Who Should We Listen To?

Comparing Parent and Child Report of Post-Concussive Symptoms

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Abstract

A significant proportion of people worldwide are impacted by the effects of traumatic brain injury (TBI). Research into the incidence and severity of TBI demonstrates that the majority of injuries are mild (such as concussion) and are experienced by children and adolescents. Despite the significance of concussion in young people, there is limited research exploring the impact of this injury on this age group. This is compounded by a lack of clarity on how best to assess concussion symptoms with regard to the measure utilised, timing of assessment, and informant reporting. Assessing concussion in children and adolescents is complicated by the child's ability to report on concussion symptoms and negotiating reporting from parents and children simultaneously. Previous research has identified gaps in the literature including: lack of acute assessment of symptoms, few longitudinal studies into the pattern of symptom reporting over time, and lack of research associating subjective symptom reports with other objective symptom measures. Therefore, the main aims of this study were:

i) To assess parent and child concordance when reporting concussion symptoms over time.

ii) To determine the association between parent and child ratings of concussion symptoms and objective symptom measures.

This research was part of a wider pilot study, Concussion Recovery and Assessment in New Zealand Adolescents and Children (CRANIAC). It involved 49 pairs of children and their parents or caregivers. Twenty-seven children had sustained a concussion and 22 comprised a comparison group of children with an upper limb injury. The children and their parents completed the Post Concussive Symptom Inventory (PCSI) and Sports Concussion Assessment Tool (SCAT)) on four occasions after injury (one to four days, two weeks, one month, three months). Correlations were used to assess concordance between parent and child ratings at

each time point and how the subjective PCSI ratings were associated with the objective symptom assessments from the SCAT.

Results showed parents and children from both injury groups reported most symptoms acutely after injury and fewer symptoms at every subsequent time point. There were fewer symptoms recorded and lower agreement for parents/children with an upper limb injury than those with concussion. Parents and children appeared to agree least about symptoms during the acute period of injury and agreement generally strengthened over time as symptom number and severity decreased. Additionally, there was more agreement about the presence or absence of symptoms rather than the severity. Finally, the PCSI ratings from parents or children did not relate to objective SCAT domain measures. This suggests that these scales may be measuring different constructs.

In conclusion, symptom report and parent/child concordance for children with concussion is distinct from another injury. When children have sustained a concussion, it is beneficial to obtain reports from the child and a caregiver, particularly closer to injury. This is because parents and children report similar amounts of symptoms but there are discrepancies in the severity and types of symptoms reported by both raters. Therefore, it is not a case of asking who we should listen to, but acknowledging both parents and children give complementary information about concussion. It is especially important to obtain parent and child reports in the acute period after concussion. Similarly, subjective symptom report and objective ratings create a more comprehensive assessment. Future research into parent and child symptom reporting with a larger sample would allow analyses by age group, as well as an analysis of differences between reports. In a broader sense, future research into parent and child agreement across general measures of health and wellbeing may also be beneficial.

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Introduction

This introduction discusses key literature concerning concussion symptom assessment in children. To begin, information about the prevalence of mTBI and concussion is presented to establish the importance and impact of concussion. Next, the definition of concussion is provided, followed by a description of symptom presentation and duration. A description of the methods of concussion assessment and treatment illustrates the way in which concussion presence and recovery has been measured. Throughout the introduction, comparisons are made between adults and children to identify current gaps in research concerning childhood concussion. Finally, research into concussion symptoms in children is outlined, comparing the findings, methodology, conclusions, and limitations of previous studies.

Prevalence of concussion

Traumatic brain injury (TBI) has a significant impact on children, adolescents, and families worldwide (Feigin et al., 2013). Publicity around TBI and concussion may lead people to believe the most common cause of injury is sport or accidents, yet there are various ways the injury can occur, including falls and exposure to mechanical force (Merritt, Padgett, & Jak, 2019). Every year, approximately 10 million people seek hospital treatment for a new instance of TBI (Feigin et al., 2013; Thurman, 2016). A systematic review of mild TBI (mTBI) incidence found between 100 and 300 people in every 100,000 were treated in hospital. The rate of self-reported mTBI in the general public is estimated to be higher, 600 of every 100,000 (Holm, Cassidy, Carroll, & Borg, 2005), indicating that many people do not seek medical treatment. This suggests that the incidence of TBI could be higher than estimated (Feigin et al., 2013). In New Zealand, a population-based study of TBI found that 95% of cases were mild and the incidence of mTBI was approximately 750 in every 100,000 (Feigin et al., 2013). Therefore, it is evident that mTBI is a common injury and as such should be considered a

significant public health issue (Bressan et al., 2016). More recently, concussion has been described as an epidemic. This may seem indicative of an increase in occurrence; however, the change in perception of the seriousness of the injury may have increased awareness and reporting. Previously, concussion was thought of as a minor accident with short-term impact. More recently, research reporting potential long-term symptoms and complications in recovery have increased public interest and concern about concussion (Bressan et al., 2016; Merritt et al., 2019).

A review of the literature reporting incidence of TBI in children in New Zealand, Australia, Europe, and North America found that a median estimate of 691 in 100,000 sought treatment from emergency departments per annum (Thurman, 2016). In a New Zealand population based study of TBI, the majority of TBIs recorded occurred in children and young adults (under age 35) (Feigin et al., 2013). Worldwide, an estimated four million children present with concussion at emergency departments each year. This is estimated to only represent a small proportion of children who experience concussion, which could be as prevalent as 33 million children worldwide, per year (Davis, Anderson, et al., 2017; Paniccia et al., 2018). The incidence of mTBI varies by ages. In New Zealand incidence per 100,000 was between 1069 and 1455 in children under four years, between 720 and 920 for children aged five to fourteen years, and between 887 and 1054 for adolescents and young adults aged 15 to 34 years. This shows the prevalence of mTBI is significant enough to warrant focussed research. As children experienced higher incidence than adults, research into childhood concussion is particularly important (Feigin et al., 2013).

Concussion Definition

Concussion is commonly understood as a form of mTBI (Bressan et al., 2016; Sady, Vaughan, & Gioia, 2014). Consequently, although they are not synonymous, mTBI and concussion are

often used interchangeably in the literature. This is indicative of wider lack of clarity around the definition of concussion. Concussion can be experienced with varying severity ranging from mild (without loss of consciousness) to severe (with extended loss of consciousness and post traumatic amnesia) (Holm et al., 2005; King, 2014). The World Health Organisation (WHO) suggests that concussion should be diagnosed by medical professionals and is characterised by a Glasgow Coma Scale score between 13 and 15 (Carroll, Cassidy, Holm, Kraus, & Coronado, 2004). For the purposes of this thesis, the definition provided by the International Consensus for Concussion in Sport is used (McCrory et al., 2017). As such, concussion is defined as an impact that results from force to the head and is followed by acute signs. These signs affect functioning through at least one of the following clinical domains: somatic, cognitive, or emotional symptoms, physical signs, impaired balance, behavioural change, sleep disturbances, and cognitive impairment. Symptoms need to be clearly linked to a force to the head and not otherwise explained by alcohol, drugs, medication, injury, or comorbidities.

Concussion Symptoms

Common public perceptions of concussion typically consider headaches as the only painful consequence of concussion when the reality of post injury symptoms can be more complicated (Kwan, Vo, Noel, & Yeates, 2018). This is shown in the definition of concussion provided by McCrory et al. (2017) which included a range of symptoms that can follow injury and impair functioning. In New Zealand, the Ministry of Health provides guidelines for identifying concussion within the scope of head injuries (Ministry of Health, 2018). Typical symptoms include possible loss of consciousness, memory loss, confusion, concentration difficulties, impaired judgement, impaired coordination, dizziness, slurred speech, headache,

nausea, vomiting, ringing in ears, different pupils, visual changes, light sensitivity, loss of smell, and loss of taste.

As there is such a variety of potential symptoms, to more easily identify them during assessment or monitoring, concussion symptoms can be organised into different categories. In adults, symptoms of concussion are often categorised as cognitive, somatic, or emotional (Sady et al., 2014). This is consistent with the Zurich consensus statement on concussion in sport which categorises symptoms into somatic, cognitive, emotional, physical, behavioural, and sleep symptoms (McCrory et al., 2017). Somatic symptoms refer to headaches, light and noise sensitivity, vision, dizziness, and nausea. Cognitive symptoms include decreased attention, learning, memory, processing speed, feeling in a fog, and reaction time. Emotional symptoms refer to affect, low tolerance, irritability, anxiety, depression, decreased motivation, and lower apathy. Physical symptoms include loss of consciousness and memory loss. Behavioural changes include acting on irritability or low mood. Lastly, sleep disturbances include fatigue, insomnia, and drowsiness.

Symptoms can interact with each other and impact on day-to-day functioning. For example, cognitive symptoms can influence school work, cause frustration, and influence emotional symptoms, such as provoking anxiety in students (Bressan & Babl, 2016). As not all individuals present with symptoms in every category, organising symptoms into sub-groups can help improve understanding of how the injury has affected a person.

The symptoms described above are not specific to concussion and are commonly experienced by the general public. While it is understood they can occur more frequently, and in a more severe manner following a concussion (Grubenhoff, Kirkwood, Deakyne, & Wathen, 2011; Sady et al., 2014), the normal levels of these symptoms in children and youth have not been established (Davis, Anderson, et al., 2017; Hunt, Paniccia, Reed, & Keightley,

2016). Given the common occurrence of these symptoms, understanding pre-injury presentation would be helpful to accurately evaluate the impact of concussion and to identify recovery.

Symptom Duration

The next stage of understanding concussion is recognising how long symptoms take to resolve. The typical duration of concussion symptoms ranges from one week to 10 days for adults (Bressan & Babl, 2016) and two to four weeks for children and adolescents (Ledoux et al., 2019; Purcell, Harvey, & Seabrook, 2016). For children, the majority of symptom improvement is expected to happen within the first two weeks (Ledoux et al., 2019). The difference in recovery time is possibly explained by the different methods of sample identification in research, such as people reporting to emergency departments or those seeking advice at medical centres (Davis, Anderson, et al., 2017). Overall, between 10 and 30% of people with concussion experience symptoms for longer than is typically expected (Bressan et al., 2016; Makdissi et al., 2017; Zemek, Osmond, & Barrowman, 2013). One month following concussion, 25% to 35% of children still suffer from post-concussive symptoms, decreasing to 10% at three months, and less than 5% still experience symptoms one year after injury (Bressan & Babl, 2016). This shows that while there is an expected duration for which concussion symptoms are typically present, recovery differs across individuals.

The inclusion of post-concussive syndrome in diagnostic manuals acknowledges the potential for persist symptoms following mTBI. The Diagnostic and Statistical Manual of Mental Disorders 4th edition- text revision (DSM-IV-TR) defines post-concussive syndrome as the presence of symptoms for three or more months. In comparison, the International Statistical Classification of Diseases and Related Health Problems 10th revision (ICD-10) does not note a specific duration of symptoms for diagnosing post-concussive syndrome. The ICD-

10 does specify that for post-concussive syndrome there should have been loss of consciousness and symptoms present within four weeks of injury. In contrast, the DSM-IV-TR does not list loss of consciousness as a requirement and states symptoms should present shortly after injury (Bressan & Babl, 2016; Mayer, Quinn, & Master, 2017). The fifth and most recent edition of the DSM does not have a specific diagnosis, but recognises the impact of persistent symptoms under neurocognitive disorders resulting from traumatic brain injuries (Mayer et al., 2017). While there is some variance in defining post-concussive syndrome, for children that have prolonged recovery, ongoing symptoms can cause significant impairment to their functioning and general wellbeing. For example, ongoing symptoms can affect concentration, memory, schooling, mental wellbeing, sporting, socialising, family distress, cognitive impairments, depression, and overall quality of life (Bressan & Babl, 2016; Bressan et al., 2016; McCrory et al., 2017; Zemek et al., 2016)). While a small proportion of children experience post-concussive syndrome, it is hard to know which children will have symptoms long-term (Bressan & Babl, 2016). Some studies have identified certain predictors, including being female, at least 13 years old, a history of migraines, previous concussion, specific symptoms (headache, noise sensitivity, fatigue, and answering slower), and a score of at least 4 on the tandem stance Balance Error Scoring System (Zemek et al., 2016).

Concussion Assessment

There are differences in the way concussion is defined, the range of symptoms that follow, and the duration of symptoms after injury. Therefore, it is not surprising that there is not yet one agreed upon measure for diagnosing concussion (Albicini & McKinlay, 2018; Grubenhoff et al., 2011). In the absence of a single agreed upon assessment tool, a multidimensional approach to assessment is generally recommended. It is important to obtain a prompt, detailed assessment following injury because a concussion's presentation can worsen or

resolve over time (Bernard et al., 2017; Makdissi et al., 2017; McCrory et al., 2017). As concussion symptoms are changeable, assessment can be useful for diagnosis, as well as to measure severity, track progress, and identify successful recovery (Araujo et al., 2014; Hunt et al., 2016).

Research has shown that the method used to measure symptoms can affect how they are reported (Edmed & Sullivan, 2014). For example, patients report a greater number of symptoms when endorsing items from a list in comparison to open-ended interview (Hunt et al., 2016; Miller & Leathem, 2016). This demonstrates the need to identify a standardised post concussive assessment tool that is reliable and valid (McLeod & Leach, 2012; Sady et al., 2014). In particular, concussion assessments appropriate for children or adolescents are limited (Babl, 2017; McCauley et al., 2012; Teel et al., 2019). Sady et al. (2014) suggest that concussion measures should include the following characteristics: "multiple informants, developmentally appropriate wording and item content, correct groupings of symptoms, and appropriate reliability and validity for specific purpose" (p. 349).

Most concussion assessments include a symptom checklist that, depending on the child's age, can be completed by the child and a parent (Gioia, Schneider, Vaughan, & Isquith, 2009). One such measure is the post-concussion symptom inventory (PCSI) which has parent, child, and teacher versions. A literature review conducted by Gioia et al. (2009) was undertaken to examine the psychometric properties of different concussion symptom rating measures, including the PCSI. PCSI versions demonstrated good reliability (internal consistency, test-retest reliability, and inter-rater reliability) and validity (internal structure, discriminating group differences with age and injury, change over time, convergent validity, discriminant validity, identifying symptom base rates, concurrent validity, and criterion validity). Although Gioia et al. (2009) do not explicitly identify a single measure that is best to

use, the PCSI meets more standards of reliability and validity than other measures that were reviewed. This was especially evident for measures appropriate for children and as such identifies the PCSI as an adequate concussion assessment tool.

Self-report measures. Concussion measures generally assess symptoms by utilising self-report questionnaires and interviewing the injured person. For children with concussion, parent or caregiver report is also typically obtained. Recording the presence of concussion symptoms therefore rely on the honesty and accuracy of self-report (Lange, Iverson, & Rose, 2010). As people can inaccurately report their symptoms following concussion, especially to exaggerate impairment (Araujo et al., 2014), there is a need to ensure that the symptoms reported are resulting from concussion and not explained by alternative reasons (Olsen, Bloch, & Bloch, 2007). Comparing reports of symptoms given by patients with concussion to the reports of a control group can help mitigate bias and reports of false positives (Miller & Leathem, 2016). Measures should report the frequency and severity of symptoms, not just record their presence. Rating the severity of symptoms does, however, introduce more subjectivity than simply identifying presence (Miller & Leathem, 2016). Research into concussion symptoms in a paediatric population (Grubenhoff et al., 2011) stresses that measuring severity of symptoms is too inherently subjective and variable between raters. Grubenhoff et al. (2011) recommend that it is better to focus on the presence or absence of symptoms for clinical decision making. It seems that concussion symptom assessment involves subjectivity from self or proxy report and so whether assessing for severity as well as symptom presence is worth the added subjectivity, is an important consideration.

Concussion Recovery

As concussion assessment centres around symptoms, recovery from concussion is then understood as the absence of symptoms, or return to pre-injury levels (Teel et al., 2019),

indicated by unhindered return to school, work, sport and normal activities (McCrory et al., 2017). Recovery differs according to individual characteristics and the nature of the injury (McNally et al., 2013), and most children recover completely (Bressan & Babl, 2016; Emery et al., 2016).

Usually treatment of concussion includes a period of rest, physically and cognitively, followed by a slow, gradual return to normal activities (Davis, Anderson, et al., 2017). This approach is based on the assumption that symptoms will resolve without intervention over time (Bressan & Babl, 2016; Makdissi et al., 2017). Returning to schooling, activities, and sports prematurely can prolong symptoms. For example, children who engage in high levels of cognitive activity tend to take longer to be asymptomatic than their peers (Bressan & Babl, 2016). Interestingly, the opposite is also true; when patients were given strict rest for an extended period, they also reported more symptoms for a longer period (Davis, Anderson, et al., 2017). Therefore, an active rehabilitation approach to recovery is thought to be beneficial in reducing the severity of post-concussive symptoms (Dobney et al., 2017; Lishchynsky et al., 2017; Strelzik & Langdon, 2017). As such, clinicians are tasked with balancing physical or cognitive exertion for the individual so that engagement in activities does not exacerbate symptoms.

