was also reported to be experiencing an increase in his obsessive compulsive symptoms, and had begun demonstrate sexually disinhibited behaviour. He was continuing to receive psychiatric and psychological support from local services, however given the above documented concerns with regards to Case Eleven’s cognitive functioning, he was also provided with further neuropsychological assessment, specifically related to memory and executive functioning.
Table 3.2 Results of neuropsychological testing for all cases.

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Pre-discharge data is presented on the top row for each variable, with post-discharge data beneath. WASI/WISC-IV indices and Word Reading are presented as standard scores, and sub-tests are presented as scaled scores.

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Table 3.3 Results of psychosocial measures for all cases.

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<td>98</td>
<td>113</td>
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<tr>
<td>(Vineland-II)</td>
<td>115</td>
<td>70</td>
<td>129</td>
<td>116</td>
<td>69</td>
<td>102</td>
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<td>74</td>
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<td>Daily Living Skills</td>
<td>109</td>
<td>76</td>
<td>95</td>
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<td>Socialization</td>
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<td>66</td>
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<tr>
<td></td>
<td>Pre-discharge</td>
<td>Post-discharge</td>
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<td>(Vineland-II)</td>
<td>129 69 129 112 71 100  57  81  75 95 70</td>
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<tr>
<td>Psychosocial QoL</td>
<td>85 28* 100 58* 52* 42* 27* 82 80 28* 38*</td>
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<td>(PedsQL 4.0)</td>
<td>77 48* 88 88 52* 45* 20* 43* 42* 57* 28*</td>
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<tr>
<td>Physical QoL</td>
<td>100 28* 88 75 100 16* 13* 0* 100 0* 0*</td>
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<td>(PedsQL 4.0)</td>
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<tr>
<td>Total QoL score</td>
<td>90 29* 97 64* 68 33* 22* 53* 87 18* 25*</td>
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<td>(PedsQL 4.0)</td>
<td>78 46* 88 86 60* 53* 13* 30* 33* 58* 37*</td>
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<tr>
<td>PIP-Frequency</td>
<td>115 146 72 118 161 154 160 128 46 144 178</td>
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<td>48 158 101 61 105 80 178 91 115 108 133</td>
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<tr>
<td>PIP-Difficulty</td>
<td>94 121 42 100 140 138 168 101 42 127 164</td>
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<td>48 136 104 54 96 62 196 70 115 101 152</td>
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</tbody>
</table>

Pre-discharge data is presented on the top row for each variable, with post-discharge data beneath. PI-ED and PIP scores are presented as total raw scores. SDQ sub-scales are presented as scale scores. Vineland-II sub-scales are presented as standard scores. PedsQL 4.0 scores are presented as percentages.

Key:
* denotes a score above (PI-ED) or below (PedsQL 4.0) a clinical cut-off, and ‘high’ or ‘very high’ scores (SDQ)
/ denotes missing value
3.3 Summary of outcomes

In addition to the individual case descriptions, each of the eleven participants was rated according to four dichotomous (yes/no) outcome variables at the post-discharge follow-up:

- Return to full-time schooling
- No intervention with psychological services required
- No intervention with social services required
- Parent perception of child’s personality remains unchanged

These ratings allowed for a summary of outcomes as ‘positive’ or ‘negative’ within the group of participants under study. A child’s return to school full-time indicated that they had successfully reintegrated back into a structured educational environment, were able to cognitively meet the demands that this setting required. Furthermore, returning to full-time education is not only indicative of a recovery post-injury, but also contributes to rehabilitation, maximising the child’s opportunities for continued learning and minimising the risk of them falling further behind their age-matched peers.

A lack of service involvement within this cohort of participants was indicative of a positive outcome given that the individuals remaining under the care of services were those who required additional support for neuropsychological, psychological or social concerns. Of particular note, five participants required further cognitive assessment including comprehensive testing of memory, attention and executive abilities. Eight participants were receiving continued support in relation to their emotional and behavioural functioning, from tertiary or secondary care services. Furthermore, two participants demonstrated significant post-injury functioning that warranted a referral and follow-up from social care services. Finally, parents frequently reported during clinical interview, the sense that their child’s personality had changed subsequent to experiencing their TBI.

In order for interpretation of these outcomes in relation to the groupings of mild or severely injured participants, Table 3.4 illustrates a summary of all cases according to the four outcome variables described above. It can be noted from Table 3.4 that amongst those sustaining mild injuries (GCS 13-15), three of the five participants (Cases One, Three and Four) demonstrated an excellent recovery, and were rated positively across the four outcome variables. With regard to the remaining participants within this group, they demonstrated difficulties across three of the four domains. However it is worth noting that Case Two had experienced extensive injuries in addition to his mild TBI, and this likely
contributed to his lengthy inpatient stay and complex rehabilitation back in to the community. In contrast, Case Five had evidenced significant pre-injury deficits that appeared to be exacerbated in light of his mild head injury.

With regard to the severe group (GCS 3-8); all participants were rated as demonstrating complicated recovery processes across multiple domains of psychosocial functioning. Only two of these six cases had returned to full-time schooling, and both required additional support from teaching assistants within their educational setting. Significantly, all of the participants with severe head injury required continued involvement with psychological services, either additional neuropsychological assessment, support in relation to emotional or behavioural management, or indeed both. The two participants requiring onward referrals to social care were also those who fell within the severely injured group. Case Seven had demonstrated inappropriate sexually disinhibited behaviour, whilst Case Ten had demonstrated behaviour which indicated suicidal intent. Finally, all parents of participants who had sustained severe TBI perceived that their child’s personality was changed post-injury.
Table 3.4 Summary of dichotomous post-discharge outcomes

<table>
<thead>
<tr>
<th></th>
<th>Return to full-time schooling</th>
<th>No intervention with psychological services required</th>
<th>No intervention with social services required</th>
<th>Parent perception of child’s personality unchanged</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild injury (GCS 13-15)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case One</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Case Two</td>
<td>X</td>
<td>X</td>
<td>✓</td>
<td>X</td>
</tr>
<tr>
<td>Case Three</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Case Four</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Case Five</td>
<td>X</td>
<td>X</td>
<td>✓</td>
<td>X</td>
</tr>
</tbody>
</table>

| Severe injury (GCS 3-8) |                               |                                                    |                                             |                                               |
| Case Six          | X                             | X                                                  | ✓                                           | X                                             |
| Case Seven        | X                             | X                                                  | ✓                                           | X                                             |
| Case Eight        | ✓                             | X                                                  | ✓                                           | X                                             |
| Case Nine         | X                             | X                                                  | ✓                                           | X                                             |
| Case Ten          | ✓                             | X                                                  | X                                           | X                                             |
| Case Eleven       | X                             | X                                                  | ✓                                           | X                                             |

Key:
✓ denotes positive outcome
X denotes negative outcome
CHAPTER IV: DISCUSSION

This study aimed to follow a case series of children and adolescents with TBI throughout the post-acute and initial recovery period. The cohort was examined in terms of their cognitive and psychosocial functioning, in order to assess outcome within these domains, and over time. This chapter provides a summary of the results of this study, with links to the theoretical background of paediatric TBI. Limitations of the study are discussed, followed by the clinical implications of the study and recommendations for future research.

4.1 Review of results

Eleven children; nine males and two females with mild (n= 5) or severe (n= 6) TBI were assessed prior to their discharge from hospital and once again between three-six months post-discharge. Children were assessed in consideration of their intellectual functioning, academic attainment and emotional distress. Parents completed measures relating to their child’s adaptive and behavioural functioning, health-related quality of life and paediatric-related parenting stress. Each child’s outcome was also rated at the follow-up assessment according to four variables that were considered to indicate positive recovery. This section provides a summary of the main findings of this study, giving consideration to the aims and research questions outlined in section 2.4.

Do children and adolescents with severe injury demonstrate greater difficulty in returning to full-time schooling after TBI than their mildly- or moderately-injured counterparts?