Return to school is a key component of concussion recovery unique to children and adolescents. General advice suggests students do not need to be asymptomatic before returning to school and so a significant proportion of students (35-73%) need to adapt their routine to accommodate for symptoms. This may be taking more breaks, allowing more time, shorter periods of focus, and modifying seating arrangements so symptoms are not exacerbated (Davis, Anderson, et al., 2017). Following successful return to school, then return to play, recommencement of sporting activities should be considered with caution to prevent

future occurrence of concussion (Albicini & McKinlay, 2018; Davis, Anderson, et al., 2017). Unlike returning to school, recommendations for return to play tend to advocate for waiting until symptoms are back to baseline levels. Return to sport should be also graduated, where each new step is undertaken when the previous step has been managed without symptom resurgence (McCrory et al., 2017). The gradual approach to recovery and return to normal activities such as school and sport suggests that assessing concussion symptoms over time, as a child recovers, may provide useful information for treatment planning.

While there are time periods within which adults and children are expected to recover from concussion, there is less knowledge of how concussion symptoms naturally progress, change, and resolve (Ledoux et al., 2019). Measures of concussion symptoms in children often reference an overall total symptom score, rather than individual symptoms. This gives an overall idea of when symptoms are increasing or decreasing but does not provide detail on the individual symptoms. It is therefore valuable to examine the symptoms of concussion in children, including number of different symptoms, symptom severity and impact on functioning, and how these may influence recovery (Davis, Purcell, et al., 2017). For example, those with fewer symptoms are predicted to have the best recovery (McCrory et al., 2017); also symptoms typically resolve in a sequential order (Bressan & Babl, 2016). Physical symptoms generally present and resolve first; in comparison, cognitive symptoms present acutely but also persist throughout the recovery period, whilst emotional symptoms can take longer to appear (Bressan & Babl, 2016). Interestingly, adolescents had a higher number of symptoms with greater severity than younger children (8-12 years old). Consequently, the younger group tended to recover and be asymptomatic sooner (Davis, Anderson, et al., 2017). This suggests that obtaining detailed assessment of concussion symptoms on multiple occasions may provide the most comprehensive insight to concussion recovery.

Why Focus on Childhood Concussion?

It is clear that concussion can result in a range of complications (McCrory et al., 2017). Gravel et al. (2017) states that "concussion has clinical, societal, and financial impacts" (p. 344). This suggests that the impacts of concussion can go beyond experiencing symptoms for a short period to have significant wider life impact. For example, the period of inactivity that commonly follows concussion can lead to isolation and lifestyle changes and thus negatively influence wellbeing (Worthen-Chaudhari et al., 2017). This may be especially impactful during adolescence when a person's sense of self is typically being formed through social relationships and interaction. Therefore, raising public awareness about concussion, risk, and potential long-term consequences can be useful (McCrory et al., 2017). This includes understanding the unique factors in concussion recovery for children and youth. This knowledge is important for health care providers to communicate age appropriate information to adequately prepare families following concussion (Purcell et al., 2016).

Davis, Anderson, et al. (2017) pose the salient question: "given the variability of physical, emotional, behavioural and cognitive maturation, at what age do adult management criteria become suitable for children?" (p. 6). Currently, concussion recommendations centre around research on adults. Yet it is evident that children do not experience concussion in the same way. Therefore the impact, measurement, or management of concussion for children cannot be generalised from research on adult populations (Bernard et al., 2017). For example, concussion in childhood may pose greater risks due to brain development and an increased chance of sustaining multiple concussions in the future. Children are at the most risk of recurrent concussion in a week to 10 days following injury (Bressan & Babl, 2016). This is important to note as cumulative damage from multiple concussions is an area of concern (Bressan & Babl, 2016; Durish, Yeates, & Brooks, 2018; Plourde, Yeates, & Brooks, 2018). Also,

research on sports-related concussion in children is limited, as is research involving children between five and 12 years old (Davis, Anderson, et al., 2017). This gap in the literature is noted throughout concussion research (Babl, 2017; Bernard et al., 2017; Bressan & Babl, 2016; Davis, Anderson, et al., 2017; McCrory et al., 2017; Purcell et al., 2016). A significant proportion of research assessing concussion in children is conducted between one- and three-months following injury. The time of these assessments is insufficient, as it is after the expected period of recovery for two-thirds of children. This demonstrates a need to focus on acute (i.e. within the days and first few week post-injury) symptoms (Bressan et al., 2016; McNally et al., 2013). The high prevalence of concussion in children, the different experience of injury in comparison to adults, and the current gaps in literature regarding recovery timeframes justifies the need for further research with a specific focus on children and adolescents.

Issues Affecting Symptom Reporting

Future research focusing on concussion in children is needed, but this brings unique challenges. In terms of assessing concussion in children, difficulties include parents' and children's ability to identify concussion symptoms, accurate reporting of symptoms, as well as the complicated process of navigating both parent and child reporting of a range of symptoms.

First, determining the ability of parents or children to accurately identify symptoms of concussion is paramount. A study with teenagers (13 to 18 years old) and their caregivers found approximately 70% of respondents did not have accurate knowledge of concussion symptoms (Hassen et al., 2018). Further research into caregiver knowledge of concussion found that mothers tended to identify symptoms more accurately than fathers (Coghlin, Myles, & Howitt, 2009). Parent knowledge of concussion symptoms also differed according

to the type of symptom. For example, headaches and difficulty with memory were readily recognised as concussion symptoms, yet sleep difficulty, disorientation, and increased emotion or irritability were not (Coghlin et al., 2009). Findings from Coghlin et al. (2009) poses limitations, as symptom assessment tools were modified with the addition of distractor items for the purpose of identifying parental ability to recognise symptoms specific to concussion, rather than recognising symptoms of concussion in their child following injury. Research by Willix-Payne (2015) in New Zealand, supported findings that there is a need to improve parental knowledge of symptoms of concussion because parents and caregivers play an important role in identifying concussion in their children. Other research on parent report of difficulties following mTBI suggests parents can find internalising problems related to emotional difficulties harder to observe (Jones et al., 2018). This may explain why some symptoms, such as increased emotion or irritability, were not as easily recognised by parents (Coghlin et al., 2009). Parent input may therefore add valuable insight into children's symptoms following concussion; however, they may be better at observing certain types of symptoms.

Symptom embellishment is one way that self-report can be inaccurate. Adults had been found to embellish self-reported symptoms; the relationship between effort and ratings given by children was examined to see if this was also an issue for children under 18 years of age (Araujo et al., 2014). Effort was assessed by comparing participant responses to baseline cut-off scores on post-concussion assessment tools. As with adult report, suboptimal effort was found to be a predictor of children endorsing a higher rate of symptoms. This is important when considering parent and child report, as incorporating both respondents' reports of symptoms gives different perspectives, potentially increasing accuracy (Grills, Ollendick, & Grills, 2002). However, when children exaggerated symptoms by reporting more, parental

report also increased (Araujo et al., 2014). This suggests parents may be more aware of symptoms, or even unintentionally encourage symptom exaggeration, therefore making it difficult to detect over-reporting of symptoms. This shows one of the potential complications when assessing children's concussion symptoms.

The subjectivity of self-report of concussion symptoms is an issue generally and with children the additional involvement of parent report adds further complication (Lovell et al., 2006). This introduces debate about who should report on concussion symptoms- the children themselves, or their parents. Some arguments propose parental input may bring added value, providing information that the children themselves may be unable to report (Grills et al., 2002). Nevertheless, disagreement or conflicting information from parents and children brings about additional challenges for assessing concussion in children (Cleridou, Patalay, & Martin, 2017). This suggests that there may be multiple factors influencing reports of children's symptoms after a concussion.

A Comparison of Parent and Child Report in Measures of Child Health.

Many measures of child health and wellbeing include versions for both parents and children. Examining the psychometric properties of instruments that utilise report from children and their parents may therefore provide useful information about symptom reporting and assessment. Concordance between parent and child report of problems was examined in a study of a measure of general functioning, the Paediatric Quality of Life Inventory Version 4.0 (PedsQL 4.0), (Varni, Burwinkle, Seid, & Skarr, 2003). The PedsQL 4.0 has scales developed to be appropriate for responses from parents, children from five to seven years, children from eight to 12, and adolescents between 13 and 18 years. Parent and child ratings of the overall score and symptom subscale scores were correlated. The strength of intercorrelations increased between responses across all scores as children's age increased. Overall, there was

considerable cross-informant variance found within intercorrelations, demonstrating the value of measuring both parent and youth perspectives on symptoms (Varni et al., 2003).

In comparison, a study comparing parent and child responses on the Strengths and Difficulties Questionnaire (SDQ), (Goodman, 1997) did not find that the child's age was a factor for differences in parent and child agreement (Cleridou et al., 2017). This stresses the importance of comparing child and parent reports, especially because symptom endorsement can have clinical implications guiding recovery and treatment planning (Cleridou et al., 2017). This is further supported by a review of literature on parent and child agreement about a range of children's health problems measured by four health-related quality of life (HRQL) instruments, including the PedsQL, Child Health Questionnaire, Child Health Ratings Inventory and the LQ-KID (Upton, Lawford, & Eiser, 2008). Upton et al. (2008) used correlations to assess parent and child agreement overall, and within symptom domains on the measures. Some studies showed higher agreement on physical symptoms and others had higher agreement on psychosocial domains (Upton et al., 2008). Higher agreement between parents' and child's reporting across certain categories of symptoms may indicate the symptoms that are most relevant to the health difficulties of the child (Upton et al., 2008). This could explain findings on the SDQ that show children with conduct or emotional problems had higher agreement with their parents for these types of symptom (Cleridou et al., 2017). Poor agreement may be influenced by differences in assessment tools, such as item wording and scale length, that can see parents and children responding to different constructs (Upton et al., 2008). Although there may be differences in parent and child versions of measures, agreement between respondents can still be influenced by the types of symptoms present. Since the types of symptoms rated similarly by parents and children were related to the child's injury (Upton et

al., 2008), this shows that research into parents' and children's reporting of symptoms following concussion may help identify which symptoms are most salient after a concussion.

After a concussion, children typically present with physical symptoms first, such as headaches, fatigue, or dizziness (Bressan & Babl, 2016). Symptoms related to cognitive impairment are most often evident for some time after injury and may interfere with children's schooling and socialising (Bressan & Babl, 2016). Longitudinal research into outcomes from paediatric concussion showed children with concussion consistently reported symptoms related to cognitive and somatic categories (including sleep), but not emotional and behavioural symptoms, when initially assessed within three weeks of injury (Ayr, Yeates, Taylor, & Browne, 2009). Children reported more emotional-type symptoms over time than initially, while parents reported both emotional and behavioural type symptoms more consistently than their children (Ayr et al., 2009). A more recent study of persistent symptoms supported these findings (Durish et al., 2018). It would therefore be interesting to explore if parent and child agreement is stronger between symptom report on physical/somatic and cognitive domains in comparison to agreement about less common symptoms of concussion.

Parent and Child Concordance.

As obtaining both parent and child report introduces additional subjectivity and room for disagreement, this presents the question; what should health practitioners do when concussion symptom reports differ amongst respondents? There are a range of different options for managing poor parent and child concordance, including: focusing on either parent or child report, only accepting a diagnosis or problem if there is agreement, or combining information from parents and children (Grills et al., 2002). Each of these approaches bring different challenges when considering the value of assessment information. Utilising one respondent's report, or only trusting agreed upon symptoms is limiting, as it can ignore

valuable information that could be useful regarding the problem and aiding recovery. Integrating parent and child report also creates issues regarding synthesizing information, especially if it is conflicting. Despite the potential difficulties, incorporating both parent and child input is advocated by Gioia et al. (2009) who argue that parental figures are typically actively involved in their children's health and their input can increase the sensitivity of concussion symptom assessment.

Parent and child agreement has been assessed within multiple other health measures. This is of relevance because although the measures discussed may not assess concussion symptoms, they provide useful information about obtaining parent and child symptom reports. One such study was conducted by Jones et al. (2018) who explored the relationship between parent and child reporting on a measure of child behaviour, the Behaviour Assessment System for Children- second edition (BASC-2), using Bland-Altman limits of agreement. The sample included 99 children aged between eight and 15 with mTBI and their parents from a larger population-based study in NZ, Brain Injury Incidence and Outcomes New Zealand in the Community (BIONIC). The findings indicated that parents and children focus on, or report, more of different types of symptoms. Parents tended to report more outwardly observable symptoms and behaviour problems, whereas children tended to report more internal thoughts and feelings. Children may also report problems within a questionnaire that they have not raised with their parents. This is consistent with other findings examining symptoms from concussion (Hajek et al. (2010), as well as other health concerns for children (Cleridou et al., 2017; Grills et al., 2002), that have shown parents report more externalising symptoms and children report more internalised symptoms. Furthermore, although Jones et al. (2018) found parents' and children's symptom ratings were not the same, both groups indicated a similar recovery pattern. This suggests that obtaining input from both sources is

valuable in understanding the pattern of concussion recovery. While the sample in Jones et al. (2018) is directly concerned with outcomes from childhood concussion, the BASC-2 is a measure of behaviour and not a specific measure of concussion symptoms. Further research using a similar approach with a concussion symptom assessment tool will help us to understand if these patterns of parent and child ratings are similar to information obtained about post-concussive symptoms.

A number of studies have been conducted to explore similarities and differences between parent and child reports of concussion and further examine the issue of symptom reporting. Gioia, Isquith, and Vaughan (2013) assessed the use of a paediatric concussion assessment battery for identifying the presence of concussion. Scores on the PCSI in two different age groups of children with concussion (22 children aged five to seven and 67 aged eight to 12 years) and their parents were compared to uninjured children and their parents. Significant differences were found between child and parent ratings of symptoms in the concussion and uninjured groups across both age ranges. The identification of different group scores shows a need to look at parent and child endorsement of symptoms. Gioia et al. (2013) concluded that such assessment is adequate for concussion diagnosis; however, focusing on diagnosis has limitations as it neglects to look at the specific symptoms or symptom types reported. Further information on where the differences lie in endorsing symptoms, if there are any patterns or similarities, will help to increase our understanding (Gioia et al., 2013).

Another study analysed responses on the PCSI to establish differences between the rates that children and parents endorsed post-concussive symptoms (Miller & Leathem, 2016). A total of 272 participants aged between five and 18 years of age were involved, 61 of whom had previously experienced a head injury. Findings showed that children who had a previous concussion, but were no longer experiencing symptoms, endorsed all symptoms at

a higher rate than their parents, as well as endorsing distractor items. Also, children reported the presence of internal symptoms, including headaches, worry, remembering, and confusion more than their parents, whereas there was more concordance with the externalising symptoms reported (Miller & Leathem, 2016). This is consistent with the findings previously described that suggest parents find it harder to report less outwardly apparent symptoms (Cleridou et al., 2017; Grills et al., 2002; Jones et al., 2018). Further research on symptoms ratings between children and adults is needed to better understand any similarities or differences.

Ayr et al. (2009) also compared parent and child ratings of concussion symptoms; however, they did not involve an uninjured comparison group. Concussion symptoms were assessed across cognitive, somatic, emotional, and behavioural symptom categories in 186 children aged between eight and 15 with a mTBI using the Health Behaviour Inventory (HBI) (a post-concussion symptom assessment tool with self and parental report). Assessments were conducted at four time points: within three weeks of injury, after one month, after three months, with the final follow-up one year after injury. Parents also gave a retrospective report of pre-injury functioning, but this was not obtained from children. Through exploratory factor analysis, cognitive and somatic symptoms were found to be the most common symptoms reported by children and their parents. Emotional symptoms were identified as of relevance for some children, but only from their parents' ratings. In contrast, analysis showed parents and children rated few behavioural symptoms on the HBI. The lack of significant behavioural symptoms was theorised to be related to the mild nature of the TBI in this instance, as this is more relevant for severe injuries (Ayr et al., 2009). Moderate correlations revealed that parents and children rated cognitive (r= .27) and somatic (r= .39) symptoms with similar strength and direction. Correlations between parent and child ratings of emotional symptoms

were weaker (*r*= .18), and almost non-existent for behavioural symptoms (*r*= .04). This suggests that there is better agreement with the types of symptoms that were most common. The finding of Ayr et al. (2009) are limited due to their focus on the dimensional structure of reported concussion symptoms. Accordingly, comparisons of symptom presence and severity would provide further information about parent and child concordance on symptom reports.

Hajek et al. (2010) aimed to build on the research conducted by Ayr et al. (2009), examining agreement on the HBI and post-concussion symptom interview. The same 186 children with concussion as Ayr et al. (2009) and a comparison group of 99 children with orthopaedic injury were involved. Like Ayr et al. (2009), agreement between parents and children were measured at four time points with composite scale correlations based on post-concussion symptom interviews and HBI scores. Agreement on individual items was assessed with Pearson's *r* correlations from HBI responses and with the kappa coefficients on dichotomous data drawn from the post-concussion symptom interview. Findings showed significant correlations for composite scores between parents and children in both the mTBI and comparison groups over time on both measures. Of interest, they found the comparison group had higher parent-child agreement. This may be explained by concussion presenting with more fluctuating symptoms, of which parents may be less aware, than orthopaedic injuries. The highest correlation between parent and child rating was for cognitive symptoms. Overall, children endorsed concussion symptoms at a higher rate than their parents. Interestingly, parent and child agreement changed over time, with an increase in difference on somatic symptom reporting. This suggests using only parent or child report may result in the loss of valuable symptom information and obtaining both reports may lead to a more comprehensive understanding of concussion. Strengths of Hajek et al. (2010) research include multiple assessments over time and involvement of a comparison group. A limitation is the

timing of the first assessment, when responses were obtained within three weeks of injury. While 80% of responses were completed by two weeks, this is a significant time period after injury for concussion, and symptoms are likely to differ at this time to how they initially presented. This is consistent with other research, as few studies have focussed on the acute post-injury period.

Sady et al. (2014) examined the psychometric properties of the PCSI across three different age appropriate versions. The sample included 633 children with concussion aged between five and 18 years and their parents. Comparisons were made with a group of 1016 uninjured children to distinguish factors unique to children with concussion. Participants were assessed within 30 days of injury. Mean and standard deviations of severity ratings of individual symptoms in each PCSI version and injury group were obtained. With the exception of one symptom (sleeping less), all symptoms were rated more severely in the mTBI group than the comparison group. Parent and child concordance was explored overall (the total number of symptoms) and also examined for the subtypes of symptoms using t-tests and correlations for children over 13 years and Kappa coefficients for children under 12 years. Symptoms were assessed based on their presence or absence, rather than severity rating, given the different rating scales across the different age appropriate versions of the PCSI. There was low to moderate concordance between parent and children on the individual PCSI items (concussion symptoms). Parent report suggested that they may recognise concussion symptoms, such as irritability and balance problems, that their child does not. Children also reported symptoms that their parents did not, as shown by higher endorsement of the symptom nervousness. When comparing correlations across symptom domains, concordance was stronger for physical and cognitive symptoms than emotional or fatigue-type symptoms. This is consistent with other findings concerning different symptom categories (Ayr et al.,

2009). Sady et al. (2014) also found that parent and child concordance was moderate to high on the subscales and total scales. This supports obtaining both parent and child report, as the various perspectives are complimentary in creating a more complete picture of concussion. It is suggested that the different ratings are explained by parents' separate observation of children's behaviours and the child's inner experience. Sady et al. (2014) emphasise that parent perspective is especially important in children under 12-years-old. The assessment of concussion on only one occasion, within 30 days of injury, is a limitation as it does not allow for discussion of how symptoms change over time. Furthermore, the expected recovery period for concussion in children (between two and four weeks from injury) falls within the timeframe that this assessment was conducted. Therefore, future research on the acute presentation of concussion symptoms would be useful.

Finally, Cleridou et al. (2017) argue that parent and child report of child difficulties should be compared to clinician evaluation to provide an external reference on the value of each report. This helps to move the discussion on parent and child agreement away from subjective perception to more measurable, objective presentation of difficulties. Jones et al. (2018) also argue for the importance of obtaining parent and child symptom ratings, given their clinical implication. Thus, both reports provide a basis for the discussion of symptom reporting.

> It seems particularly salient to determine the extent to which parents and their children agree in their ratings, and whether the extent of agreement differs throughout the recovery period. Such information is important in aiding clinicians in the accurate detection of child behaviour problems following mTBI and appropriate treatment recommendations. (Jones et al., 2018, p. 1)

Summary

Understanding the impact of concussion in children has been identified as an important area for research (Feigin et al., 2013). Assessing recovery in children is more difficult than in adults due to complications with symptom reporting. This includes, but is not limited to, the child's ability to comprehend and report on concussion symptoms, accuracy of symptom observation from parents, and complications integrating multiple informants' reports. Concussion measures are used for diagnosis and assessing recovery and inform clinical decisions to provide the best care and advice following injury. It is therefore important to be informed by symptom reports which are as accurate as possible. For children and adolescents, concussion measures tend to be completed with self-report on symptoms, as well as parent report on symptoms (Sady et al., 2014).

Previous research into parent and child report of symptoms on other types of children's health assessment tools by Jones et al. (2018) has shown that examining reporting over time is important. It allows analysis into the pattern of reporting and thus helps strengthen understanding about how children and parents describe recovery, as opposed to giving information about one time after an injury. Prior studies on concussion symptom reporting have previously focussed on one assessment time, for example, Sady et al. (2014). If measuring over time, like Hajek et al. (2010), the pattern of parent and child reporting has not been directly explored. This identifies a need for further research into the patterns of parent and child concussion symptom reports over time. Another key limitation identified in previous research is the time that concussion symptoms are assessed after the injury is sustained. The expected period of recovery from concussion for children has been identified as within two to four weeks, with most symptoms resolving within the first two weeks (Ledoux et al., 2019). Yet, the studies on concussion symptoms do not assess children within this time

period. This demonstrates a gap in the literature discussing the assessment of concussion symptoms in children when they are most impactful. This study aims to address these gaps by obtaining parent and child reports of concussion symptoms as soon as possible after injury and continuing to assess on multiple occasions during recovery. This will provide insight into parent and child concordance and discrepancies of symptom report in the acute injury timeframe, as well as track and compare the patterns of reporting over time.

Obtaining report of concussion symptoms from both parents and children is suggested to provide valuable information regarding the child's injury (Gioia et al., 2009). However, there is a lack of research that compares subjective symptom ratings from parents or children to objective assessments of symptoms. This may be useful in determining the accuracy of symptom reports. This study also aims to address this gap by comparing parent and child subjective symptom ratings to objective ratings of symptoms on another concussion measure.

Study Aims

This research aims to examine concussion symptom reports of parents and children, with the aim of improving our understanding of how to best assess concussion in children. This study will address the following aims:

1. To assess parent and child concordance when reporting concussion symptoms (considering the pattern of reporting over time, reporting in a comparison group, the age of the child at injury, symptom categories, and individual symptom reports).
2. The association between parent and child ratings of concussion symptoms and objective symptom measures.

Method

This thesis is a part of a larger project called Concussion Recovery Assessment of New Zealanders in Adolescence and Childhood (CRANIAC). The CRANIAC study is a pilot study using a similar method to the Australian Take C.A.re (concussion assessment and recovery research) study (Bressan et al., 2016).

The CRANIAC study involved two groups of participants: 1) children/adolescents who have sustained a concussion and their parent or caregiver, 2) a comparison group with an upper limb injury and their parent or caregiver. Age appropriate information about symptom prevalence and severity was gathered from both the children with the injury and their parent or caregiver. The main area of interest for this thesis was examining the similarities and differences between parent and child reports of symptoms. For clarity from this point forward the terms 'children' or 'child' are used to refer to the participants (children and adolescents) and 'parent' refers to the adult (parent or caregiver) unless otherwise specified.

Ethics

Ethical approval for the CRANIAC study was obtained from the Health and Disabilities Ethics Committee and the University of Waikato (Health) Ethics Committee (HDEC reference number 18/CEN/81).

Participants

Potential participants with concussion or upper limb injury were identified via the Waikato Hospital's Emergency Department (ED). Diagnosis of concussion or upper limb injury was confirmed via a review of the discharge notes of each patient and discussion with the participant and their parent to determine eligibility.

Inclusion criteria. Children and adolescents who were included in the study were required to meet the following inclusion criteria. The primary basis for inclusion was that participants had either sustained a concussion or an upper limb injury. The criteria for

concussion was determined by the NZ TBI Guidelines and the Zurich consensus statement on Concussion in sport (McCrory et al., 2017). This included assessing the mechanism of injury (direct or indirect force to the head) and whether one or more post concussive symptoms (somatic, cognitive, emotional, physical, behavioural change, or sleep disturbance) are present as a result of the head injury. The criteria for an upper limb injury was defined as a mild injury on the upper limbs; including an uncomplicated fracture, lacerations, sprains, strains, contusions and abrasions.

Inclusion criteria also involved time restrictions as participants were required to be available for assessment within four days of injury in order to obtain an acute measure of symptoms. Participants also had to be at least five years-old and under 18 years-old and a resident of the Waikato area.

Exclusion criteria. As participants were organised into separate injury groups, concussion or upper limb injury, they were excluded if they had both types of injuries. In the concussion group, participants were excluded if they had a more moderate or severe brain injury. Exclusions on the basis of severity were made by removing potential participants who scored below 13 on the Glascow Coma Scale, needed neurosurgical intervention or general anaesthesia to manage the injury, had evidence of a cerebrospinal fluid leak, or intracranial injury such as a haematoma or haemorrhage. Participants in the upper limb injury group were excluded if they required anaesthesia or sedation, such as ketamine, due to the potential of concussion-like symptoms being prompted by these drugs.

In both injury groups, participants were also excluded if there were factors impeding their ability to complete the assessments, such as intellectual disability or an insufficient understanding of English. Drug or alcohol use within six hours prior to the injury or non-

accidental injury also excluded potential participants from the study. Finally, if participants had any additional injuries, these could not be of a greater than mild severity.

Participant characteristics. In the CRANIAC study, 90 children with concussion and 148 with an upper limb injury were identified as potential participants. Figure 1 shows the recruitment flow diagram below.

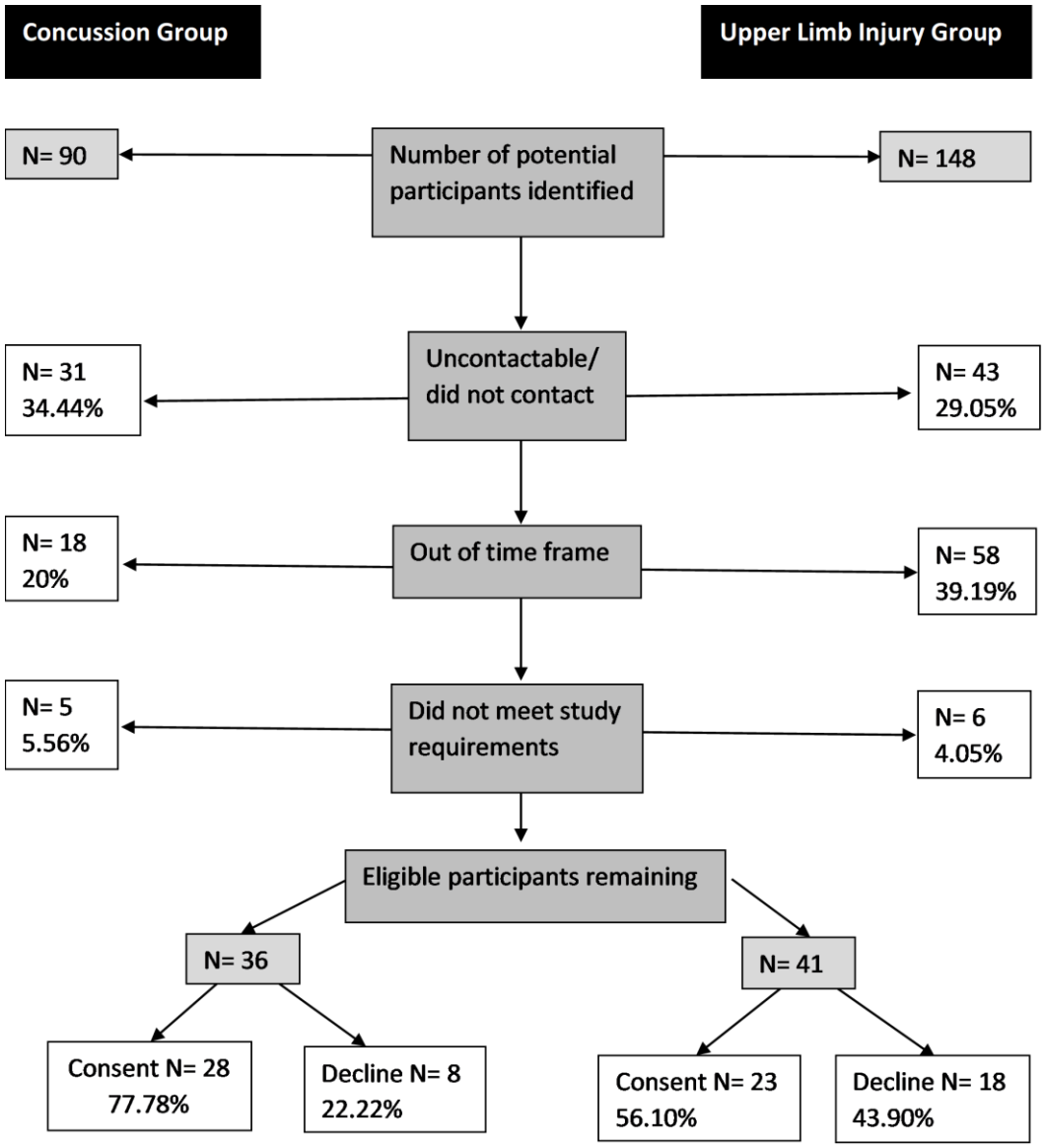

Figure 1. Flow chart illustrating the recruitment and consent rate of participants in both injury groups.

This study included 27 participants with a concussion and a comparison group of 22 participants with an upper limb injury. Over assessments, several participants dropped out due to three common reasons (discontinued because they were too busy, uncontactable and therefore unable to set up the next assessment, and out of study timeframe). At the time of this study, assessments for the upper limb injury group were ongoing. Figure 2 shows a flow diagram of participant retention at each time point.

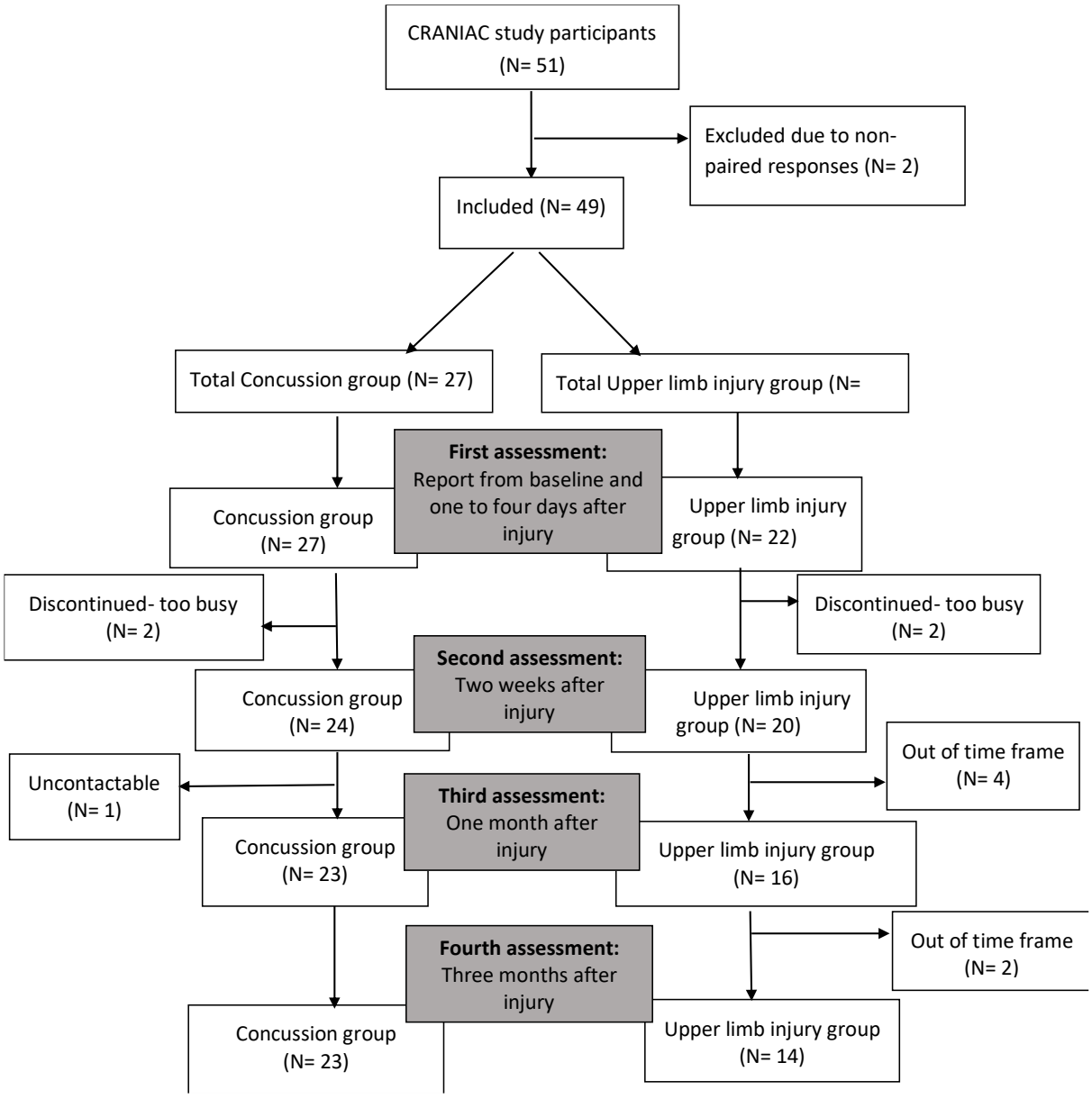

Figure 2. Flow chart illustrating the number of concussion and upper limb injury participants included at each time point.