Four of the six severely-injured participants (67%) had not returned to full-time schooling by the post-discharge follow-up, and were involved in phased return to school programmes. The transition back to school appeared, to varying degrees, to present further challenges to this group. The two participants who had fully returned to school required additional support from teaching assistants, with one of these participants having never received such prior to his injury. Comparatively, two of the five mildly-injured participants (40%) had not returned to school full-time by the follow-up assessment. However, it seemed significant that Case Five did not have a full-time educational placement prior to his injury, and therefore this variable remained unchanged pre- to post-injury. With regard to the other mild-injured participant (Case Two), he had sustained extensive injuries in addition to his TBI that required a lengthy hospitalisation and led to a complicated recovery process. Therefore, this cohort of children and adolescents with TBI appeared to
experience greater difficulty with the transition back to full-time schooling when severe injury had been sustained. However, those with mild injuries were not exempt from such problems, particularly when there was evidence of pre-injury difficulties within educational settings, or where multiple injuries had been sustained.

Difficulties in returning to school have been documented within a wide-range of paediatric conditions, including after acquired brain injury, cancer, heart or lung transplantation, and chronic fatigue (Prevatt, Heffer, & Lowe, 2000; Sankey, Hill, Brown, Quinn, & Fletcher, 2006; Sharp, Bye, Llewellyn, & Cusick, 2006; Wray, Long, Radley-Smith, & Yacoub, 2001). As the Barnados ‘From Hospital to Home’ paper highlights, the inclusion of children with health needs within educational settings is crucial for ensuring their sense of a ‘normal life’, and appropriate provision of care must be balanced with allowing the individual independence and integration within their peer group (Noyes & Lewis, 2005).

*Do children and adolescents with severe TBI demonstrate greater impairment in neuropsychological and psychosocial domains following TBI than those with mild or moderate injuries?*

All of the participants with severe TBI (100%) required on-going involvement from psychological services subsequent to the follow-up assessment. Five of the six participants within this group were offered further neuropsychological assessment to investigate their cognitive functioning within memory and executive domains. Additionally, five of the six within this cohort required intervention relating to emotional or behavioural management. Two severely-injured participants also required onward referrals to social care services (Case Seven, Case Ten) and a referral to child psychiatry services (Case Ten). In contrast, only two of the five mild-injured participants (40%) required onward support of psychological services subsequent to the follow-up assessment. Of note, these were the same participants who had not yet returned to full-time schooling.

In summary, greater impairment in neuropsychological and psychosocial domains was observed within the severely-injured group, leading to on-going involvement from psychological and social services. This finding is consistent with the wider literature reporting on outcome after paediatric TBI. Studies investigating outcome within physical, intellectual, memory, attention, behavioural and family functioning domains have indicated that poorer functioning is associated with injury severity, with children sustaining severe
injury at risk of multiple and enduring impairments (Anderson et al., 2005b; Fay et al., 2009).

**Do parents of children and adolescents with TBI describe changes in their child’s personality post-injury?**

All parents of children with severe TBI (100%) perceived that their child’s personality had changed post-injury. Furthermore, 40% of parents of children with mild TBI also acknowledged feeling that their child’s personality had changed post-injury. Thus, it is noteworthy that within this cohort of children, personality changes were observed across the injury spectrum. Again, this finding coincides with that indicated by other studies, where personality change was reported in 12-22% of TBI cases across a two year follow-up (Max et al., 2005c; Max et al., 2006). Within these studies, presence of personality change was again associated with injury severity, as found within the current case series.

### 4.2 Outcome following paediatric TBI

Over recent years the literature examining outcome after paediatric TBI has grown, initially examining cognitive and physical sequelae, before moving on to study the psychosocial impact of childhood head injury. The section that follows discusses the findings of this case series in the context of the existing outcome literature within neuropsychological and psychosocial domains.

#### 4.2.1 Cognitive functioning

Significant numbers of studies have investigated the neuropsychological impact of paediatric TBI, with particular interest in the domains of information processing, attention, memory and learning (Anderson et al., 2001). A meta-analysis evaluating studies that examined general intellectual functioning, attention, executive function, memory, visual perception or motor skills identified that children with mild TBI tended to demonstrate fewer difficulties across neurocognitive domains (Babikian & Asarnow, 2009). Similar findings were observed within this case series, given that none of the mildly-injured participants were noted to have significant changes in their cognitive functioning post-injury. Some parents qualitatively acknowledged subtle difficulties in relation to organisation and forgetfulness (Case One and Case Three). However, these of participants had transitioned to secondary school between the pre- and post-discharge assessments, and
both parents suggested that their perceptions may have been a result of this transition, and in particular the greater demands placed on them within their new school setting.

Whilst none of the mildly-injured participants were felt to require further neuropsychological evaluation at the time of the post-discharge assessment, the paediatric psychology service offered by the regional trauma centre operates an open referral and long-term surveillance policy, whereby these individuals could access additional support or assessment in the future, where this was deemed appropriate. This arrangement is particularly pertinent for paediatric trauma services given that research has indicated that children may ‘grow into their deficits’, only beginning to demonstrate impairments as they fail to achieve developmental gains and fall further behind their peers over time (Anderson et al., 2011; Bond-Chapman & McKinnon, 2000).

With regards to the neuropsychological functioning of the severely injured children within this case series, five of the six within this group were offered and provided with more detailed cognitive assessment due to concerns at the post-discharge follow-up assessment. These findings are again in accordance with the results of Barbikian and Asarnow’s (2009) review, which indicated that those children with severe TBI demonstrated significant neuropsychological impairments across cognitive domains up to two years post-injury. These authors concluded that for this group in particular, their onward development was hampered by the impact of their head injury, such that they were unable to match the developmental gains made by their age-matched peers over time (Babikian & Asarnow, 2009).

The extant literature and findings of this case series highlight the importance of screening and onward monitoring of children and young people with TBI for neuropsychological impairment. Within this cohort of children, early impairments appeared to be associated with poorer psychosocial outcome at follow-up, and without early screening, many of these children may have been lost to discharge without the essential support they required from services (Baron, 1995). Over time as difficulties persist and become more entrenched, more significant problems can develop, requiring a higher degree of support from services. These findings are supported by policy, including the Department of Health’s acquired brain injury exemplar (2004) that advocate for multi-disciplinary approaches to patient care following TBI, including the completion of timely psychological screening and intervention. In order to improve trauma outcomes within the UK, the recent reorganisation
of neuroscience services has reiterated the importance of offering specialised and standardised multi-disciplinary packages of care to all children who encounter trauma (NHS Specialised Services, 2012). Again, these recommendations include the provision of neuropsychological assessment, and where appropriate early intervention. However, what is lacking within these policies is specific guidance as to the most appropriate way to identify those most at need of support in the post-acute period. This case series would suggest that early screening assessment of cognitive difficulties and continued follow-up within the post-acute period is essential for monitoring of difficulties over time, and identification of those most at risk of neuropsychological and psychosocial intervention.

4.2.2 Psychosocial functioning

In addition to the assessment of outcome within neuropsychological domains, literature is also available that documents the psychosocial sequelae of paediatric TBI, specifically in relation to behavioural, psychological, adaptive and family outcomes. The widely-reported ‘dose-response’ relationship between injury severity and cognitive outcome does not appear to hold to the same extent with regard to psychosocial outcomes after TBI (Anderson et al., 2005b; Noggle & Pierson, 2010). This was indeed true for the current case series in which two of the five mildly-injured participants required onward support of psychological services for emotional and behavioural management (Case Two and Case Five).