Demographic characteristics of participants (parents and children) are shown in Table 1. The most common ethnicity was New Zealand European, but a significant proportion of Māori and other ethnicities were also represented. Interestingly, the majority of caregivers in the study were mothers, although a small proportion of fathers, grandparents, and one other type of relationship to the participant were also involved. For the children with concussion and upper limb injuries, there were slightly more males than females represented in our study. Also, 20.4% of children in the overall sample had sustained a concussion previously. This proportion of children was approximately evenly distributed in both injury groups. Further details are shown in Table 1.

Table 1

Demographic Characteristics of Participants (Children and Caregivers)

Characteristic	Concussion Group		Upper Limb Injury Group		Full Sample	
	n	%	n	%	n	%
Ethnicity						
NZ European	17	63	13	59.1	30	61.2
Māori	6	22.2	4	18.2	10	20.4
Samoan	1	3.7	1	4.5	2	4.1
Tongan	1	3.7	0	0	1	2
Indian	0	0	1	4.5	1	2
Other	7	25.9	8	36.4	15	30.6
Relationship to child						
Mother	22	81.5	15	68.2	37	75.5
Father	3	11.1	4	18.2	7	14.3
Grandparent	2	7.4	2	9.1	4	8.2
Other	0	0	1	4.5	1	2
Parent gender						
Male	3	11.1	6	27.3	9	18.4
Female	24	88.9	15	68.2	39	79.6
Non-binary/ third gender	0	0	1	4.5	1	2
Child gender						
Male	16	59.3	12	54.5	28	57.1
Female	11	40.7	10	45.5	21	42.9

Table 1

Demographic Characteristics of Participants (Children and Caregivers)

Characteristic	Concussion Group		Upper Limb Injury Group		Full Sample	
	n	%	n	%	n	%
Child previous concussion						
Yes	6	22.2	4	18.2	10	20.4
No	21	77.8	17	77.3	38	77.6
Unknown	0	0	1	4.5	1	2
Parent education beyond secondary school						
None	3	11.1	4	18.2	7	14.3
NCEA L1/ School certificate	4	14.8	1	4.5	5	10.2
NCEA L2/ 6th form certificate	3	11.1	3	13.6	6	12.2
NCEA L3/ university entrance	8	29.6	4	18.2	12	24.5
Other qualification gained in NZ	1	3.7	2	9.1	3	6.1
Other qualification gained overseas	7	25.9	6	27.3	13	26.5
Prefer not to answer	1	3.7	2	9.1	3	6.1
Parent employment						
Employed	20	74.1	13	59.1	33	67.3
Unemployed	7	25.9	9	40.9	16	32.7

*Note.*n= number of participants; % = percentage of participants.

Measures

As with the Take C.A.Re study (Bressan et al., 2016), the wider CRANIAC study involved a variety of measures related to various different domains thought to be relevant to concussion recovery in children and adolescents. This included demographic information, symptom

presence, symptom severity (PCSI), information on return to school and activities, participant quality of life (the Pediatric Quality of Life Scale (PedsQL)), participants behaviours (the Child Behaviour Checklist (CBCL)) and parent distress levels (Kessler Psychological Distress scale (K10)). Parents and children each provided information on these measures, with the exception of the K10 and CBCL which were only completed by the parents in the study.

Central to the primary focus of this thesis, parent and child ratings of concussion symptoms, the following measures: demographic information, the Post-Concussion Symptom Inventory (PCSI) and the Sport Concussion Assessment Tools (SCAT5/Child-SCAT5) are described in detail below.

Participant and parent responses were each recorded on a Dell inspiron touch screen laptop computer, using the offline Qualtrics questionnaire survey platform.

Demographic Information. Demographic information was obtained from the child and their parent in a Qualtrics questionnaire. Children and adolescents provided information on their age, language, gender, ethnicity, employment, schooling, and writing. Parents also answered questions about the child's ethnicity and schooling. Furthermore, data from parents included information about their language, age, gender, ethnicity, employment, qualifications, relationship status, relationship to the child, and living situation.

Post-Concussion Symptom Inventory (PCSI). The PCSI was the primary measure used to gauge the participant's symptoms following their injury at each time point (baseline, one to four days, two weeks, one month and three months post injury). The PCSI was developed by adapting the Post concussive Scale (Lovell et al., 2006) to be an appropriate tool when measuring concussion symptoms in children (Sady et al., 2014).

The PCSI requires participants to indicate the presence and severity of symptoms common to concussion. These include headaches, nausea, balance problems, dizziness,

fatigue, sleep, drowsiness, light sensitivity, noise sensitivity, irritability, sadness, nervousness, emotion, mental fogginess, feeling slowed down, concentration, memory, vision, confusion, clumsiness, and difficulty answering questions (Sady et al., 2014).

The PCSI has been developed into four versions where the wording, content, rating scales, and numbers of questions are tailored to different age groups (1. PCSI-P parent report, 2. PCSI-SR13 self-report ages 13 years to 17 years 11 months, and 3. PCSI-SR8 self-report ages eight years to 12 years 11 months, and 4. PCSI-SR5 self-report ages five years to seven years 11 months).

Sady et al. (2014) found the PCSI to be both psychometrically and developmentally appropriate for assessing concussion in children and adolescents. Reliability of the PCSI is demonstrated through strong internal consistency (α=0.94 to 0.90) of total symptom scores across the PCSI-P, PCSI-SR13 and PCSI-SR8 for concussion and comparison groups. The internal consistency of the PCSI-SR5 was found to be lower (α=0.67); however, this is likely explained by the small number of items included in the version (Sady et al., 2014). The PCSI was also found to be a valid measure of concussion symptoms in comparison to other widely used measures in this area. This can be seen where convergent validity shows significant relationships with other validated concussion symptom checklists on the PSCI-P, PCSI-SR13 and PCSI-SR8 for children with concussion (r_s= 0.93-0.86, p= <.001). In comparison, the PCSI-SR5 did not show as significant convergent validity with other concussion measures (r_s= 0.60, p .29). This was also likely due to the lower number of symptoms assessed in this age group (Sady et al., 2014).

The PCSI-P included 20 questions which were rated on the full seven-point Likert scale of 0-6, from no problem, to a moderate problem, to a severe problem. Parents were introduced to the PCSI-P by the following statement: *"We would like to know if your child has*

had problems with these symptoms yesterday and/or today. Please answer all the items the best you can. Do not skip any items. Please select the number to tell us how much of a problem this symptom has been for your child."

In comparison, participants aged 13 years to 17 years 11 months provided data on 21 questions that covered all symptoms included in the measure. These were rated according to the same scale as their parents. Participants in this adolescent age group were introduced to the PCSI-SR13 by the following statement: *"I am going to ask you to rate some symptoms from not a problem, to a moderate problem, to a severe problem thinking about how you are feeling now. Rate each symptom from 0-6. Have you been experiencing any of the following?"*

Participants aged between eight years and 12 years 11 months gave information on 17 questions about their symptoms on the PCSI-SR8. Symptoms were endorsed on a three-point Likert scale represented by the descriptors "no," "a little," and "a lot." This was presented as follows: *"I am going to ask some questions about how you are feeling now. Please tell me if any of the questions apply to you and if they do, is it a little or a lot? How do you feel today?"*

Lastly, in comparison to other participants, on the PCSI-SR5 the younger participants were only asked five questions about headaches, nausea, dizziness, irritability, and concentration. They also indicated symptom presence and severity on a three-point Likert scale represented by the descriptors "no," "a little," and "a lot". On occasion the researcher would clarify symptom severity by asking if the symptom was present "a little" or "a lot." This was introduced in the following description: *"I am going to ask you some questions about how you are feeling now. How do you feel today?"*

Preinjury information was sought to obtain a baseline measure of functioning for individual participants. During the first assessment parents and children were asked to rate

symptoms on the PCSI according to how the child usually is, preinjury. To aid with recall of preinjury functioning they were asked to think of a normal day last week. This information is important for scoring as it allows for an examination of the change in function after injury. This was done during the first assessment where participants were asked to rate preinjury symptoms concurrently with current acute symptoms. This comparative way of posing questions was developed to clearly distinguish between preinjury and postinjury symptom report.

The PCSI provides two summary scores. The total symptom score reflects how many symptoms participants report experiencing. This score is comprised of the total number of symptoms endorsed by the parent or child using dichotomous assignment of values, a rating of zero or no was counted as zero; and all other ratings were counted as one. The total symptom score out of 20 was reported for parents, out of five for participants between five and seven years 11 months, out of 17 for participants between 8 and 12 years 11 months, and finally out of 21 for participants 13 years-old and above.

Information about the severity in which symptoms are experienced overall is summarised with the symptom severity score. It is calculated by adding all symptom ratings based on their value on the corresponding Likert scale. The symptom severity score is reported out of 120 for parents, out of 15 for participants between five and seven years 11 months, out of 51 for participants between eight and 12 years 11 months, and out of 126 for participants aged 13 years-old and over. A difference score is also calculated by subtracting the baseline report of symptoms from the report of symptoms after the injury to determine the change from typical functioning (Bressan et al., 2016).

The PCSI also breaks down symptoms into separate categories: physical, cognitive, emotional, and fatigue (Sady et al., 2014). PCSI items are sorted according to the type of

symptom they reflect. Physical items include: dizziness, balance problems, sensitivity to light, sensitivity to noise headache, clumsy, nausea, visual problems, and moving slowly. Cognitive symptoms include: difficulty concentrating, difficulty remembering, mentally foggy/hard to think clearly, confused, and answers slowly. Emotional symptoms are: irritability, feeling more emotional, sadness, and nervousness. Fatigue symptoms include: fatigue/tired, sleeping more, and drowsiness (Sady et al., 2014). Items are not equally distributed across subscales, with most symptoms in the physical scale, followed by cognitive, emotional, and least commonly, fatigue-type symptoms. Subscale scores can be calculated to represent the amount and severity of symptoms in each category. Due to the small number of items answered by the youngest group, subscale scores could not be calculated for those participants (Sady et al., 2014).

Sport Concussion Assessment Tools (SCAT5/Child-SCAT5). In this study, two different versions of the Sports Concussion Assessment Tool- 5th edition (SCAT5) were used to cater to the age-appropriate groups. The SCAT5 (Echemendia, Meeuwisse, et al., 2017) was administered to those aged 13 years and above, and the Child SCAT5 (Davis, Purcell, et al., 2017) was used for those aged five to 12 years 11 months. The SCAT was originally developed in 2004 at the Second International Conference on Concussion in Sport as a standardised tool for concussion assessment. Since then, it has been updated and improved several times to the current versions of the SCAT5 and Child-SCAT5 (McCrory et al., 2017).

The SCAT5 and the Child SCAT5 are made up of a variety of different measures that assess domains likely to be affected by concussion. This includes assessment of immediate memory, delayed recall, balance, orientation, neck pain, coordination, concentration, and self-reported symptoms (Echemendia, Meeuwisse, et al., 2017). The full measure (omitting some orientation questions) was administered as part of the wider CRANIAC study. The SCAT5

and Child-SCAT5 symptom checklists were developed from the Health Behaviour Inventory, a validated symptom checklist for child and parent symptoms of concussion (Gioia et al., 2009). The symptom checklist from the SCATs cover similar symptoms to the PCSI; however, the SCAT5 symptom checklist is designed to be an adequate report of symptoms based primarily on self-report. Parent report of the SCAT5 symptom checklist for the 13 to 18 age group is not sought. The HBI has not been validated for use with children aged between five years and seven years 11 months. As the Child SCAT5 symptom checklist was drawn from the HBI, the youngest group did not complete this measure (Echemendia, Broglio, et al., 2017). Additionally, unlike the PCSI, the SCAT5 and Child SCAT5 do not include appropriately worded versions for obtaining baseline report of typical functioning. Due to these instances where paired parent and child report were not obtained and the lack of baseline symptom report recorded, the PCSI symptom checklist was used in the analyses, rather than the SCAT and Child SCAT symptom checklists.

The SCAT and Child SCAT are unique in the inclusion of objective symptom assessment domains that are thought to enhance clinical utility (McCrory et al., 2017). This includes cognitive assessments of immediate memory, delayed recall and concentration domains, and a balance examination (Echemendia, Broglio, et al., 2017). There are slight differences in the way that these domains are assessed for each version of the SCAT.

Child SCAT. On the Child SCAT (Davis, Purcell, et al., 2017), immediate memory is assessed by reading the child a list of five or 10 words at a pace of one word per second. There are six possible five-word lists and three versions of 10-word lists. The different versions of lists give assessors an opportunity to retest immediate memory without being influenced by previous testing. Accordingly, at each time point, participants were tested using a version that differed from the previous assessment. The assessor introduced the measure with the

following description: *"I am going to test your memory. I will read you a list of words and when I am done, repeat back as many words as you can remember, in any order."* The words recalled by the child were circled and then totalled under trial one. Next, the same list was read a further two times and scored accordingly. All three trials were administered regardless of the number of words the child remembered correctly. The second and third trials were introduced by the following description: *"I am going to repeat the same list again. Repeat back as many words as you can remember in any order, even if you said the word before."* The number of words remembered in each trial were summed to give the domain score for immediate memory out of a possible maximum score of 30 for the child.

The time was recorded after the third trial was completed and, five minutes after the completion of the immediate memory task, delayed memory was assessed using the same list of words. This task is introduced using the following introduction: *"Do you remember that list of words I read a few times earlier? Tell me as many words from the list as you can remember in any order."* One mark was given for each word recalled. This number was recorded as the delayed recall domain score out of a possible 10.

The concentration domain score was comprised of two tasks. The first task was digits backwards and assessed the child's concentration by reading from a list of numbers. The task was introduced with the following description: *"I am going to read a string of numbers and when I am done, you repeat them back to me in reverse order of how I read them to you. For example, if I say 7-1-9, you would say 9-1-7."* The concentration number lists began with strings of two numbers and gradually increased to six numbers. If the child repeated the first string of numbers backwards correctly, then the string of three numbers was read, and so on. There are two strings of numbers at each level; thus, if a child made a mistake, there was a second opportunity to complete the trial. Digits backwards was stopped after two incorrect

attempts at any same string of numbers, or once the child had finished attempting the string of six numbers. A point was allocated for each string of numbers for a possible total score of five. Like immediate memory, there were six different versions of lists to choose from and therefore children could be tested using a different list version at each of the time points.

The second concentration task asked the child to recall the days of the week in reverse order with the following instructions: *"Now tell me the days of the week in reverse order. Start with the last day and go backward. So you'll say Sunday, Saturday. Go ahead."* A point was allocated if all seven days were recalled in the correct order. The scores from days in reverse order and digit backwards were summed to produce the concentration domain score.

The balance examination is adapted from the balance error scoring system and involves three balances exercises for the child to complete (Davis, Purcell, et al., 2017). To begin, the child's non-dominant foot was identified, and the testing surface and footwear were recorded. The three stances included a double leg stance, single leg stance on the non-dominant foot (completed only by those above 10 years) and tandem stance with the non-dominant foot at the back. For each stance, the child placed their hands on their hips, closed their eyes and attempted to hold the position for a total of 20 seconds. Each stance was demonstrated by the assessor prior to timing and participants were instructed to hold the position as best they could and return to position quickly if they lost balance. The number of errors out of a possible 10 were recorded for each stance, with a maximum of 30 errors in total. Errors included: hands lifted, opening eyes, a step, stumble or fall, moving their hip into more than 30 degrees abduction, lifting forefoot or heel, and remaining out of test position for more than five seconds. If multiple errors occurred at the same time, only one was recorded.

SCAT. The SCAT (Echemendia, Meeuwisse, et al., 2017) measured the immediate memory, delayed recall, and balance difficulty domains in the same way as the Child SCAT. Within the concentration domain, digits backwards was very similar to the Child SCAT; however, the lists started from strings of three numbers, rather than two, given the older age of participants. This meant there was a possible total score of four instead of five. Next, within the concentration domain, the older children were asked to recall the months, rather than days, backwards with the following directions: *"Now tell me the months of the year in reverse order. Start with the last month and go backward. So you'll say December, November. Go ahead."* They were given a point for correct recall of a total of five potential scores within the concentration domain.

Procedure

A poster about the CRANIAC study was hung in the Waikato Emergency Department. This poster alerted potential participants and their caregivers to the study, explaining that the University of Waikato was looking to research concussion recovery in children and adolescents. It was designed to inform the caregivers of potential participants that if they were at the Emergency Department with a child aged between 5 and 17 years who had either a concussion or an upper limb injury, they may be contacted about participating in this study. If they did not wish to participate, the poster included a telephone number, email address, and cell phone where people could call, email, or text to opt out of being contacted within 24 hours of their visit to the ED.

Potential participants were identified through daily checks of admissions to the ED. These potential concussion and upper limb injury participants were then contacted by a research assistant to ascertain their interest in taking part in the study and check their

eligibility. Participants who were 16 years old and over were spoken to directly, whereas the parents or caregivers of participants under 16 were spoken to on their behalf.

During the initial phone call, potential participants were informed of the study purpose and what participation would entail. This information was also sent out via email prior to the first assessment (Appendix A). After interest and eligibility were confirmed, research assistants obtained contact details and injury-related information, then arranged the first assessment at the participant's home or other location of their choosing. Assessments were conducted on four occasions: within four days of injury, two weeks after injury, one month after injury, and three months after injury. Participants were sent a text reminder before each assessment.

The research assistant started the assessment by going through the appropriate information sheet with the parent and then the child to ensure they understood the study and their role in it, including the limitations of privacy and confidentiality surrounding their information. Participants were reassured that the information they provided would be kept anonymous, and their rights and responsibilities were outlined, including deciding to withdraw or forego answering certain questions and the responsibility to answer truthfully. The content and presentation of information sheets were tailored to the appropriate age of the participant.

Children under 8 years-old were not given an information sheet, but the study was explained to them at an age-appropriate level. Once the study had been explained and any questions had been answered, the researcher went through the consent form verbatim (Appendix B). Following the signing of appropriate consent forms by the researcher, participant, and caregiver, a copy was kept for the study records and another was provided to the participant and parent.

After consent had been obtained, the research assistant completed the appropriate baseline and time point one (one to four days following injury) survey for the relevant age with the child participant. The Qualtrics offline survey platform was used on a one touch screen laptop. A second laptop was also set up with the appropriate survey corresponding to the parent using the offline Qualtrics questionnaire survey platform.

The duration of assessments varied between 30 minutes to one hour depending on the age of participants, literacy competency of participants and their parents, computer capabilities of the participant and parent, number of research assistants attending, and home environment distractions.

Following completion of the parent and participant assessments, the research assistant checked for any at risk symptoms or issues of concern. If any concerns were raised during the assessment, the researcher consulted the appropriate measure to clarify the level of concern ("red flag," "at risk," or "issue of concern"). Details of these concerns and measures are shown in Appendix C. 'Red flags' on the SCAT5 and Child SCAT5 were discussed with the parent or participant. Parents or participants were recommended to contact their GP about the concern identified and the research assistant offered to contact their GP on their behalf. On measures of child behaviour (CBCL) and parental mental health (K10+), a similar protocol was adhered to. When an 'issue of concern' arose, the research assistant discussed this with the participant and/or parent as appropriate and recommended that they contact their GP. Research assistants also offered to make this contact on behalf of the participant. When concerns were determined to be "at risk," the research assistant informed the participant and/or parent of the nature of the concern and sought permission to make a referral to their GP. A referral was then made to the GP explaining the participant and/or parent involvement in the CRANIAC study and the concern that arose.

Following completion of the assessment, the researcher gave the family a $20 countdown voucher as a thank you for their time and involvement in this research. Finally, the next appointment was scheduled for the appropriate time point.

After the assessment, the research assistant completed the final details of the Qualtrics parent and child forms and uploaded them into the survey database to collate all information. The following assessments at two weeks (T2), one month (T3), and three months (T4) post-injury followed the same format, with slight differences in the questions asked and measures included at specific time points as appropriate.

Statistical Analyses

This thesis sought to examine parent and child agreement when reporting symptoms of concussion. Data was exported from Qualtrics into an SPSS statistics file compiling all respondent forms from children and parent at each time point. The resulting data was organised by participant variables created to identify and allow analyses according to injury group (upper limb injury or concussion) and age range (five to seven years 11 months, eight to 12 years 11 months, and 13 to 17 years 11 months).

The integrity of the data was checked using descriptive statistics to identify outliers. Following this, data was checked to ensure there was report from both parents and children for each participant at each time point. As a result, two participants were excluded from the analysis because there was no parent data. An additional two participants had data excluded at one month and three months post injury because they did not have paired parent and child responses.

Parent and child agreement on concussion symptoms was explored through a range of analyses. To begin, parent and child agreement over time and in relation to a comparison group were assessed using PCSI summary scores (symptom total and symptom severity). First,

the mean parents and child symptom severity scores were calculated at each time point and for each group (concussion and upper limb injury). Next, to identify any differences in symptom reporting between raters, a series of two (rater: parent or child) by two (group: concussion or upper limb injury) ANOVAs (analyses of variance) were performed for the scores at each time point.

Nonparametric Spearman's correlations were calculated for the parent and child PCSI scores for each group at each time point. Additional analyses (nonparametric Spearman's correlations) were conducted at each time point to assess the relationship between parent and child report for the PCSI symptom severity and symptom total scores for each age group. Correlation strength was classified as small (0.1), medium (0.3) or large (≥ .50) (Field, 2013).

The next analyses focussed on parent and child agreement for different types of concussion symptoms (i.e. physical, cognitive, emotional, and fatigue). Participants in the youngest age group (< 8 years) were excluded from these analyses as their measure did not have the relevant subscales. As with previous analyses, the mean scores and standard deviations for each subscale were calculated first. Then, to assess for differences in reporting symptoms in each subscale over time, a series of two (rater: parent/child) by five (time: baseline, one to four days after injury, two weeks, one month, and three months after injury) mixed ANOVAs were conducted. Following this, bivariate nonparametric Spearman's correlations between parent and child report of subscale scores were conducted at every time point.

We then assessed agreement between parents and children for individual symptoms. Five symptoms were chosen for this analysis (headaches, nausea, dizziness, irritability, and difficulty concentrating) because they were the included in all versions of the PCSI. The frequency and percentage of parent/child raters endorsing each symptom at each time point

were calculated. Next, kappa coefficients for parents and children overall were calculated to assess the level of agreement between parents and children endorsing each symptom at each time point.

The final analysis compared parent and child ratings of concussion symptoms on the PCSI with objective measures of performance on the SCAT. PCSI items recording parent and child subjective rating of symptoms were matched with the relevant SCAT score (immediate memory, delayed recall, concentration, and balance errors). To make balance error scores consistent for all children, the errors recorded from the single leg stance which children under 10 did not attempt were subtracted from the total. Then, bivariate nonparametric Spearman's correlations were conducted between parent and child ratings and relevant participant SCAT performance scores.

Results

Mean Symptom Severity Scores

The first stage of analysis focussed on the primary research question and explored *parent and child concordance when reporting concussion symptoms.* The analyses examined levels of agreement over time and levels of agreements in the concussion and upper limb injury. Analyses were conducted on the PCSI symptom severity score, followed by the PCSI symptom total (i.e., the number of items endorsed).

The mean symptom severity scores for the parents and children at each time point are presented in Table 2. The means for the overall sample are displayed on the upper rows, followed by data for the concussion and upper limb injury groups.

Table 2

Summary of the Mean Symptom Severity Scores by Group at Each Time Point

	Time Point									
Injury Group	B		T1		T2		T3		T4	
	M	SD	*M*	SD	*M*	SD	*M*	SD	*M*	SD
Total										
Parents	6.73	9.05	22.04	22.48	9.66	17.02	5.36	11.71	2.51	4.26
Children	6.78	10.76	14.14	20.22	10.48	18.51	7.80	15.86	3.97	8.30
N	49		49		44		39		37	
Concussion										
Parents	8.11	9.34	29.04	23.79	15.25	21.38	7.26	14.50	2.78	3.95
Children	7.48	11.08	19.96	24.10	14.46	22.42	9.78	18.93	4.09	8.74
N	27		27		24		23		23	
Upper Limb										
Parents	5.05	8.60	13.45	17.72	2.95	3.91	2.63	5.08	2.07	4.84
Children	5.91	10.56	7.00	10.91	5.70	11.08	4.88	10.63	3.79	7.83
N	22		22		20		16		14	

Note. M= Mean; SD= standard deviation; N= number of respondents; scores are rounded to two decimal places; B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one-month post-injury; T4= three months post-injury.

The average symptom severity rated by parents and children in the overall sample followed the same pattern of reporting over time. Symptom severity increased in the days

after injury, then decreased two weeks after injury. The average ratings of symptom severity continued to decrease at one month and again three months after injury. This pattern of reporting symptom severity was consistent across parent and child ratings in both injury groups. Also, children and parents rated severity lowest on average three months after injury, reporting scores lower than those recorded at baseline.

As the PCSI symptom scales for children have a different number of items and different sized Likert scale response options, this restricts their opportunity to rate symptom severity to the same degree as their parents. Thus, mean symptom severity scores cannot be compared between parents and children; however, comparisons can be made between the two injury groups. Despite similarities in reporting patterns, Table 2 shows that parents of participants with concussion reported higher symptom severity scores than parents in the upper limb injury group at each time point. At T1, the mean symptom severity score reported by parents in the concussion groups was double that reported by the parents of the upper limb injury group. At two weeks post-injury, parents in the concussion group rated symptom severity over five times as severe as the comparison group. These differences between injury groups are also evident in the children's ratings; participants with concussion rated symptom severity higher on average than those with an upper limb injury at every time point. Like their parents, the greatest differences between injury groups ratings were found in at T1 (one to four days) and T2 (two weeks) after injury.

A series of two (rater: parent/child) by two (group: concussion/upper limb injury) mixed ANOVAs were conducted to explore if there were statistically significant differences between the groups and the parent/child symptom severity ratings at each time point. To account for the variability created by different numbers of items and different response scales, mean symptom severity scores for parents and children were used for these analyses.

There was no significant interaction between rater and group (F (1,47) = .361, p= .551, ηp^2 = .008) for symptom severity scores at baseline. Additionally, the main effects of rater (F (1,47) = .202, p =.655, ηp^2 = .004) and group (F (1,47) = .867, p= .357, ηp^2 = .018) were not statistically significant.

In the one to four days following injury, symptom severity ratings showed no statistically significant interaction between rater and group (F (1,47) = 3.73, p= .059, ηp^2 = .074) and no significant main effect of rater (F (1,47) = .047, p =.830, ηp^2 = .001). Conversely, the main effect of group was significant (F (1,47) = 11.07 p= .002, ηp^2 .191), with the concussion group reporting greater symptom severity compared to the ULI group. Similar results were found two weeks after injury (interaction between rater and group: F (1,42) = 1.406, p= .242, ηp^2 = .032; rater: F (1,42) = 1.059, p =.309, ηp^2 = .025; group: F (1,42) = 4.677, p= .036, ηp^2 = .100).

Similar to baseline, symptom severity one month after injury showed no significant interaction between rater and group (F (1,37) = .200, p= .657, ηp^2 = .005). The main effects of rater (F (1,37) = 3.580, p =.066, ηp^2 = .088) and group (F (1,37) = .874, p= .356, ηp^2 = .023) were not statistically significant either. Additionally, three months after injury, no significant effects were found (interaction between rater and group: F (1,35) = .154, p= .697, ηp^2 = .004; rater: F (1,35) = 3.033, p =.090, ηp^2 = .080; group: F (1,35) = .014, p= .908, ηp^2 = .001). Graphs showing these data are included in Appendix D.

Mean Symptom Total Scores

A similar set of analyses were then conducted for the symptom total scores. The Symptom total is the number of symptoms that a parent or child has endorsed (regardless of the severity of the symptoms). Table 3 summarises the mean symptom total scores calculated for

the overall sample, concussion group and the upper limb injury group, organised according to the type of rater, parent or child, at each time point.

Table 3

Summary of the Mean Symptom Total Scores by Group at Each Time Point

Injury Group	Time Point									
	B		T1		T2		T3		T4	
	M	SD	*M*	SD	*M*	SD	*M*	SD	*M*	SD
Total										
Parents	3.84	4.84	9.10	6.91	4.84	5.69	3.00	4.22	1.57	2.61
Children	4.27	5.14	7.10	6.03	5.20	5.88	4.18	6.25	2.57	4.29
N	49		49		44		39		37	
Concussion										
Parents	4.93	5.41	11.85	6.61	7.04	6.46	4.00	4.57	1.96	2.75
Children	4.74	5.65	9.70	6.04	6.96	6.75	5.00	7.10	2.70	4.75
N	27		27		24		23		23	
Upper Limb										
Parents	2.50	3.74	5.73	5.76	2.20	3.05	1.56	3.29	.93	2.30
Children	3.68	4.49	3.91	4.31	3.10	3.84	3.00	4.77	2.36	3.59
N	22		22		20		16		14	

Note. M= Mean; SD= standard deviation; *N*= number of respondents; scores are rounded to two decimal places; B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one-month post-injury; T4= three months post-injury.

The overall mean symptom total scores for parents and children in this sample followed the same pattern of reporting as the symptom severity scores. Scores were low at baseline, increased in the acute period after injury, then decreased two weeks after injury and then again at one month. The lowest average score was recorded three months after concussion. This pattern was consistent for parents and children in the concussion and upper limb injury groups.

Although symptoms were endorsed as present or absent by parents and children alike, differences in the number of symptoms across PCSI versions does not allow for comparison between parent and child scores, but between-group comparisons can be made. Despite

similarities in the pattern of reporting, Table 3 shows that the concussion group reported a greater number of symptoms at every time point, including baseline.

Parent and Child Agreement of Severity and Number of Symptoms

Bivariate nonparametric Spearman's correlations were conducted between the parent rating and the child rating of symptom severity and symptom total. Given there were significant differences found in reported symptoms between injury groups, correlations were carried out separately for each group. Table 4 shows the correlations between parent and child reports of symptom severity over time in each injury group.

Table 4

Spearman's Correlation of Parent and Child Ratings of Symptom Severity Over Time

Injury Group	Time Point									
	B		T1		T2		T3		T4	
	r_s	p	r_s	p	r_s	p	r_s	p	r_s	p
Overall	.149	.167	.329*	.021	.572**	<.001	.318*	.048	.479**	.003
Concussion	.311	.114	.294	.137	.664**	<.001	.440*	.036	.475*	.022
Upper Limb	.072	.750	.060	.790	.232	.326	.287	.281	.597*	.024
N										
Overall	49		49		44		39		37	
Concussion	27		27		24		23		23	
Upper Limb	22		22		20		16		14	

Note. B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one-month post-injury; T4= three months post-injury; *= significant at 0.05 level; **= significant at 0.01 level; r_s= spearman's rho; p= significance value; *N*= number of respondents.

Correlations between the overall sample of parents and children are also included in Table 4 for information only. Table 4 shows that there were significant positive medium and large correlations between parents and child report of symptom severity two weeks, one month, and three months after injury in the concussion group. In contrast, for the upper limb injury group, the only statistically significant correlation was three months after injury. Correlations in the concussion group were stronger at every time point, except for three months after injury. This suggests that there is a greater association between symptom

severity reports from parents and children in the concussion group. The weakest correlation for both groups was at T1. Next, bivariate nonparametric Spearman's correlations were conducted to compare the reports of symptom total between parents and children by group and over time. The correlations are summarised in Table 5.

Table 5

Spearman's Correlation of Parent and Child Ratings of Symptom Total Over Time

Injury Group	Time Point									
	B		T1		T2		T3		T4	
	r_s	p	r_s	p	r_s	p	r_s	p	r_s	p
Overall	.293*	.041	.465**	.001	.577**	<.001	.300	.063	.453*	.005
Concussion	.416*	.031	.465*	.015	.687**	<.001	.404	.056	.433*	.039
Upper Limb	.166	.461	.101	.654	.263	.263	.331	.210	.565*	.035
N										
Overall	49		49		44		39		37	
Concussion	27		27		24		23		23	
Upper Limb	22		22		20		16		14	

Note. B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one-month post-injury; T4= three months post-injury; *= significant at 0.05 level; **= significant at 0.01 level; r_s= spearman's rho; p= significance value; n= number of respondents.

All correlations displayed in Table 5 are positive. Correlations between the parent and child ratings of symptom total for the concussion group were statistically significant at all time points except one month after concussion. The strongest correlations were two weeks after injury, when the number of symptoms reported began decreasing; however, correlations were of at least medium strength at every time point. In contrast, there was only one statistically significant correlation between parent and child report in the upper limb injury group at three months post injury. Table 5 shows r_s was larger in the concussion group at all time points, except three months after injury. This suggests that there were stronger relationships between parent and child symptom total report from the concussion group. In comparison to correlations of parent and child reports of symptom severity, the correlations

of symptom total report in the concussion group suggest that there was better agreement on the presence of symptoms, rather than severity.