Behavioural concerns have been well-documented post-TBI, including specific psychiatric syndromes of attention-deficit hyperactivity disorder, oppositional defiant disorder and conduct disorder (Gerring et al., 1998; 2009; Max et al., 1998b). Studies investigating general behavioural disturbance have suggested that children and adolescents with TBI are more likely to demonstrate increases in such behaviour, when compared with non-injury or orthopaedic controls (Andrews et al., 1998; Light et al., 1998; Taylor et al., 1999). Within this case series, behavioural difficulties were evident, and to a larger degree within the severe group (Cases Five, Six, Seven, Eight, Ten and Eleven). A specific behavioural concern that was raised by several parents was an increase in post-injury aggression (Cases Seven, Eight and Ten). This falls in line with previous research that has identified an increase in the prevalence of aggressive behaviours following paediatric TBI (Andrews et al., 1998; Cole et al., 2008).
Psychological distress and mental health disorders have also been examined in relation to childhood TBI, including depression, anxiety, posttraumatic stress disorder and personality change. Poggi et al. (2005) studied the rate of psychological disorders within a TBI and brain tumour population. They found that whilst 26.7% of the brain tumour group were classified as having a psychological disorder, a rate twice that of 57.1% was observed in the TBI group. The participants studied within the current case series were not administered a diagnostic tool that could assess presence of psychological disorder. However, the self-report measure of psychological distress employed within the current study indicated that seven of the eleven children within the cohort reported levels of psychological distress that were above the cut-off, and therefore should be considered of clinical concern.

Particular psychological difficulties that were evident within this case series related to anxiety. Three participants (Cases Two, Nine and Eleven) demonstrated difficulties including separation anxiety and obsessive compulsive disorder (OCD). The relationship between anxiety disorders and TBI has been examined, with researchers indicating significant increases in anxiety from pre- to post-injury (Vasa et al., 2002). Furthermore, the rate of sub-clinical anxiety disorders following paediatric TBI has been indicated to be in the region of 17% (Max et al., 2011). The prevalence of anxiety difficulties within the current cohort (27%) exceeded that suggested within the literature. However, previous research has indicated that there is a greater risk of post-injury psychological disorder where children have experienced pre-injury disturbance (Brown et al., 1981). Notably, Case Nine was reported by her parents to be a very shy and anxious child, and Case Eleven had a pre-existing diagnosis of OCD, the symptoms of which were reported to be exacerbated by his TBI.

Several families within this case series presented with complex social circumstances and had multiple service involvement. This provided a sample of participants who were at times ‘hard to reach’, but were a clinically interesting and relevant population. Particularly by the post-injury assessment, several of the participants presented with a complex clinical picture, and a high index of need. In total, eight participants were offered further intervention from the psychological services. Subsequent to completion of the research, these individuals required careful monitoring, and in two instances, safeguarding issues led to onward referrals to social care.
In combination with the cognitive findings, the psychosocial outcomes observed within this case series supported the use of psychological screening tools post-TBI, and continued surveillance over time. Guidelines issued by the Department of Health (2004) acknowledge the importance of the psychological well-being of patients and their families following brain injury. Specifically, they state that holistic care for the child and family should be available, including emotional support for parents during the critical care and later rehabilitation stages. The recommended role for clinical neuropsychologists is also outlined, and should include provision of clinical assessment of functional abilities, and assessment/management relating to behavioural or emotional changes. Therefore, in order to fulfil the recommendations of policies that advise on the management of TBI (Department of Health, 2004; NHS Specialised Services, 2012), and to meet the long-term needs of individuals such as those considered within this case series, pre-discharge psychological screening appears crucial. Screening for neuropsychological or psychosocial concerns could highlight early-onset difficulties, and allow for provision of timely interventions. Where there is no immediate need for service involvement, routine screening would ensure the availability of baseline data, in order that individuals are not simply ‘lost to the community’. The information obtained from screening would also prove useful following the emergence of delayed-onset sequelae of TBI, providing greater accessibility to the specialised services that can meet the needs of an individual with brain injury.

4.3 Recruitment
As described in section 2.3, significant difficulties were experienced in recruiting sufficient numbers of participants to fulfil the originally planned study design. This large-scale, multi-centre study had intended to provide a greater understanding of the factors that predict poor outcome following paediatric TBI, through the use of regression analysis. Although the completed case series provided pilot data that considered the clinical utility of screening for neuropsychological and psychosocial impairment, this small data set was unable to answer the research questions asked of the originally planned project.

The recruitment difficulties encountered within this study highlighted the challenges of completing research within NHS settings. A recent report identified that the major obstacles to conducting clinical research included obtaining R&D approval, costs implicated in completing the research, the time required to complete clinical research projects, negotiating contracts between NHS sites, and the NHS research culture (Swan, Robertson & Evans, 2009). Giving specific consideration to the current study, the required
R&D applications for the additional research sites delayed recruitment in the additional research sites, thus limiting the time-frame available for data collection. Furthermore, as the field supervisors in these locations were primarily clinicians, it appeared that not having a member of the core research team on site, further impeded recruitment. On reflection, it was likely that the originally planned study was too ambitious for a clinical psychology doctoral research project, given the time-constraints and availability of resources.

4.4 Limitations

4.4.1 Sample

This case series comprised a study with a small sample size, and therefore the generalisability of its findings are limited. Although the sample was representative of the general paediatric TBI population in terms of its male/female ratio and mechanisms of injury (Anderson et al., 2001; Hawley et al., 2003), it was less representative with regard to injury severity classifications, or in terms of its ethnic and cultural diversity. The inclusion of moderately-injured (GCS 9-12), and ethnic-minority participants would have increased the validity of the findings, and would have provided a greater understanding of the relationship between TBI severity and psychosocial outcome. Prevalence rates of paediatric TBI in the UK indicate that the majority of head injuries are classified as mild (GCS 13-15; Hawley et al., 2003). The over-representation of severely-injured participants in the current study is likely to have reflected their longer inpatient stays, and the accessibility of these participants to the research team.

Given the small sample and study re-design, the originally proposed statistical analysis of multiple regression was no longer appropriate. Although this limited the conclusions that could be drawn based upon the data collected, refraining from statistical analysis on case series data is recommended within the literature (Kooistra, Dijkman, Einhorn, & Bhandari, 2009). Limiting case series analysis to descriptive statistics only, ensures a conservative approach to the interpretation of findings. Due to the small data set on which case series are based, rather than drawing definitive conclusions, case series should be viewed as a pilot for sensible hypothesis testing within future studies with greater methodological rigour (Kooistra et al., 2009).

A further limitation with regard to this study’s sample was the lack of a control group with which to compare the TBI participants. As discussed within section 1.6, studies employing
an orthopaedic injury comparison group are able to examine the specific
neuropsychological or psychosocial outcomes resulting from TBI, against a comparative
group that has also experienced the stress resulting from trauma and hospitalisation.
Inclusion of orthopaedic controls also allows researchers to control for factors which may
pre-dispose children to sustaining injury. Thus, use of a comparative group such as
children and adolescents with orthopaedic injury, would have allowed for stronger
conclusions to be drawn on the basis of findings, that such resulted from the TBI itself,
rather than any other variables not accounted for by the research design.

Whilst the majority of studies examining TBI outcomes exclude children and adolescents
on the basis of pre-existing difficulties, this exclusionary criterion is not consistently
applied. Several authors highlight the decision to include such individuals on the basis that
it increases the clinical representivity of the findings, and allows researchers to consider
risk factors, such as pre-existing difficulties, that may predispose children to head injury
(Hayman-Abello et al., 2003; Light et al., 1998). Children with pre-injury emotional,
behavioural or learning difficulties have been identified as demonstrating an increased
vulnerability to psychosocial problems post-injury (Brown et al., 1981; Cole et al., 2008;
Gerring et al., 2002; Ponsford et al., 1999). Children and young people with pre-existing
diagnoses will experience TBI, as was found within the current study, where three
participants (Cases 5, 8 and 11) had identified pre-injury difficulties. Given that these
individuals may be at an increased risk of psychosocial problems after head injury,
inclusion of these participants appears to be valuable for researchers and clinicians, who
may wish to configure services in order that these children are more carefully evaluated
post-TBI. However, whilst valuable, the inclusion of these participants may have led to an
over-representation of clinically significant difficulties within this cohort, and decreases
the applicability of these findings to the wider literature reporting on outcomes post-TBI.

4.4.2 Measures
The measures of cognitive ability employed within the current study were not considered
to be a comprehensive assessment of the participants’ neuropsychological functioning, but
were selected on the basis of their ability to screen for general ability level (WASI;
Wechsler, 1999; WISC-IV; Wechsler, 2004) and academic attainment (WIAT-II;
Wechsler, 2005). The Wechsler assessments are widely employed and well-established
measures of general ability, however there is debate regarding their utility in informing
clinicians about specific cognitive functions. A specific example relates to the Vocabulary
sub-test, found within both the WASI and WISC-IV batteries. It is reported that this task is commonly omitted from neuropsychological assessments, due to its redundancy when other verbal tasks are administered (Lezak et al., 2004).

Fiorello and colleagues (2007) have also questioned the relevance of global intelligence during their examination of the structure of intellectual functioning within groups of children with learning disability, ADHD or TBI. They argued for a multifactorial representation of intellectual functioning for these children, with little shared variance among predictors of FSIQ. In contrast, other research has suggested that the contribution of ‘g’ should not be discounted (Bodin, Pardini, Burns & Stevens, 2009), with FSIQ found to be a robust predictor of achievement within both the normal population and clinical samples, regardless of variability amongst the test’s constituent factors (Watkins et al., 2007). Thus, the current literature reporting on the validity of general ability level in child populations appears to be inconclusive. This would suggest that interpretation of performance on measures of intelligence should discount neither the global or first order factor aggregate scores.

Another shortcoming of the Wechsler assessments is their limited assessment of executive function. Levin & Hanten’s (2005) review reported increased recognition of impairment in executive functions following paediatric brain injury. These authors also argued that these higher order cognitive abilities partly mediate the psychological and behavioural sequelae of TBI. However, the assessment of executive function in children is reported to be far from robust or straightforward. The developmental trajectories of children and the insensitivity of measures that assess executive function, particularly in young children, limit the overall validity of these measures (Levin & Hanten, 2005). Children with neurological difficulties, such as those who have sustained head injury, frequently demonstrate behaviours that fall under the category of dysexecutive deficits and it is well accepted that many of these impairments manifest themselves behaviourally (Gioia, Isquith, Guy, & Kenworthy, 2000a). However, it is acknowledged that tests of executive function may not be ecologically valid, and that understanding these impairments in the context of their impact on day-to-day functioning may not be captured by formal tests of executive function (Burgess, Alderman, Evans, Emslie, & Wilson, 1998; Gioia et al., 2000a).
Particularly in the case of child populations, measures that assess behavioural dysfunction, such as the SDQ (Goodman, 2001) appear to be valuable tools in screening for possible executive problems after TBI. An alternative measure that potentially may have had even greater value in identifying a broader range of executive deficits may have been the parent-report version of the Behavior Rating Inventory of Executive Function (BRIEF, Gioia et al., 2000a). The BRIEF is a parent-, teacher- and self-report rating measure of a child’s qualitative behavioural expression of executive function competence in real-world settings. The validity and clinical utility of the BRIEF has been examined in a group of children with mild, moderate and severe TBI, in comparison with a group of children with orthopaedic injuries (Gioia, Isquith, Guy, & Kenworthy, 2000b). The TBI group demonstrated global executive dysfunction as compared to matched controls. However, the SDQ was selected for use within this case series given that it is a briefer measure that seemed most appropriate for use as a screening tool. Furthermore, the SDQ is a widely employed measure within child and adolescent mental health services, and as such the results of such are readily acceptable to a wide-range of professionals, who may not be neuropsychologically trained. The SDQ appeared beneficial in identifying aspects of behavioural and executive difficulty, including inattention and hyperactivity that was then able to be further explored through a measure such the BRIEF, or through formal tests of executive function.

Selection of different measures of general ability at the pre- and post-discharge stages intended to reduce practice effects that can arise through repeated administration of sub-tests. Despite the WASI and WISC-IV measures containing different sub-test content, the absolute practice effects of this method are unknown (Lezak et al., 2004). It is possible that participants’ post-discharge scores were inflated due to practice effects. Furthermore, direct comparison of the WASI’s Verbal IQ and Performance IQ with the WISC-IV’s Verbal Comprehension Index and Perceptual Reasoning Index respectively, is limited in that the WISC-IV’s aggregate scores each contain an additional sub-test (Comprehension, Picture Concepts) which contribute to their composite scores. Therefore, comparisons between the verbal and non-verbal composites must be tentative, given that the participants’ scores at follow-up will have been influenced by their performance on the additional sub-tests.

With regard to the measures of psychosocial functioning, the Vineland-II (Sparrow et al., 2005), provided a comprehensive assessment of adaptive functioning. Parents appeared to
find this measure lengthy and difficult to complete. Frequently, the research team were required to contact parents to complete missing questions or sections. The Vineland-II is not validated on a UK population and therefore the participants’ scores were compared against US norms, which may not be readily comparable to the sample under study. A briefer and more accessible measure may have been more appropriate for this study, however to the author’s knowledge, no measure exists which would have been applicable across the entire age range of the sample. Finally, employment of the PI-ED (O’Connor et al., 2010), which has only been formally validated on individuals aged 8 to 16 years, limits the interpretation of Case Nine’s self-reported emotional distress. However, given that this questionnaire has a reading age of seven years; administration was considered permissible in this instance.

4.5 Clinical implications and future directions
This study provided preliminary evidence in favour of screening children and adolescents with TBI for cognitive and psychosocial difficulties within the initial post-injury period, successfully identifying those individuals requiring further assessment or intervention. Early identification and timely interventions are recommended throughout the literature reporting on the sequelae of childhood head injury (Luis & Mittenberg, 2002; Max et al., 1998c; Poggi et al., 2005). This has important public health implications, given that such difficulties can impede rehabilitation processes, particularly as they can become more entrenched over time (Anderson et al., 2001; Max et al., 2011; Vasa et al., 2002). To date, service structures and resources in the UK have prevented standardised assessment for children and adolescents with head injury. However, the publication of recent policy highlights the need for change in paediatric neuroscience services, in order that all children and families obtain a high-quality service for this complex and specialist condition (NHS Specialised Services, 2012). The findings of this study indicate that psychological screening would be a valuable clinical tool in assisting the delivery of services which meet this population’s needs through timely identification of post-injury problems, provision of appropriate assessment and intervention, and improving long-term accessibility to services.

However, given this study’s small sample size, it is important that future research aims to replicate these results with larger numbers of children with TBI, including those with mild, moderate and severe injuries, to improve the power and generalisability of the results. Similar studies may also wish to strengthen their research design with the inclusion of orthopaedic case controls. The large-scale study that was originally intended for this thesis
would have provided a greater understanding of the predictive and clinical utility of psychological screening in identifying those children at-risk of developing psychosocial difficulties. Given the pressures facing healthcare services, and the inconsistent presentation of psychosocial difficulties amongst those children sustaining TBI, having a greater understanding of how to predict those children who may be most vulnerable to future difficulties would be invaluable. Completion of such a project will likely require a longer period of time and greater resources than that which is available for a clinical psychology doctoral research project. Employment of a research nurse would likely facilitate recruitment of TBI and orthopaedic participants, and despite its challenges, having multiple research sites involved would increase the generalisability of the findings.

This case study could have been extended through further follow-up of participants at one and two years post-injury. This design would be beneficial for both future research and clinical services, given that the literature reporting on outcome after paediatric TBI documents persisting impairment, particularly after severe injury (Anderson et al., 2005b, Fay et al., 2009). Long-term follow-up would also allow for monitoring of late-onset difficulties, such as executive difficulties, that may not present in younger children until these abilities naturally develop and are integrated within an individual’s cognitive system (Anderson et al., 2001). Given the findings of this case series, it is recommended that the National UK Trauma Centres adopt a systematic screening of all head-injured children and adolescents, commencing pre-discharge and with follow-up psychosocial assessment at six, twelve and twenty-four months post-injury. At the pre-discharge stage, written materials documenting the common sequelae of TBI, simple parenting strategies, local support services and referral pathways to appropriate services would also be beneficial to families. The provision of such information is also recommended within the Department of Health’s acquired brain injury exemplar (2004).