Parent and Child Agreement by Age Group

Next, further analyses were conducted to explore parent-child correlations in symptom reporting by participant age group (five to seven years 11 months, eight to 12 years 11 months and 13 to 17 years 11 months). Tables 4 and 5 show that there were differences in parent-child correlations for the different injury groups. As this thesis is primarily concerned with concussion, the remaining analyses focus on the concussion group (in the interests of brevity). Tables showing upper limb injury mean scores and correlations for symptom severity and symptom total in each age range are presented in appendices E and F for information. The concussion group mean symptom severity scores for each age and time are shown in Table 6.

Table 6

Summary of the Mean Symptom Severity Scores across Age Ranges in the Concussion Group

Rater and age range	Time Point									
	B		T1		T2		T3		T4	
	M	SD	*M*	SD	*M*	SD	*M*	SD	*M*	SD
5-7:11										
Parent	11.80	11.76	14.00	16.49	4.33	7.51	4.33	3.51	6.00	6.56
Child	.60	.89	2.60	2.19	1.67	.58	.00	.00	1.00	1.00
N	5		5		3		3		3	
8-12:11										
Parent	5.67	7.32	33.75	25.53	5.00	6.93	3.09	4.35	1.64	2.91
Child	3.83	5.27	11.58	7.22	5.55	7.01	3.09	6.92	1.91	4.18
N	12		12		11		11		11	
13-17:11										
Parent	9.20	10.40	30.90	23.63	29.80	26.43	13.33	21.97	3.11	3.98
Child	15.30	14.30	38.70	30.99	28.10	29.53	21.22	26.09	7.78	12.76
N	10		10		10		9		9	

Note. M= Mean; SD= standard deviation; *N*= number of respondents; scores are rounded to two decimal places; B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one-month post-injury; T4= three months post-injury.

The youngest age range has a sample size that is too small to be meaningful; therefore, these participants have been included in Table 6 for reference, but the results are not discussed further. In the older two age ranges, parents' and children's mean symptom severity scores followed the pattern of reporting shown in the overall sample, with severity scores increasing in the days after injury and then decreasing from two weeks after injury. For both age groups, parents' and children's reported symptom severity scores were lowest three months after concussion.

Table 6 shows that parents in both age groups reported similar mean symptom severity in the days following injury. In contrast, parents of participants under 13 years reported a greater decrease in symptoms two weeks after injury than the parents of teenage participants. Mean ratings of symptom severity one month after injury also show parents in the oldest age group continued to report higher scores at this time point.

As the teenage participants had the opportunity to rank a greater number of symptoms on a higher point Likert scale, it is expected that their scores may be higher and this is evident in Table 6. Table 6 shows that children in the middle age range rate symptom severity below baseline levels one month after injury, whereas children in the older group take longer to do so (three months after injury).

Table 7 presents the mean symptom total scores rated by parents and children in the concussion group across the three separate age ranges at each time point. Similar to Table 6, mean symptom total scores from the youngest age group are presented in Table 7, but not discussed due to the small sample size. The pattern of reporting shown over time is similar to symptom severity ratings. Parents of the older participants endorsed more symptoms than the middle age group parents at each time point. Similar to symptom severity reports, the middle age range parents showed a quicker decrease in reporting of symptom total with

scores similar to baseline ratings after two weeks, whereas it was one month after injury before parents of teenagers rated symptom total similar to baseline level. Children in the middle age range reported symptom total below baseline level one month after concussion, yet teenaged participants did not until after three months.

Table 7

Summary of the Mean Symptom Total Score by Age Ranges in the Concussion Group

Rater and age range	Time Point B		T1		T2		T3		T4	
	M	SD	*M*	SD	*M*	SD	*M*	SD	*M*	SD
5-7:11										
parent	4.80	3.96	6.60	6.66	2.67	4.62	3.33	2.08	3.67	3.51
child	.40	.55	2.40	1.82	1.00	.00	.00	.00	1.00	1.00
N	5		5		3		3		3	
8-12:11										
parent	3.58	4.38	12.83	6.38	3.64	4.57	1.91	2.17	.82	1.40
child	3.00	3.64	9.25	4.07	4.45	4.70	2.27	4.58	1.45	3.01
N	12		12		11		11		11	
13-17:11										
parent	6.60	6.96	13.30	6.17	12.10	5.47	6.78	5.97	2.78	3.42
child	9.00	6.43	13.90	5.86	11.50	7.03	10.00	8.03	4.78	6.51
N	10		10		10		9		9	

Note. M= Mean; SD= standard deviation; *N*= number of respondents; scores are rounded to two decimal places; B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one-month post-injury; T4= three months post-injury.

Parent Child Correlations by Age Range

To explore if the agreement between parent and child report of symptom severity and symptom total differed by age, separate correlations were conducted by age group. This was of interest because the child measures have a different number of items depending on the child's age and insight into their symptoms, which may impact the levels of agreement. As with the mean scores and standard deviations, in the youngest age range the sample size is too small to be meaningful. Accordingly, the data is presented in Tables 8 and 9 for completeness, but not discussed. Table 8 shows the correlations between participants with

concussion and their parents' ratings of symptom severity across time points and separated according to age group.

Table 8

Spearman's Correlation of Concussion Group Parent and Child Ratings of Symptom Severity Over Time by Age Group

Age range	Time Point									
	B		T1		T2		T3		T4	
	r_s	p	r_s	p	r_s	p	r_s	p	r_s	p
5-7:11	.894*	.041	-.632	.253	-1**	.	.	.	.	.
8-12:11	.336	.285	.483	.111	.598	.052	.166	.626	.690*	.019
13-17:11	.669*	.034	.079	.828	.371	.291	.467	.205	.376	.319
N										
5-7:11	5		5		3		3		3	
8-12:11	12		12		11		11		11	
13-17:11	10		10		10		9		9	

Note. Child's age is presented in years: months; B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one month post-injury; T4= three months post-injury; *= significant at 0.05 level; **= significant at 0.01 level; r_s= spearman's rho; p= significance value; *N*= number of respondents; .= unable to be calculated.

Table 8 shows that symptom severity reported by children aged between eight years and 12 years 11 months was strongly correlated to parent report three months after injury. In comparison, the strongest correlation between symptom severity reports for participants over 13 was at baseline. This suggests that the older participants and their parents have the most similar estimate of symptom severity before injury, whereas the middle age range have stronger agreement when symptoms are at the lowest post-injury. Table 8 also shows that the parent-child correlations in the middle age group were strongest closer to the injury. Table 9 displays the correlations between parent and child reporting of symptom total over time in each age range.

Table 9

Spearman's Correlation of Concussion Group Parent and Child Ratings of Symptom Total Over Time by Age Group

Age Group	Time Point				
	B	T1	T2	T3	T4

	r_s	p	r_s	p	r_s	p	r_s	p	r_s	p
5-7:11	.577	.308	-.632	.253	.	.	.	.	.	.
8-12:11	.304	.336	.429	.164	.599	.052	.100	.770	.667*	.025
13-17:11	.683*	.029	.414	.235	.591	.072	.527	.145	.328	.389
N										
5-7:11	5		5		3		3		3	
8-12:11	12		12		11		11		11	
13-17:11	10		10		10		9		9	

Note. Child's age is presented in years: months; B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one month post-injury; T4= three months post-injury; *= significant at 0.05 level; r_s= spearman's rho; p= significance value; *N*= number of respondents; .= unable to be calculated.

Table 9 shows that the strongest correlation between parent and child reports for the middle age group was three months after injury. In comparison, teenage participants and their parents' symptom total reports was most strongly correlated prior to injury (similar to correlations for symptom severity shown in Table 8). In contrast to the symptom severity parent-child correlations, there was similar strength correlations from both age groups in the days and two weeks following injury. Symptom total reports one month after injury correlated most strongly between parents and children in the older age range.

Agreement Across Concussion Symptom Types

Next, the pattern of agreement between parents and children across types of concussion symptoms was examined. The PCSI has four subscales: physical, cognitive, emotional, and fatigue. As the PCSI for children under eight years only contained five items, they were excluded from this analysis. First, the descriptive data for parents and children is shown in Table 10.

As different numbers of symptoms are loaded on the symptom subscales, for example physical subscale contains over twice as many items as the fatigue subscale, comparisons between the mean scores reported on each subscale cannot be made. Table 10 shows the pattern of reporting by parents and children on each subscale was consistent with the pattern

shown by larger summary scores such as symptom severity and symptom total over time. Each subscale showed an increase at T1 from baseline, then ratings continuously declined across subsequent time points.

Table 10

Summary of Parent and Child Mean Symptom Subscale Scores for Participants (> 8 years) in the Concussion Group

Symptom Subscale	Time Point									
	B		T1		T2		T3		T4	
	M	SD	*M*	SD	*M*	SD	*M*	SD	*M*	SD
Physical										
Parent	2.77	3.58	12.95	9.29	6.24	9.56	2.15	5.61	.70	1.49
Child	3.00	4.50	9.73	10.08	6.67	9.67	3.90	7.52	1.55	3.66
Cognitive										
Parent	2.05	3.21	8.64	6.99	3.38	4.98	2.15	4.40	.25	.55
Child	2.23	3.25	6.82	7.89	4.67	7.01	3.45	6.29	1.45	2.80
Emotional										
Parent	1.45	1.95	6.14	5.92	3.95	4.87	2.25	3.24	.90	1.94
Child	2.77	3.87	3.55	4.90	2.48	4.60	2.15	3.91	.75	1.68
Fatigue										
Parent	1.73	1.80	6.64	4.72	3.95	5.01	1.30	2.34	.40	.68
Child	1.41	1.87	4.23	3.84	3.23	3.91	1.95	2.95	1.00	2.22
N	22		22		21		20		20	

Note. M= Mean; SD= standard deviation; *N*= number of respondents; scores are rounded to two decimal places; B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one-month post-injury; T4= three months post-injury.

A series of two (rater: parent/child) by five (time: baseline, one to four days after injury, two weeks, one month, and three months after injury) mixed ANOVAs were conducted to explore if there were differences between the ratings on the different subscales at each time point. Because the number of items and the response scales differed by age and rater, the mean (rather than total) symptom subscale scores for parents and children were used for these analyses. The ANOVA results were adjusted using the Greenhouse Geisser correction, as the sphericity assumption was violated for time.

ANOVA findings were similar across the symptom subscales. There was no significant interaction between rater and time (physical: F (1.29, 24.46) = 1.39, p= .26, ηp^2 = .07;

cognitive: F (1.71, 32.41) = 1.63, p= .21, ηp^2 = .079; emotional: F (2.74, 52.00) = 2.16, p= .11, ηp^2 = .10; fatigue: F(1.52, 28.78) = 1.09, p= .33, ηp^2 = .05). Additionally, the main effect of rater was not statistically significant for any subscale either (physical: F (1, 19) = .12, p= .73, ηp^2 = .01; cognitive: F (1, 19) = .40, p= .54, ηp^2 = .02; emotional: F (1,19) = .19, p= .67, ηp^2 = .01; fatigue: F (1,19) = .11, p= .74, ηp^2 = .01). In comparison, the main effect of time was statistically significant across all subscales, reflecting the increase in scores between baseline and T1, and then the decrease in scores from T1-T4 (physical: F (1.86, 35.31) = .15.84, p= <.001, ηp^2 = .46; cognitive: F (1.81, 34.37) = 12.96, p= <.001, ηp^2 = .41; emotional: F (2.10, 39.85) = 9.64, p= <.001, ηp^2 = .34; fatigue: F (2.20, 41.82) = 18.80, p= <.001, ηp^2 = .50).

Parent and Child Correlations by Symptom Subscales

Whilst there were no significant differences in the parent and child ratings, we were also interested in exploring the correlations between parent and child scores bivariate nonparametric Spearman's correlations were carried out between parent and child scores for each symptom subscale. These correlations at each time point are shown in Table 11.

Table 11

Spearman's Correlations Between Parent and Child Ratings on Symptom Subscales for Participants in the Concussion Group Between Eight and 17 Years 11 Months

Symptom Subscale	Time Point									
	B		T1		T2		T3		T4	
	r_s	p	r_s	p	r_s	p	r_s	p	r_s	p
Physical	.469*	.028	.264	.236	.698**	<.001	.557*	.011	.706**	.001
Cognitive	.328	.136	.116	.608	.537*	.012	.554*	.011	.539*	.014
Emotional	.307	.164	.255	.252	.480*	.028	.493*	.027	.603**	.005
Fatigue	.345	.115	-.065	.772	.605**	.004	.443	.050	.343	.138
N	22		22		21		20		20	

Note. B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one-month post-injury; T4= three months post-injury; *= significant at 0.05 level; **= significant at 0.01 level; r_s= spearman's rho; p= significance value; *N*= number of respondents.

Table 11 shows that correlations between parent and child scores on all of the PCSI symptom subscales were weakest in the one to four days after concussion, when the mean scores in each subscale were at the highest point as shown in Table 10. Two weeks after injury, correlations for symptom reporting on all subscales increased in strength (and statistical significance). One and three months after concussion, correlations between raters remained significant and strong for all subscales, except for fatigue. Overall, the strongest correlations were shown in the physical subscale.

Ratings of Individual Symptoms

Next, agreement between raters was analysed by examining reporting on individual concussion symptoms. Children from the different age ranges and their parents responded to different versions of the PCSI, which included different numbers of symptoms that were considered age-appropriate. There were five concussion symptoms (headaches, nausea, dizziness, irritability, and difficulty concentrating) included in the PCSI version for participants under eight. Items assessing these symptoms were also included on the PCSI for the older children; therefore, the following analyses focussed on these five symptoms. Due to the different rating scales at each of the age ranges, this analysis focussed on symptom endorsement (i.e., presence/absence), rather than rating of severity. The number and percentage of parents and children endorsing each symptom at each time point was calculated. Table 12 presents the number and percentage of the sample endorsing each of the five PCSI symptoms. Additional tables showing the frequency counts and percentage of parents and children who endorsed each symptom in each age group are included in Appendix G for reference.

Table 12 shows that each of the individual symptoms (headaches, nausea, dizziness, irritability, and difficulty concentrating) were endorsed by the highest percentage of parents

and children in the acute period following concussion, after one to four days. The pattern of reporting by parents and children was similar and generally consistent with the pattern of reporting symptoms over time established by the symptom severity and symptom total scores in Tables 2 and 3. This is evident with an increase in the symptoms reported after injury from baseline levels, with a gradual decrease in the symptom endorsement over time.

Table 12

Frequency Counts and Percentage of Endorsement of PCSI symptoms by the Concussion Group

Symptom	Time Point									
	B		T1		T2		T3		T4	
	n	%	n	%	n	%	n	%	n	%
Headache										
Parent	11	40.7	23	85.2	10	41.7	3	13	4	17.4
Child	10	37	22	81.5	11	45.8	6	26.1	5	21.7
Nausea										
Parent	6	22.2	14	51.9	5	20.8	5	21.7	2	8.7
Child	3	11.1	15	55.6	7	29.2	4	17.4	4	17.4
Dizziness										
Parent	4	14.8	14	51.9	6	25	2	8.7	0	0
Child	5	18.5	15	55.6	10	41.7	5	21.7	2	8.7
Irritability										
Parent	9	33.3	19	70.4	14	58.3	13	56.5	6	26.1
Child	10	37	16	59.3	9	37.5	6	26.1	5	21.7
Difficulty concentrating										
Parent	10	37	21	77.8	10	41.7	6	26.1	1	4.3
Child	11	40.7	16	59.3	12	50	7	30.4	7	30.4
N	27		27		24		23		23	

Note. PCSI= post-concussion symptom inventory; B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one-month post-injury; T4= three months post-injury; % = percentage of respondents endorsing the symptom; n= number of respondents who marked the symptom as present; *N*= total number of respondents.

Kappa coefficients were chosen as an appropriate assessment to measure parent and child agreement on individual symptoms, providing a conservative analysis accounting for chance agreement. Kappa values are noted as significant for p<.05.

Table 13

Kappa Coefficients Showing Agreement Between Parent and Child Ratings of Individual Symptoms in the Concussion Group

Symptom	Time Points									
	B		T1		T2		T3		T4	
	K	p	K	p	K	p	K	p	K	p
Headache	.455*	.018	.069	.718	.577**	.005	.327	.086	.311	.132
Nausea	.087	.623	.331	.085	.780**	<.001	.587**	.004	.246	.203
Dizziness	.335	.079	.628**	.001	.455*	.017	.511**	.005	.	.
Irritability	.108	.573	-.202	.280	.600**	.001	.263	.123	.404	.051
Difficulty concentrating	.300	.118	-.073	.675	.167	.408	.679**	.001	.188	.122
N	27		27		24		23		23	

Note. K= Kappa coefficient; p= significance value; B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one-month post-injury; T4= three months post-injury; *N*= number of valid cases; .= not computed as parent or child report was constant; *= significant within 0.05; **= significant within 0.01.