Within the current study, there was a high prevalence of neuropsychological and psychosocial difficulty observed, particularly following severe brain injury. For these families, the provision of written information may not have proved sufficient, yet a group-based intervention for parents may have provided a clinically relevant resource. Group interventions are economically valuable tools, given that delivery of interventions are capturing a greater number of service-users. The provision of education regarding the common sequelae of childhood head injury and parenting strategies for managing difficulties may assist families in adjusting to and managing potential difficulties.
Furthermore, the sharing of experiences and support offered within the group, from individuals who are likely to be describing similar experiences, may provide a more therapeutic and normalising experience for parents. Similarly, group interventions for children and adolescents with TBI could provide a forum in which they were able to communicate the challenges they encountered in relation to living with an acquired brain injury.

In addition to supporting the needs of patients and families, medical staff working within clinical neuroscience services would also benefit from an increased awareness of the findings of this study. In the absence of physical disability, healthcare teams may be surprised to learn of the incidence of psychosocial difficulties within the paediatric TBI population. Given that inadequate communication between the medical and research team was felt to significantly contribute to poor recruitment rates, increasing our medical colleagues’ understanding of the prevalence and nature of post-TBI difficulties could assist in engaging the multidisciplinary team in future large-scale research. Furthermore, providing the medical team with a greater appreciation for the potential role of psychological services, and in particular the importance of screening after paediatric TBI may improve the consistency of service provision, and assist in the early detection of neuropsychological or psychosocial difficulties. In particular, A&E staff are likely to regularly encounter head injury, particularly those that are mild in severity. Training these key members of staff in engaging children and adolescents with TBI within screening programmes would ensure that those individuals who are most at risk of a swift discharge back to the community, without adequate follow-up from neuropsychological services are not missed.

Completion of this study highlighted the challenges of maintaining engagement with this population after a child’s discharge from hospital. Therefore, a further implication for the design and configuration of trauma services is to provide greater outreach into communities. This would provide families with the opportunity to receive ongoing involvement from services at a local level, potentially within the school setting. One well-regarded and widely utilised intervention within paediatric burns services is a school reintegration programme (Blakeney, 1994). A similar provision within trauma services could educate teachers and class-mates about the experience of and potential implications of head-injury, and would assist in preparing the system around the child for the on-going rehabilitation process.
Of further benefit within clinical settings, would be the development of a psychosocial screening tool that adequately assesses the domains of functioning that have been identified as important predictors of outcome. One recently developed tool for use with paediatric acquired brain injury is the Brain Injury Alert (Rasquin et al., 2011). This tool comprises 10 items assessing cognition, and a further nine items assessing emotional and social functioning, all of which are considered against a four-point Likert scale. The developers validated the Brain Injury Alert on a small sample of 42 parents of children with TBI. The psychometric properties of the scale appeared questionable (internal consistency $\alpha = .68$, inter-rater reliability $r > .66$, test-retest reliability $r > .46$). Given the brevity of the Brain Injury Alert and its limited psychometric reliability and validity, it is recommended that more comprehensive and psychometrically sound screening tools are developed.

As two of the participants within the current study presented with behavioural dysfunction of a sexual nature (Cases Seven and Eleven), new screening tools may wish to incorporate assessment of this behavioural difficulty. Currently, measures of psychosocial functioning do not appear to give adequate consideration to this aspect of functioning, yet given the potential risks associated with such behaviour, it is clearly a clinically important consideration. The development of a screening tool with both parent- and child-report versions would also be useful, in order to enrich the information that can be obtained by clinicians and researchers. This would further assist research investigating the relationships between parent and child informants in this field.

4.6 Conclusion
This was the first study to investigate the clinical validity of pre-discharge screening within a paediatric TBI population. This case series aimed to establish whether a screening assessment completed soon after injury was indicative of outcome at a post-discharge follow-up completed between three-six months after injury. The findings of this research supported the extent literature which highlights the prevalence of neuropsychological and psychosocial difficulty after paediatric TBI. This was particularly pertinent where severe injury has been sustained. Thus, this research indicated that pre-discharge screening was a beneficial clinical tool for identifying those children who required long-term follow-up and the involvement of psychological services. Due to the small data set on which these findings are based, it is recommended that large-scale studies aim to replicate these findings within a larger population and with orthopaedic controls.
Paediatric trauma networks are responsible for the specialised care of the complex condition of TBI. On the basis of this case series, it is recommended that National Trauma Networks provide psychological screening and onward monitoring of children and adolescents with TBI. This would ensure that all individuals with TBI are captured by services prior to leaving hospital, baseline information obtained, and a standardised service provided. Screening would detect those individuals requiring further assessment and/or intervention at the earliest opportunity, to minimise the risk of post-injury difficulties becoming entrenched over time. Long-term surveillance also appears crucial to detection of those difficulties that are not present at the pre-discharge stage, but that may develop over time. This would also ensure that these individuals are directed to the services that are best placed to meet their needs. Standardised care such as this would also provide a comprehensive dataset relating to paediatric TBI that could benefit continuing research within this field; investigating long-term outcome, variations across age-groups and geographical regions.
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Appendix 1: Parent consent form
Injury factors as predictors of psychosocial outcome in a paediatric traumatic brain injury population

CONSENT FORM FOR PARENT/CARER SIGNING ON BEHALF OF THE CHILD PARTICIPANT

1) I confirm that I have been given a written explanation of the study by the investigator named on this form and I have been given the opportunity to ask questions.

2) I have had enough time to think about the study, and to decide without pressure if I want my child to take part.

3) I understand that my child’s participation is voluntary and that I am free to withdraw my child at any time, without giving a reason and without my child’s medical care being affected.

4) I give consent for the researchers involved to access my child’s medical records.

5) I am aware that if I provide information which indicates a potential risk, the researchers may need to breach confidentiality.

6) I give permission for the researchers to contact me by telephone in relation to my child’s involvement within the research.

7) I understand that the study will generate information about my child and his/her progress and I would like to be informed about this information.

8) I am willing for my general practitioner to be notified of my child’s participation in this research.
9) I am aware that I can obtain results of the study from my child’s Paediatric Psychology department.

10) I understand that data collected during the study may be looked at individuals from the University of Manchester, regulatory authorities or from the NHS Trust, where it is relevant to my child taking part in this research. I give permission for these individuals to have access to my child’s data.

Name of Child Participating

_________________________  __________  ______________________
Name Parent                  Date          Signature

_________________________  __________  ______________________
Name of researcher          Date          Signature
Appendix 2: Child assent form (6-10 years)
PAEDIATRIC PSYCHOSOCIAL DEPARTMENT
Harrington Building
Royal Manchester Children's Hospital
Hathersage Road,
Manchester M13 9WL

Tel:  0161 701 4514/ 5683

What affects the outcome of childhood head injury?

ASSENT FORM FOR 6-10 YEAR OLD CHILDREN

Please tick each box

1) I have read the information sheet about the project and have asked the questions that I want to.  

2) I have had enough time to think about the project, and to decide that I want to join in.  

3) I know that I am allowed to stop being in the project whenever I want and that the hospital would still look after me.  

4) I am happy for the people doing the research to look at my hospital notes.  

5) If I tell the researchers something and they are worried, I know that they will talk to my parents about this.  

6) I know that the project will tell me about my progress and that this will be explained to me.  

__________________________
My name

__________________________  ______________________  ______________________
Name of researcher  Date  Signature
Appendix 3: Child assent form (11-15 years)
What affects the outcome of childhood head injury?

ASSENT FORM FOR 11-15 YEAR OLD CHILDREN/YOUNG PEOPLE

Please tick each box

1) I have read the information sheet about the project and have asked the questions that I want to. [ ]

2) I have had enough time to think about the project, and to decide that I would like to take part. [ ]

3) I know that I am allowed to withdraw from the project at any point and that the hospital would still take care of me. [ ]

4) I am happy for the researchers to look at my hospital records. [ ]

5) If I tell the researchers something which they feel worried about, I am aware that they may wish to discuss this with my parents and/or other people involved in my care. [ ]

6) I understand that this research will inform me about my progress and that this will be explained to me. [ ]

__________________________________________
My name

__________________________________________  __________________________  __________________________
Name of researcher    Date    Signature
Appendix 4: Child consent form (16-17 years)
Injury factors as predictors of psychosocial outcome in a paediatric traumatic brain injury population

CONSENT FORM FOR YOUNG PEOPLE AGED 16-17 YEARS

1) I confirm that I have been given a written explanation of the study by the investigator named on this form and I have been given the opportunity to ask questions.