Table 13 displays the kappa coefficients between the parents and children in the concussion group for each of the five symptoms. A summary of the kappa coefficients for the same symptoms organised by age group are included in Appendix H for reference.

The first symptom shown in Table 13 is 'headaches'. The strongest and most significant kappa coefficients between parent and child endorsement of headaches were found at baseline and two weeks after injury. Also, the weakest kappa coefficient for headaches was when they were most commonly endorsed, one to four days after injury. The strongest kappa coefficients concerning parent and child endorsement of nausea were found in the two weeks and one month after concussion. In comparison, the weakest agreement between raters' endorsement of nausea is shown at baseline. Parent and child endorsement of dizziness produced the most significant and strongest kappa coefficients out of the five symptoms.

These are seen one to four days, two weeks and one month after injury. This is different to the pattern over time shown in other ratings because correlations of PCSI summary scores for symptom total, severity and domains were typically weaker at T1 and increased over time; whereas reports of dizziness correlated strongly from the first assessment. For irritability, the kappa coefficients were weakest in the days after concussion, and strongest after two weeks. Finally, parent and child endorsement of difficulty concentrating, like ratings of irritability and headaches, produced the weakest kappa coefficient in the days after concussion. Table 13 also shows the strongest kappa coefficient for rating of difficulty concentrating was found one month after injury.

Correlations Between Self and Parent Reported Symptoms and Presentation of Symptoms

Parent and child agreement on concussion symptoms have been analysed by comparing ratings between groups, age ranges, symptom subscales, and individual symptoms over time. These analyses rely on the subjective reporting of parents and children to establish the presence of concussion symptoms in participants. Although analyses have focussed on the PCSI, the concussion assessment tools SCAT and child SCAT were also utilised to assess concussion symptoms. The SCAT and child SCAT are unique from the PCSI as they also include measures of cognitive screening that assess immediate memory, delayed recall, concentration, and balance errors. Participants' scores across these domains were matched with scores on relevant PCSI items. These matchings were as follows: immediate memory and delayed recall with *"had difficulty remembering"* (parents and participants over 13) and *"has it been hard for you to remember things? (like things you heard or saw, or places you have gone)"* (participants eight to 12 years 11 months), concentration scores with *"had difficulty concentrating"* (parents and teenage participants) and *"has it been hard for you to pay attention to what you are doing? (like homework or chores, listening to someone, or playing*

a game)" (children under 13), balance error scores with *"had balance problems"* (parents and teenage participants) and *"have you had any balance problems, or have you felt like you might fall when you walk, run or stand?"* (children between eight and 12 years 11 months). Then, bivariate nonparametric Spearman's correlations were conducted to correlate parent and child reports of relevant PCSI symptoms with objective measures of performance on the SCAT. Correlations were performed at each time point, with the exclusion of baseline because there were no SCAT recordings prior to injury.

Table 14

Spearman's Correlations Between Participant's SCAT domain Scores and Parent or Child Ratings of Relevant PCSI Items

Rater and SCAT domain	Time Point							
	T1		T2		T3		T4	
	r_s	p	r_s	p	r_s	p	r_s	p
Immediate memory								
Parent	-.162	.471	-.028	.905	-.320	.169	-.421	.065
Child	.204	.364	.060	.798	-.099	.678	.189	.425
N	22		21		20		20	
Delayed recall								
Parent	-.103	.650	.147	.524	-.086	.719	-.499*	.025
Child	.107	.636	.307	.176	-.147	.538	-.002	.993
N	22		21		20		20	
Concentration								
Parent	.070	.730	-.197	.357	.037	.867	-.364	.088
Child	-.184	.359	.012	.955	.004	.985	.088	.689
N	27		24		23		23	
Balance Errors								
Parent	.260	.243	.345	.124	.302	.195	.223	.346
Child	.175	.437	.556**	.009	.612**	.004	.223	.346
N	22		21		20		20	

Note. r_s = spearman's rho correlation; p= significance value; Parent= all parents of children with concussion; T1= one to four days post-injury; T2= two weeks after concussion; T3= one month after concussion; T4= three months after concussion; *N*= number of respondents.

Table 14 displays the correlations between SCAT domain scores and the relevant PCSI items endorsed by parents and children. Children in the youngest age group did not complete

PCSI symptoms corresponding to immediate memory, delayed recall, and balance or concentration; therefore, these participants were excluded from analysis on these scores.

Table 14 shows that parent ratings correlated with participant SCAT immediate memory scores in the expected direction (negatively). These correlations were stronger than the children's ratings; however, they were not statistically significant. Similarly, SCAT delayed recall scores also correlated with relevant parent ratings in the expected direction (negatively), at three time points (one to four days after injury, one month and three months). The strongest and only statistically significant correlation was at three months after injury. In comparison, the child ratings only correlated with delayed recall scores in the expected direction at one and three months after injury. These correlations were weaker and did not reach the threshold for statistical significance. Similar to the previous two SCAT domains, parent ratings of symptoms produced correlations in the expected direction (negative), more commonly with concentration domain scores. Correlations with parent ratings were stronger than correlations with children's ratings (although no correlations were statistically significant). Accordingly, correlations between child symptom ratings and SCAT concentration scores were not significant and only one correlation in the days after concussion was in the expected direction.

Participant's SCAT scores regarding immediate memory, delayed recall, and concentration rarely correlated with parent or child ratings with any notable strength. Exceptions include moderate correlations with parent report and participant SCAT scores three months after injury for all three domains, and one month after injury for the immediate memory domain only. Conversely, parent and child ratings of balance difficulties both correlated in the expected direction, positively, at all time points. Distinct from the previous SCAT domains, children's ratings of balance difficulties correlated more strongly than their

parents' ratings with SCAT balance error scores. This is particularly evident two weeks and one month after concussion, with stronger r_s values as shown in Table 14.

Summary of Findings

Concussion symptoms are reported in a consistent pattern over time by both children with concussion and their parents. Parents and children report an increase in concussion symptoms after injury, followed by a gradual decrease in symptoms reported over the following three months. In comparison, children with upper limb injury and their parents also endorse concussion symptoms in a similar pattern over time; however, they report fewer and less severe symptoms than those with concussion. Differences between the concussion and upper limb injury groups were identified as statistically significant when reporting symptom severity in the days and two weeks after injury. Correlations between parent and child report of symptoms were stronger and statistically significant in the concussion group. This indicates parent and child concordance when reporting concussion symptoms is stronger when the child has a concussion, rather than another injury. Interestingly, in both injury groups, correlations were weakest and showed less agreement for symptoms closer to injury. This shows that concordance in concussion symptom report may increase over time. Also, the symptom total correlations had better r_s values than symptom severity correlations, demonstrating there is likely to be more agreement on the number of symptoms present than their severity.

When comparing the report of concussion symptoms for children of different ages, parents indicated that older children experienced more symptoms, with more severity, for a longer time. Given the small sample sizes, it is difficult to draw further conclusions about differences in symptom agreement across the age groups. Analyses of PCSI subscales show that parent and child reporting of concussion symptoms follows a similar pattern over time,

regardless of the type of symptom. Similar to wider symptom reporting, parent and child agreement across symptom subtypes was lowest in the days after injury, with the weakest correlations corresponding to the time when higher symptoms were reported. As correlations increased over time, this suggests that parents and children reported more similar rates of symptoms as reporting decreased.

Analyses of individual symptoms, headaches, nausea, dizziness, irritability, and difficulty concentrating showed they were reported by the highest percentage of respondents in the days after injury. The strength of correlations differed across the individual symptoms. For headaches, irritability, and difficulty concentrating, correlations were worst (weakest/in the wrong direction) at T1. This is consistent with the pattern of reporting shown by correlations of overall symptom scores which are weakest at baseline and when first assessed after injury. Not consistent with this pattern was reporting of dizziness, with the strongest and most significant correlations at T1. Parent and child endorsement of headaches, nausea, and irritability correlated strongest and most significantly two weeks after injury. Endorsement of difficulty concentrating had the strongest correlation after one month. Overall, ratings appeared to correlate most strongly two weeks after injury.

Finally, correlations between SCAT participant scores and PCSI ratings suggest that parent and child ratings of concussion symptoms do relate to scores from an objective assessment. Objective measures of immediate memory, delayed recall, and concentration correlated weakly with parents' ratings. Although parents PCSI report did not correlate well with the child's ability to perform associated SCAT tasks, these correlations were greater than with children's reporting. In contrast, children's ratings of balance difficulties correlated more strongly with balance error scores, reaching statistical significance. Therefore, children may be better at identifying balance difficulties than their parents.

Discussion

When a child experiences a concussion, it is common practice for the child and an adult, usually a parent or caregiver, to report symptoms experienced by the child (Miller & Leathem, 2016). Accordingly, it is of interest to determine how parent and child reports relate to each other for the purposes of assessing the value of obtaining either report. The aim of this study was to explore parent and child concordance when reporting concussion symptoms (considering agreement over time, a comparison group, the age of the child at injury, symptom categories, and individual symptom level) and the association between parent and child ratings of concussion and objective symptom measures.

Parent and Child Concordance When Reporting Concussion Symptoms (Aim 1)

A return to baseline symptom levels is used to indicate recovery from concussion (McCrory et al., 2017). In the concussion group, parents reported that the number and severity of symptoms had returned to baseline levels one month after injury; however, symptom ratings from children with concussion were above baseline levels until three months after injury. In comparison, the upper limb injury group parents and children reported symptoms below baseline levels comparatively sooner, after two weeks.

Parent and child ratings of concussion symptoms followed a similar pattern over time. This is consistent with the study by Jones et al. (2018) into parent and child ratings of behavioural and emotional functioning (BASC) following concussion. Jones et al. (2018) indicate that there may be differences in the specifics of symptom reporting by respondents, such as the amount or types of symptoms endorsed, but they follow the same pattern over time. Whilst parent and child symptom severity ratings could not be compared in our study (due to differences in item numbers and response options), correlations indicated that in the concussion group there was less agreement between parent and child ratings of symptom

severity at baseline and in the days after injury. Yet, the least agreement about the number of symptoms was at a different time point, after a month from injury.

Parents and children in the concussion group experienced a greater number of symptoms of a greater severity, compared to the upper limb injury group. This is consistent with research which demonstrates that, although symptoms on many concussion symptom inventories may be experienced by the general population, they are more prevalent following concussion (Bernard et al., 2017; Grubenhoff et al., 2011).

In the concussion group, there was better agreement between parents and children on the presence or absence of symptoms, rather than the severity. This is consistent with previous findings which suggest that rating symptom severity introduces more subjectivity (Grubenhoff et al., 2011; Miller & Leathem, 2016). Accordingly, this supports the recommendation that rating presence of concussion symptoms is more clinically useful for guiding recovery than assessing for the level of severity (Grubenhoff et al., 2011).

Sady et al. (2014) reported similar findings to the current study. Pearson's correlations were used in the Sady et al. (2014) study to compare parent and child reports from a group of children with concussion and a comparison group of uninjured children. Symptom report was recorded on one occasion for each participant within one month of injury. Our study aimed to expand on this by comparing symptom reports over time, with ratings obtained at five time points within a three-month period. Due to the larger sample size, Sady et al. (2014) were able to organise correlations according to age ranges of each PCSI version. Similar to our findings in Table 5, parent- and self-report of the number of symptoms from the concussion group (5-7 years: r= .44; 8-12 years: r= .56; 13-17 years: r= .65) produced stronger correlations than the comparison group (5-7 years: r= .18; 8-12 years: r= .16; 13-17 years: r= .13) at all age ranges. This shows that agreement about presence of concussion symptoms is stronger when

reports concern children with concussion, rather than children who have a different type of injury or are not injured. It also suggests that the symptoms within the PCSI are more specific to concussion. In our study, the only strong and significant correlations within comparison group ratings of severity and number of symptoms were found three months after injury. This follow-up time is later post-injury than recorded by Sady et al. (2014) and likely to be the time point at which symptoms are lower. Therefore, it may be that agreement was shown at this time from injury as raters in our comparison group were similarly reporting minor symptom severity.

One difference between our findings concerning parent and child concordance and those reported by Sady et al. (2014), is that Sady et al. (2014) found no significant correlations between parent and child reports of the number of symptoms in the concussion group for any of the age groups. In comparison, as shown in Table 9, we found significant correlations three months after injury for children between eight and 12 (r_s= .667*) and at baseline for adolescents (r_s= .683*). These differences cannot be generalised because of the small number of participants. Looking at the concussion group overall in our study, however, there were significant correlations between parents and children for the number of symptoms reported at all time points, except for one month after injury. While significant correlations are important for showing statistical support for correlation coefficients it is also useful to look at the strength of the correlation coefficient, as this is independent of the sample size.

The different times when symptom reports were obtained for this study and the research by Sady et al. (2014) may explain the different concordance recorded through correlations. Our study recorded a pattern of symptom reporting on multiple occasions, from the days (1-4 days) after injury up to three months later. In comparison, the Sady et al. (2014) study recorded one rating of symptom report obtained within a month of concussion, at

which point we had recorded symptom report relating to four separate times from injury. Interestingly, Sady et al. (2014) found no differences between symptoms reported by participants within a week of injury and those reported by others between two weeks and a month after concussion. Our findings differ and show the number and severity of symptoms reported within days of injury decrease when recorded again two weeks after injury and continue to decrease after a month and three months. Furthermore, the strength of correlation between parent and child report in our study generally improved over time, as the prevalence of symptoms decreased. A key difference between this study and the study by Sady et al. (2014) is that we assessed symptom reports at multiple time points. This provided additional information, showing parent and child ratings correlated differently over time. Weaker correlations closer to injury suggest that there are more discrepancies between parent and children's subjective symptom reports when most symptoms are experienced. Therefore, ensuring concussion symptom assessment incorporates both reports, especially closer to injury, may be helpful to provide the widest breadth of assessment information.

Hajek et al. (2010) compared parent and child agreement over time (baseline, one month, three months, and 12 months after injury) on another concussion measure, the PCS. Correlations between symptom reports from parents and children aged from eight to 15-years old were calculated according to two injury groups, mTBI (186 participants) and orthopaedic injury (99). While this age range is smaller than our study, children are the focus in a similar way and raters also recorded the total number of symptoms present. Hajek et al. (2010) did not look at acute symptoms as we did; their first reported correlations were obtained from parents' and children's symptom reports one month after injury. Our findings concerning symptom report in the days after injury, particularly because of the change in correlation strength over time, therefore shows the significance of this study in addressing an

important gap in the literature. One month after injury, correlations between parent and child report of the number of symptoms present found by Hajek et al. (2010) (r= .44*) were very similar to findings in our study at this time point (r_s= .404). Also, three months after injury correlations were similar (r= .31*), but not as strong as our findings (r_s= .433*).

When examining correlations across injury groups, Hajek et al. (2010) showed stronger agreement between parents in the comparison group than the TBI group at each time point after injury. Hajek et al. (2010) noted this was unexpected, as agreement had been hypothesised to be better regarding children with mTBI as found by Sady et al. (2014) and in our study. The unexpected stronger agreement between parents and children in the comparison group was attributed to the injury status of participants in their study and steady symptom resolution in comparison to the fluctuating symptoms experienced by children with concussion (Hajek et al., 2010).

There is unequal distribution of symptoms across types and so descriptive statistics could not be used to draw conclusions about which types of symptoms were reported more frequently. Nevertheless, previous research (Ayr et al., 2009; Durish et al., 2018) and greater representation on the PCSI suggests that physical and cognitive types of concussion symptoms are most common. In our study, when comparing agreement between parents and children, of all the symptom subtypes, correlations between ratings of physical symptoms were strongest (and most likely to be statistically significant) over time, especially after two weeks from injury (T2 r_s= .698**; T3 r_s= .557**; T4 r_s= .706**). Sady et al. (2014) found that parent child agreement on ratings of physical (8-12 years r= 0.61; 13-18 years r= 0.62) and cognitive symptoms (8-12 years r= 0.49; 13-18 years r= 0.62) were also strongest. As physical symptoms are thought to be most common, it is also consistent with previous research that suggests concordance is best on reports of the most relevant types of difficulties experienced

by the child (Cleridou et al., 2017; Upton et al., 2008). Similarly, our findings show that ratings of cognitive type symptoms correlated strongly and significantly from two weeks after injury (T2 r_s= .537*; T3 r_s= .554*; T4 r_s= .539*). As cognitive symptoms are recognised as the other most significant concussion symptom type (Ayr et al., 2009; Durish et al., 2018), similar conclusions could be drawn.