2) I have had enough time to think about the study, and to decide without pressure if I want to take part.

3) I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without my medical care being affected.

4) I give consent for the researchers involved to access my medical records.

5) I give permission for the researchers to contact me by telephone in relation to my involvement within the research.

6) I am aware that if I provide information which suggests potential risk of harm (either to myself or someone else), the researchers may need to discuss this information with others.

7) I understand that the study will generate information about my progress and I would like to be informed about this information.

8) I am willing for my general practitioner to be notified of my participation in this research.
9) I am aware that I can obtain results of the study from my Paediatric Psychology department.

10) I understand that data collected during the study may be looked at by individuals from the University of Manchester, regulatory authorities or from the NHS Trust, where it is relevant to my participation in this research. I give permission for these individuals to have access to my data.

Name of participant ____________________________  Date ____________  Signature ____________________________

Name of researcher ____________________________  Date ____________  Signature ____________________________
Appendix 5: Parent information sheet
Participant Information Sheet for Parents/Carers

You and your child are being invited to take part in a research study. Before deciding whether you wish to take part, it is important that you understand why the research is being completed and what it will involve for you and your child. This information sheet outlines these details, therefore you are asked to carefully read and consider the following:

1. Title of the research project
Injury factors as predictors of psychosocial outcome in a paediatric traumatic brain injury population

2. What is the purpose of the study?
Much research has linked childhood traumatic brain injury (TBI) to various consequences for example; cognitive functioning (thinking abilities), psychological distress and behavioural difficulties. No research has explored if an assessment of children and young people’s cognitive functioning prior to discharge can help to predict their future progress. Predicting difficulties is important for guiding psychological interventions which can promote recovery and adaptation.

The present study aims to investigate whether a brief assessment of children and young people’s cognitive functioning pre-discharge is linked to psychosocial outcomes (health-related quality of life, paediatric-related parenting stress, childhood anxiety and/or depression and daily living skills) 3-6 months after discharge. It is hoped that this will help determine whether an early cognitive screen is helpful in identifying those children and young people at risk of future problems. In light of previous research evidence, this study expects to find that poor pre-discharge cognitive performance will predict poorer psychosocial outcomes post-discharge.

This study is funded by the Central Manchester University Hospitals Foundation Trust and The University of Manchester. Children aged 6-17 years who have been admitted to Royal Manchester Children’s Hospital or one of the collaborating hospitals following TBI will be invited to take part. Upon obtaining consent, the child/young person and their family will complete measures assessing the following: IQ, health-related quality of life, paediatric-related parenting stress, childhood anxiety and/or depression and daily living skills. Measures will be collected pre and post-discharge (3-6 months later). Participants will be provided with feedback on the assessments and where necessary children/young people
will be referred on to appropriate services. Participants will be involved in the research for approximately six months.

3. Invitation
Your child has been invited to take part in the research because they have been admitted to Royal Manchester Children’s Hospital, or a collaborating hospital following TBI. You have also been asked to take part in the research because we are interested in parents’/carers’ perceptions of health-related quality of life, parenting stress and your child’s adaptive functioning.
We will be asking approximately 90 other child TBI patients and their parents/carers to take part in the research.

4. Does my child have to take part?
No, it is up to you and your child to decide whether or not to take part. A decision not to take part will not affect the standard of care your child receives.
If you choose to take part in the research, you have the right to withdraw at any point. In doing so your child’s healthcare will not be affected.

5. What will happen to me and my child if we take part?
If you and your child decide to take part in this research, then you and your child will be asked to complete the following:
1) Written consent and assent forms accepting the invitation to take part in the study
2) Pre-discharge: your child will complete a brief assessment of cognitive functioning and a questionnaire assessing for depression and anxiety (lasting approximately 45 minutes). You will complete a short demographic questionnaire and three further questionnaires assessing health-related quality of life, parenting stress and your child’s adaptive functioning (taking approximately 30 minutes).
3) Between three and six months post-discharge, you and your child will be asked to complete the four questionnaire measures once again (taking approximately 30 minutes). This can be arranged at the relevant hospital outpatients department, local CAMHS department or within your own home. If it is inconvenient for you to attend a follow-up appointment, the post-discharge measures can be sent to you by post.

Following the completion of these measures, a member of the research team will analyse the results and complete a feedback report which you will receive. Should any of the assessments highlight any difficulties or concerns for you and/or your child, onward referrals to the appropriate healthcare teams will be completed. If you agree, your child’s G.P. can be notified of their involvement in the research. The G.P. and school can also be sent a copy of the feedback report should you agree to this.

6. Will what I and my child say in the questionnaire booklets be kept confidential?
All information which is collected about you will be kept confidential and only shared with others on a ‘need to know basis’. However, we have a duty to break confidentiality if you tell us something that may mean you or your child is at risk of physical or emotional harm.

After the end of your child’s involvement with the research, the completed assessments may contribute to their future healthcare provision.

Assessment booklets will only be identifiable by a participant number, and not by personal details. Data generated by the study will be kept in accordance with the Central Manchester University Hospitals NHS Foundation Trust policy for seven years after the
study has ended. Following this time the data will be destroyed according to trust
guidelines.

7. Are there possible disadvantages and risks of taking part?
The questionnaires used in this research may include topics that you and/or your child may
find upsetting or distressing. If you and/or your child did become distressed, the researcher
would be available to discuss this with you and may ask you if you wish to take a break or
terminate the session. You and your child are also able to request breaks or to terminate a
session at any time.

8. What are the benefits of taking part?
Taking part in the research and completing the assessments will provide you, your child
and their healthcare team with lots of information about their progress following TBI. It
might also provide information which is relevant to their educational progress.

We cannot promise that the study will help your child, but the information we get might
help children and young people and their families with head injuries in the future.

9. What will happen to the results of the research study?
The results of this study may be published in an academic journal. However, no one will be
able to tell that you and your child participated in the research. A summary of the study’s
findings will be available to you from your child’s Paediatric Psychology department.

10. Who is organising and funding the research?
This research has been organised and funded by the University of Manchester and Central
Manchester University Hospitals NHS Foundation Trust. The research is being conducted
as part of Sian Trenchard’s doctoral thesis in Clinical Psychology. She will not be paid for
including you in the study.

11. Who has reviewed the study?
Before any research goes ahead it has to be checked by a Research Ethics Committee who
ensures that the research is fair. This project has been checked by the Liverpool East
Research Ethics Committee.

12. Expenses and payments
It is anticipated that there will be no additional financial costs to families participating in
this research. The travelling costs incurred will be no greater than that which families may
spend attending hospital outpatients appointments. However, follow-up appointments can
be arranged at your child’s home, school or local CAMHS, or b sent to you by post.

13. Complaints
If you have a concern about any aspect of this study then please contact Sian Trenchard
who will do her best to answer your questions and address any concerns you may have. If
she is unable to resolve your concerns or you wish to make a complaint regarding the
study, please contact a Manchester University Research Practice and Governance Co-
ordinator on 0161 2757583 or 0161 2758093 or email research-
governance@manchester.ac.uk.

14. What should I do if my child and I want to take part?
If you and your child would like to take part in the research, please read and sign the
written consent form and ask your child to sign the assent form.

15. Contact for Further Information
If you have any questions, or would like to discuss any aspect of the study, then please do not hesitate to contact Sian Trenchard on 07917 611177. If your call is not answered, you can leave a message and will be called back. Sian can also be contacted at: sianolivia.trenchard@postgrad.manchester.ac.uk

Thank you for considering your participation in this research and taking the time to read this information.
Appendix 6: Child information sheet (6-10 years)
Participant Information Sheet for 6-10 year olds

What affects childhood head injury?

What is research?
Research is a way we try to find out the answers to questions. We want to see if a test called the WASI, gives us important information about children who have had head injuries.

We are asking if you would like to join in a project to find the answer to the question ‘what affects childhood head injury?’ Before you decide if you want to join in, it is important to know why the project is being done and what we will ask you to do. So please think about this information carefully. You can talk to your family, nurses, doctors or one of the researchers if you would like to.

Why are we doing this project?
Although we know quite a lot about childhood head injuries, we would like to know some more. We are really interested in finding out if the WASI can help us to tell if children will do better or worse after a head injury. This is important because if we know which children will have more problems, we can give them extra help.

Why have I been invited to join in?
You have been asked to join in our project because you are between 6 and 17 years of age and have had a head injury. We will be asking about 90 other children to join in with you.

Did anyone else check that the project is OK to do?
Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by the Liverpool East Research Ethics Committee.

Do I have to join in?
No, it is up to you and your parents/carers to decide whether or not to join in. It is ok if you don’t want to, the hospital will still help you until you are better.

What will happen to me if I join in?
If you decide to join in, then before you go home from hospital you will be asked to do some short tasks and to answer some questions about how you feel. This will take less than
one hour and you can have some breaks to make sure you do not get too tired. Your parents/carers will also answer some questions. About three months after you have gone home from hospital, someone will come and see you to ask you and your parents/carers some more questions. Answering these questions will take you about 15 minutes. If the researchers cannot meet with you, then we will send you some questionnaires in the post.

**Could anything about the research upset me?**
Some of the questions that the researcher’s ask you will be about how you feel. You might be feeling worried or sad and this project might remind you about that. If you do feel this way you will be able to talk to the researchers about this and they will be able to think about what can be done to make you feel happier.

**Will joining in help me?**
Joining in with the tasks and answering the questions will give you, your family and your healthcare team lots of information about your progress. It might also help with your progress at school.
We cannot promise the study will help you, but the information we get might help young people with head injuries in the future.

**Will my answers be kept private? Will anyone else know that I’m doing this?**
We will keep your answers private and will only tell people who need to know, like your parents/carers or a doctor. If you tell the researcher’s any information which makes them worried about you or other people, they will need to talk about this with your parents/carers and any other important people. Your usual doctor and your school can be told that you are joining in with the project if you and your parents/carers decide that you want them to know.

**What happens when the project is finished?**
After you have done the tasks and answered all the questions, all your answers will be kept safely by your hospital team and might be used in the future to help you. Joining in the project might show that you should be offered some more help in getting better. If you are offered some more help, it will be up to you and your parents/carers to decide if you want this or not.

**What if I don’t want to do the project anymore?**
If at any time you don’t want to do the research anymore, just tell your parents/carers, doctor, nurse or the researchers. They will not be cross with you and the hospital will still help you until you are better.

**What should I do if I want to join in?**
If you want to join in the project then please talk about it with your parents/carers. If you and your parents/carers both agree that you should join in, you should now sign your name on the assent form.

If you have any questions about this project, you can phone Sian Trenchard on 07917 611177. If no one answers the phone, you can leave a message and Sian will ring you back. You can also e-mail Sian at: sianolivia.trenchard@postgrad.manchester.ac.uk

Thank you for thinking about joining in with our project and for reading this information.
Appendix 7: Child information sheet (11-15 years)
PAEDIATRIC PSYCHOSOCIAL DEPARTMENT
Harrington Building
Royal Manchester Children's Hospital
Hathersage Road,
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Participant Information Sheet for 11-15 year olds

What affects the outcome of childhood head injury?

We are asking if you would like to join in a research project to find the answer to the question ‘what affects the outcome of childhood head injury?’ Before you decide if you want to join in, it is important to understand why the research is being done and what it will involve for you. So please consider this information carefully. You can talk to your family, nurses, doctors or one of the researchers if you would like to.

Why are we doing this research?
Although we know quite a lot about childhood head injuries, we would like to research this area some more. We are really interested in finding out if an assessment called the WASI can help us to identify those children and young people who will do better or worse after a head injury. This will allow us to provide extra support to the children and young people who need it.

Why have I been invited to take part?
You have been asked to take part because you are between 6 and 17 years of age and have had a head injury. We will be inviting about 90 other children and young people to take part.

Do I have to take part?
No, it is up to you. We will ask you for your permission and then ask you to sign a form. We will give you a copy of this information sheet and your signed form to keep. As you are under 16 years of age, your parents/carers will also be given an information sheet about the research and asked for their permission for you to take part.

You are free to stop taking part at any time during the research without giving a reason. If you decide to stop, this will not affect the care you receive.

What will happen to me if I join in?
If you decide to take part; before you go home from hospital you will be asked to do complete an assessment (the WASI) and a questionnaire asking you about how you feel. This will take less than one hour and you can have some breaks if you need to. Your parents/carers will also complete some questionnaires. About three months after you have been discharged from hospital, you will be given a further appointment and you and your
parents/carers will complete the same questionnaires. This will take you about 15 minutes. If the researchers cannot meet with you, we will send you the questionnaires by post.

Is there anything to be worried about if I take part?
Some of the research questions will ask you to consider how you feel. You may be feeling anxious or low. If this is the case, you will be given the opportunity to talk to the researchers about this and consider what can be done to support you to feel better.

What are the possible benefits of taking part?
Taking part in the research and completing the assessments will give you, your family and your healthcare team lots of information about your progress since your head injury. It might also be important for your educational progress. We cannot promise that the study will help you, but the information we get might help children and young people with head injuries in the future.

Will my information be kept confidential? Will anyone else know that I’m taking part?
We will keep your information in confidence. This means we will only tell those who have a need or right to know. If you tell the researcher’s any information which makes them concerned about you or anyone else, they will need to talk about this with your parents/carers and any other relevant people. Your G.P and school can be informed that you are taking part in the research if you and your parents/carers decide that you would like this.

What happens when the project is finished?
After you have completed both parts of the assessment your records will be kept safely by your hospital team and might be used in your future healthcare. If your participation shows that you would benefit from some further support, this will be offered to you. If this is the case, it will be up to you and your parents/carers to decide if you want this or not.

Who is organising and funding the research?
This research has been organised and funded by the University of Manchester and Central Manchester University Hospitals NHS Foundation Trust. The research is being completed as part of Sian Trenchard’s doctoral thesis in Clinical Psychology. She will not be paid for including you in the study.

Who has reviewed the study?
Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by the Liverpool East Research Ethics Committee.

What should I do if I want to take part?
If you want to join in the research then please talk about it with your parents/carers. If you and your parents/carers are in agreement, you should now read and sign your name on the assent form.

If you have any questions about this project, you can phone Sian Trenchard on 07917 611177. If no one answers the phone, you can leave a message and Sian will ring you back. You can also e-mail Sian at: sianolivia.trenchard@postgrad.manchester.ac.uk

Thank you for thinking about joining in with our project and for reading this information.
Appendix 8: Child information sheet (16-17 years)
Participant Information Sheet for 16-17 year olds

You are being invited to take part in a research study. Before deciding whether you wish to take part, it is important that you understand why the research is being completed and what it will involve. This information sheet outlines these details, therefore you are asked to carefully read and consider the following:

1. **Title of the research project**
   Injury factors as predictors of psychosocial outcome in a paediatric traumatic brain injury population

2. **What is the purpose of the study?**
   Much research has linked childhood traumatic brain injury (TBI) to various consequences for example; cognitive functioning (thinking abilities), psychological distress and behavioural difficulties. No research has explored if an assessment of children and young people’s cognitive functioning prior to discharge can help to predict their future progress. Predicting difficulties is important for guiding psychological interventions which can promote recovery and adaptation.

   The present study aims to investigate whether a brief assessment of children and young people’s cognitive functioning pre-discharge is linked to psychosocial outcomes (health-related quality of life, paediatric-related parenting stress, childhood anxiety and/or depression and daily living skills) 3-6 months after discharge. It is hoped that this will help determine whether an early cognitive screen is helpful in identifying those children and young people at risk of future problems. In light of previous research evidence, this study expects to find that poor pre-discharge cognitive performance will predict poorer psychosocial outcomes post-discharge.

   This study is funded by the Central Manchester University Hospitals Foundation Trust and The University of Manchester. Children aged 6-17 years who have been admitted to Royal Manchester Children’s Hospital or one of the collaborating hospitals following TBI will be invited to take part. Upon obtaining consent, the child/young person and their family will complete measures assessing the following: IQ, health-related quality of life, paediatric-related parenting stress, childhood anxiety and/or depression and daily living skills. Measures will be collected pre and post-discharge (3-6 months later). Participants will be provided with feedback on the assessments and where necessary children/young people
will be referred on to appropriate services. Participants will be involved in the research for approximately six months.

3. Invitation
You are being invited to take part in the research because you have been admitted to Royal Manchester Children’s Hospital, or a collaborating hospital following TBI. We will be asking approximately 90 other TBI patients and their parents/carers to take part in the research.

4. Do I have to take part?
No, it is up to you to decide whether or not to take part. Should you decide not to take part, the care provided to you by your healthcare team will not be affected in any way. You also have the right to withdraw from the research at any time. Again, should you do so, this would not impact on the healthcare you receive.

5. What will happen if I take part?
If decide to take part in this research, you will be asked to complete the following:
   1) Written consent form accepting the invitation to take part in the study
   2) Pre-discharge: you will complete a brief assessment of cognitive functioning and a questionnaire assessing for depression and anxiety (this should take approximately 45 minutes). Your parents/carers will also complete a short demographic questionnaire and three further questionnaires assessing health-related quality of life, parenting stress and an assessment of adaptive functioning.
   3) Between three and six months post-discharge, you and your parents/carers will be asked to complete the four questionnaire measures once again (this will take you approximately 15 minutes). This can be arranged at your hospital, local CAMHS department or within your own home. If it is inconvenient for you to attend a follow-up appointment, the post-discharge measures can be sent to you by post.

Following the completion of these measures, a member of the research team will analyse the results and complete a feedback report which you will receive. Should any of the assessments highlight any difficulties or concerns for you, onward referrals to the appropriate healthcare teams will be completed. If you agree, your G.P. can be notified of your involvement in the research. Your G.P. and your school can also be sent a copy of the feedback report, should you agree to this.

6. Will my information be kept confidentially?
All information which is collected about you will be kept confidential and only shared with others on a ‘need to know basis’. However, we have a duty to break confidentiality if you tell us something that may mean that you are at risk of physical or emotional harm.

After the end of your involvement with the research, your assessments may contribute to your future healthcare provision.

Assessment booklets will only be identifiable by a participant number, and not by personal details. Data generated by the study will be kept in accordance with the Central Manchester University Hospitals NHS Foundation Trust policy for seven years after the study has ended. Following this time the data will be destroyed according to trust guidelines.

7. Are there possible disadvantages or risks in taking part?
The questionnaires you complete may include topics that you find upsetting or distressing. If you did become upset whilst answering the questions, the researcher would be available
to discuss this with you and may ask if you wish to take a break or end the session. You are also able to request breaks or to end a session at any time.

8. What are the benefits of taking part?
Taking part in the research and completing the assessments will give you, your family and your healthcare team lots of information about your progress following your TBI. It might also be important for your educational progress.

We cannot promise that the study will help you, but the information we get might help children and young people with head injuries in the future.

9. What will happen to the results of the research study?
The results of this study may be published in an academic journal. However, no one will be able to tell that you participated in the research. A summary of the study’s findings will be available to you from your Paediatric Psychology department.

10. Who is organising and funding the research?
This research has been organised and funded by the University of Manchester and Central Manchester University Hospitals NHS Foundation Trust. The research is being conducted as part of Sian Trenchard’s doctoral thesis in Clinical Psychology. She will not be paid for including you in the study.

11. Who has reviewed the study?
Before any research goes ahead it has to be checked by a Research Ethics Committee who ensures that the research is fair. Your project has been checked by the Liverpool East Research Ethics Committee.

12. Complaints
If you have a concern about any aspect of this study then please contact Sian Trenchard who will do her best to answer your questions and address any concerns you may have. If she is unable to resolve your concerns or you wish to make a complaint regarding the study, please contact a Manchester University Research Practice and Governance Coordinator on 0161 2757583 or 0161 2758093 or email research-governance@manchester.ac.uk.

13. What should I do if I want to take part?
If you would like to take part in the research, please read and sign the consent form.

14. Contact for Further Information
If you have any questions, or would like to discuss any aspect of the study, then please do not hesitate to contact Sian Trenchard on 07917 611177. If your call is not answered, you can leave a message and will be called back. Sian can also be contacted at: sianolivia.trenchard@postgrad.manchester.ac.uk

Thank you for considering your participation in this research and taking the time to read this information.
Appendix 9: Demographic questionnaire
Injury factors as predictors of outcome in a paediatric TBI population

Please complete the following information sheet:

Child’s name…………………………… Child’s D.O.B…………………………

Parent’s/Carer’s name………………………………………………………………

Address……………………………….. Phone number…………………………
…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………

Sign……………………………………

Date……………………………………

How would you describe your child’s ethnicity:

White ☐ ☐ Black Carribean ☐ ☐
Mixed race ☐ ☐ Black African ☐ ☐
Indian ☐ ☐ Black Other ☐ ☐
Pakistani ☐ ☐ Chinese ☐ ☐
Bangladeshi ☐ ☐ Other ☐ ☐
Other Asian ☐ ☐
The following questions ask about the occupational status of the **Household Reference Person** (HRP). The HRP is the person responsible for owning or renting your home. If two people within your household share this responsibility, the HRP is the person with the highest income. Please answer the following questions in relation to the **current/most recent occupation** of the HRP and only tick **one box only** per question:

1) Does (did) the HRP work as an employee or are (were) they self-employed?
   - [ ] Employee
   - [ ] Self-employed with employees
   - [ ] Self-employed/freelance without employees (go to question 4)

2) For employees: Approximately how many people work (worked) for the HRP’s employer at the place where they work (worked)?
   - [ ] 1 to 24
   - [ ] 25 or more

   For self-employed: How many people do (did) the HRP employ?
   - [ ] 1 to 24
   - [ ] 25 or more

3) Do (did) the HRP supervise any other employees? (A supervisor is responsible for overseeing the work of other employees on a day-to-day basis)
   - [ ] Yes
   - [ ] No

4) Please tick one box to show which best describes the sort of work the HRP does. If they are not working now, please tick a box to show what they did in their last job.
   - [ ] Modern professional occupations e.g. teacher; nurse; physiotherapist; social worker; welfare officer; artist; musician; police officer (sergeant or above); software designer
   - [ ] Clerical and intermediate occupations e.g. secretary; personal assistant; clerical worker; office clerk; call centre agent; nursing auxiliary; nursery nurse
   - [ ] Senior managers or administrators (usually responsible for planning, organising and co-ordinating work, and for finance) e.g. finance manager; chief executive
   - [ ] Technical and craft occupations e.g. motor mechanic; fitter; inspector; plumber; printer; tool maker; electrician; gardener; train driver
   - [ ] Semi-routine manual and service occupations e.g. postal worker; machine operative; security guard; caretaker; farm worker; catering assistant; receptionist; sales assistant
   - [ ] Routine manual and service occupations e.g. HGV driver; van driver; cleaner; porter; packer; sewing machinist; messenger; labourer; waiter/waitress; bar staff
   - [ ] Middle or junior managers e.g. office manager; retail manager; bank manager; restaurant manager; warehouse manager; publican
   - [ ] Traditional professional occupations e.g. accountant; solicitor; medical practitioner, scientist, civil/mechanical engineer

5) Are you the HRP (please circle)?
   - [ ] YES
   - [ ] NO
For completion by researchers:

Checklist:
Participant info sheets provided
Consent/assent forms signed

Child’s GCS score: /15
☐ Mild ☐ Moderate ☐ Severe

Pre-discharge
WASI ☐ Date: ...........................................
PI-ED ☐ Date: ...........................................
Demographic sheet ☐ Date: ...........................................
PIP ☐ Date: ...........................................
PedsQL ☐ Date: ...........................................
VABS ☐ Date: ...........................................

Follow-up appt. arranged

Post-discharge
PI-ED ☐ Date: ...........................................
PIP ☐ Date: ...........................................
Peds-QL ☐ Date: ...........................................
VABS ☐ Date: ...........................................

Feedback report sent