Correlations between parent and child reports on emotional symptoms were also similar in strength and significance to cognitive symptoms in our study. Again, this is similar to findings from Sady et al. (2014) who found that parent and child endorsement of emotional symptoms was similar to cognitive symptoms, but rates of agreement were lower for fatigue symptoms. This is consistent with the argument posed by Hajek et al. (2010) that agreement is better for symptom categories most relevant to the child's injury. Yet, the high level of agreement concerning emotional type symptoms differs from conclusions made in previous research by Ayr et al. (2009) and Durish et al. (2018) who suggested that emotional symptoms were not a prevalent symptom type following concussion. Emotional symptoms fall into the more internal, less observable category (Jones et al., 2018). Finally, the weaker correlations for fatigue symptoms suggests less agreement between parents and children on these types of symptoms.

Focussing on the specific symptoms rated by all parents and children (headache, nausea, dizziness, irritability, and difficulty concentrating), agreement appeared to be strongest for dizziness, a physical symptom (as indicated by significant and moderate to strong kappa coefficients at three of the four time points after injury). Nausea showed the next best level of agreement (significant and strong kappa coefficients two weeks and one month after injury). In comparison, reporting of headaches and irritability each only showed one significant and strong measurement of agreement between parents and children two

weeks after injury. Reports of difficulty concentrating were strong and significant one month after injury. Although headaches are the most commonly acknowledged symptom of concussion by the public (Kwan et al., 2018), our findings show raters were more commonly in agreement about dizziness. This could be because headaches were the most common acute symptom that was individually examined (Table 12) and agreement was found to be lower closer to injury. The low agreement concerning irritability is supported by previous research into concussion symptoms by Coghlin et al. (2009) who identify irritability as one of the more subjective symptoms of concussion. Also, Sady et al. (2014) provide a potential explanation for the lower agreement, as they note irritability is a concussion symptom which parents may be able to identify when their child is not as aware of it.

Sady et al. (2014) found parent and child agreement was better for reports of the overall number of symptoms present and the subscale scores showing the types of symptoms present compared to reporting of individual symptoms. This is consistent with our findings of stronger correlations between reports of overall symptom experience and ratings of the different types of symptoms than reports of individual symptoms. Accordingly, reporting of symptoms overall and by type also followed a more consistent pattern of reporting over time than individual type symptoms.

The Association Between Parent and Child Ratings of Concussion and Objective Symptom Measures (Aim 2)

The second objective of this study was to assess how parents' and children's subjective reporting of concussion symptoms were associated with an objective assessment of performance on another measure. To date, there have been few reports of the relationship between parent and child subjective symptom ratings and objective symptom assessments in childhood concussion research. This analysis was undertaken to provide insight into who

might have a better sense of the difficulties experienced by the child after their concussion. We found no statistically significant correlations between subjective ratings and objective measures of immediate memory, delayed recall, and concentration. However, children's ratings of balance difficulties were significantly associated with SCAT balance error scores on two occasions (two weeks and one month after injury). Interestingly, although Sady et al. (2014) did not compare PCSI ratings to an objective symptom measure as we did, their findings suggest that parents are better at noticing balance problems than their children. This contradicts our findings and suggests that although parents may report more of some types of symptoms, further research into the accuracy of this reporting needs to be conducted. Reporting higher prevalence of symptoms does not necessarily equate to better assessment of the child's concussion.

These differences may be due to parents' and children's understanding of concussion and the resulting symptoms from parents and children. This would be consistent with research by Hassen et al. (2018) which suggests a need to better educate parents and children about the possible symptoms and difficulties when a child has a concussion. It may be that parents do not know what symptoms to look for after concussion and so, unless the child tells them about a symptom, they may not know it is present. An alternative explanation may be due to the inaccurate matching of PCSI items with SCAT domains. This was based on the appearance that they were measuring related constructs, but this assumption may be erroneous; for example, the difficulty concentrating assessed by parents and children may tap into a separate issue of concentration than the SCAT domain assesses. Further analyses into the relationship between PCSI symptoms and SCAT domains would improve our understanding of these findings.

Limitations

This research was based on a pilot study (CRANIAC) that sought to determine the pattern of recovery from concussion in New Zealand children and adolescents and assess the feasibility of a larger study. The main limitation was the sample size. The small number of participants limited comparisons to between injury groups and amongst parents and children overall. Furthermore, difficulty recruiting participants in the upper limb injury group caused time delays in obtaining data. Accordingly, it was necessary to carry out data analyses prior to the completion of data collection in the comparison group. Our initial intention was to examine responses by age group. This was to determine if correlations between parent and child differed according to the age of the injured child, given that younger children may be less able to comprehend, report, and recognise symptoms of concussion (Sady et al., 2014). Unfortunately, the sample size limited our ability to undertake this analysis. The difference in children's experience of concussion at different ages may mean that collating all children's results creates generalisations that are not accurately representative of all ages. This is supported by findings that show differences in symptom reporting across children's age groups (Bernard et al., 2017). However, results from this pilot study suggest that a larger scale study would be of value. This would allow for comparisons between age groups to determine if parent and child agreement differs dependent on child age, especially as other research has suggested parent and child concordance may improve with age (Varni et al., 2003).

Another limitation in this research is related to the use of the PCSI as the concussion assessment tool. The PCSI is a valid and reliable measure (Sady et al., 2014), but there are some issues; notably for this study, the inability to directly compare parent and child versions. This limited the types of analyses able to be conducted and the way that results could be discussed.

Strengths

A significant strength of this research is seen in the repeated application of measures over time. Existing research shows that concussion symptoms and parent and child agreement on their presence changes over time (Hajek et al., 2010); therefore, obtaining parent and child symptom report at five time points within a three month period adds to the integrity of the results. This follows from recommendations for future research identified by Sady et al. (2014) who suggest tracking concussion recovery in children over time through symptom total and subscale reports on the PCSI could provide useful insight into the effects of injury.

Another strength is in the acute measure of symptoms within four days following concussion. Prompt assessment of concussion is advised (Makdissi et al., 2017; McCrory et al., 2017) and participants were seen as soon as practical limitations of the study allowed, such as identifying and recruiting participants, obtaining consent, and organising assessment times. This addresses the limitations of previous research where concussion was assessed weeks or months after injury, when many of the symptoms have resolved (Bressan et al., 2016; McNally et al., 2013). Further research assessing the presentation of symptoms immediately after concussion would help to increase our understanding of when symptoms are more or less severe then, in comparison to days later. Presentation and severity of concussion symptoms are recognised as both worsening and improving quickly after injury (Makdissi et al., 2017; McCrory et al., 2017); therefore, it would be interesting to see how this might affect the pattern of symptoms reported here. Furthermore, the results suggest that parent and child agreement was typically weakest in the days after injury and improved over time. Accordingly, it would be interesting to determine how ratings correlated closer to the time of injury.

The inclusion of a group of parents and children with another injury was beneficial. Many concussion symptoms are also experienced by children and adolescents in the general population (Davis, Anderson, et al., 2017; Feigin et al., 2013; Thurman, 2016). Being able to compare symptom reporting from parents and children with concussion to those with another injury was useful for identifying factors of recovery specifically relevant to concussion. The increased amount and severity of symptoms in the concussion group highlight the significance of concussion compared to another mild injury and demonstrate a need to better understand their experience. Furthermore, parent and child ratings in both injury groups helped to show agreement is greater when symptoms are associated with the injury.

Conclusions and Recommendations

In conclusion, this thesis has shown there is value in obtaining both parent and child report of concussion symptoms. For example, agreement around symptom total and severity supports the importance of collating information from parents and children to provide the most comprehensive understanding of a child's needs following concussion. In addition, there are unique factors identified within symptom reporting from parents and children, especially in the days after injury, that suggests focusing on one type of respondent may mean that valuable information is missed. Also, the time at which symptoms reportedly returned to baseline levels differed between parent and child reports.

There were similarities between our findings and those of Sady et al. (2014), especially when considering agreement at the different levels of symptom reporting. The stronger agreement overall and within the types of symptoms reported demonstrates that parent and child reports are complementary. Additionally, perfect agreement was not anticipated, nor was it shown in our findings. This shows that obtaining both reports is not redundant, but

rather, a necessary aid in guiding assessment and management of concussion in children. Differences within symptom report can be used to prompt discussion into potential miscommunication between the caregiver and child and thus improve understanding of their experience following concussion so that appropriate accommodations can be made.

Having established that parent and child reports of the number and severity of symptoms do correlate, future analyses comparing differences would be useful. Jones et al. (2018) have argued that Bland-Altman plots may be an alternative way to measure agreement instead of correlation coefficients. This method of analyses measures differences between reports that cannot be directly compared, as is the case with the different versions of the PCSI. As there are three PCSI versions corresponding to the three age groups of children (5-7:11, 8-12:11, 13-17:11) and a parent version, Bland-Altman plots would have to be calculated between parent responses and each of the child PCSI versions. Our sample was not large enough to perform reliable analyses according to age groups. Future research with sample sizes that allow for analysis with Bland-Altman plots could therefore add to the understanding of parent and child agreement concerning concussion symptoms.

Future research could also examine parent and child report of concussion symptoms in comparison to an objective symptom assessment. This would be important for establishing the accuracy of self and by proxy reporting of symptoms, especially given the implications these ratings have in diagnosing concussion and managing recovery. Given our results suggest parents and children are not very accurate in their perception of the child's competence to perform a task related to a concussion symptom, this may indicate that self and parent report of symptoms is not sufficient. Alternatively, the measures may be assessing constructs that are related, but not the same. Therefore, the timing of measures, with in the moment assessment from the SCAT and rating of the previous days on the PCSI, may also have

influenced these differences. Accordingly, it would be helpful to include subjective and objective measures when assessing concussion as they provide different and more detailed information.

These findings suggest that parent and child reporting of concussion symptoms provide useful information about the child following their concussion. It would be interesting to know if these differences are specific to concussion symptoms, or if they reflect a more general variance between parents' and children's perception of a child's experiences. Investigating these patterns and contrasts between parents and children on a larger scale is important because reports are often obtained for the purpose of informing a range of clinical decisions (Grubenhoff et al., 2011). For example, report from parents and/or children can play a significant role in the assessment, diagnosis, management, recovery, and treatment planning for a range of issues concerning children (Cleridou et al., 2017; Upton et al., 2008; Varni et al., 2003). A systematic review of correlations between reports from parents and children on a range of measures of children's health and wellbeing may therefore provide useful information. If there are specific types of symptoms that parents or children are better at reporting, as suggested by Jones et al. (2018), this could have implications for providing the most effective assessment of a range of difficulties. For example, directing questions or components of an assessment to the most appropriate person may result in more accurate information and optimise time and resources to offer the best care for young people.

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Appendix A- Participant Information Sheets

Registration Number:	Participant Initials:	Date of Birth:

Parent (Child Over 16) Participant Information Sheet

Study title:	**Concussion Recovery in Children and Adolescents: A pilot study**		
Locality:	**Waikato**	Ethics committee ref.:	18/CEN/81
Lead investigator:	**Professor Nicola Starkey**	Contact phone number:	**07 8379230**

You are invited to take part in a study on symptoms that children and young people experience after concussion or after an injury to their shoulders, arms hand or fingers. Your child recently experienced a concussion or upper limb injury and gave us permission to contact you. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect your child's care. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Information sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is 6 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

WHAT IS THE PURPOSE OF THE STUDY?

Concussion is one of the most common injuries in children and adolescents. Most young people recover quickly from concussion but some have symptoms that last a lot longer. We want to find out how long it usually takes for children and adolescents to recover from concussion and to identify factors that are important in recovery.

We want to recruit children and adolescents (5-17 years) with concussion and compare their symptoms to those with injuries to their upper limbs (shoulders, arms, hand and fingers) so that we can find out about the types of symptoms that are associated with concussion specifically rather than an injury in general.

As well as finding out about the effects of concussion and upper limb injuries we would like your feedback on the study; which things we did well and how we could improve what we do for future participants

The study is supported by a grant from the University of Waikato Medium Strategic Investment Fund. If you have any questions about the study please contact the lead investigator, Dr Nicola Starkey, tel 07 8379230. Email: nicola.starkey@waikato.ac.nz

The study has been approved by the Health and Disability Ethics Committee reference 18/CEN/81.

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

You have been invited to participate in this study because you are the parent of a child/adolescent who recently visited Waikato Emergency Department who had a concussion or an upper limb injury.

If you choose to take part, your participation will be for 3 months only. There will be four assessments in total – within four days of the injury, and then two weeks, 1 month and three months after the injury. Each assessment will be carried out a place and time that is convenient for you (e.g., your home) and will take 30-60 minutes.

During the assessments we will ask you some questions about your child's symptoms, how they are feeling, their sleep, quality of life and usual day to day activities (e.g., sport and hobbies). We will also ask some questions about your general wellbeing. Your child (or other person) can be with you whilst you complete these questionnaires if you wish.

We want to finish collecting data for this study by December 2019.

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

Taking part in this study will take some of your time and require you to complete some questionnaires. There are no known risk caused by this study, however you may feel uncomfortable or embarrassed by some of the questions. You do not have to answer any questions you do not wish to do so.

Your (or your child's) usual medical care will not be affected in any way by participating in the study, or withdrawing from the study at any stage. Your (and your child's) participation in this study will be stopped should any harmful effects appear or if a doctor feels it is not in your best interests to continue. Similarly your doctor may at any time provide you (or your child) with any other treatment he/she considers necessary.

This study will be of benefit to the wider population. There is no guarantee that you will benefit directly from being involved in this study. However, you will be given an opportunity to discuss your child's injury with a researcher. The results obtained from your participation may help others with this condition in the future.

WHO PAYS FOR THE STUDY?

There should be no direct costs to you in taking part in this study

A $20 voucher will be provided to the family after completion of each assessment in acknowledgment of your contribution to this research (total of $80 per family). Assessments will be completed at your own home or other accessible location. If for some reason you need to travel for the assessment, your mileage or costs will be reimbursed.

WHAT IF SOMETHING GOES WRONG?

It is unlikely that you will be at risk of harm from taking part in this study. If something goes wrong please contact the lead investigator as soon as possible on 07 8379230.

If you were injured in this study, which is unlikely, you would be eligible **to apply** for compensation from ACC just as you would be if you were injured in an accident at work or at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery. If you have private health or life insurance, you may wish to check with your insurer that taking part in this study won't affect your cover.

WHAT ARE MY RIGHTS?

The study files and all other information that you and your child provide will remain strictly confidential, unless information is revealed that indicates you, your child or someone else is at risk.

No material that could personally identify you will be used in any reports or discussions about this study.

Your (and your child's) participation is entirely voluntary and you will be able to withdraw from the study at any time without experiencing any disadvantage.

If any information that may be of benefit to you or child emerges during the study we will contact you to let you know.

WHAT HAPPENS AFTER THE STUDY OR IF I CHANGE MY MIND?

Upon completion of the study the records will be stored for 21 years in a locked cabinet at University of Waikato by the lead investigator (Professor Nicola Starkey). All computer records

will be password protected. Any identifying information will not be shared outside of the research team without seeking your/ your child's permission
After 21 years all electronic information will be deleted and paper forms will be shredded and destroyed with the University confidential waste.
After we have looked at all the data we will send you a summary of results if you would like to receive them.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Professor Nicola Starkey, lead investigator,
Telephone number: 07 8379230
Email: nicola.starkey@waikato.ac.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

For Māori health support please contact :

Te Puna Oranga (Waikato DHB Māori Health Unit),
Hockin Building, Level 1, Pembroke St, P.O.Box 934, Hamilton.
Ph: 07 834 3644. Fax: 07 834 3619.

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS
Email: hdecs@moh.govt.nz

Please keep this for your information.
Thank you for interest in this study

Registration Number:	Participant Initials:	Date of Birth:

Parent (Child Under 16) Participant Information Sheet

Study title:	**Concussion Recovery in Children and Adolescents: A pilot study**		
Locality:	**Waikato**	Ethics committee ref.:	18/CEN/81
Lead investigator:	**Professor Nicola Starkey**	Contact phone number:	**07 8379230**

You and your child are invited to take part in a study on symptoms that children and young people experience after concussion or after an injury to their shoulders, arms hand or fingers. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Information sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is 6 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

WHAT IS THE PURPOSE OF THE STUDY?

Concussion is one of the most common injuries in children and adolescents. Most young people recover quickly from concussion but some have symptoms that last a lot longer. We want to find out how long it usually takes for children and adolescents to recover from concussion and to identify factors that are important in recovery.

We want to recruit children and adolescents (5-17 years) with concussion and compare their symptoms to those with injuries to their upper limbs (shoulders, arms, hand and fingers) so

that we can find out about the types of symptoms that are associated with concussion specifically rather than an injury in general.

As well as finding out about the effects of concussion and upper limb injuries we would like your feedback on the study; which things we did well and how we could improve what we do for future participants

The study is supported by a grant from the University of Waikato Medium Strategic Investment Fund. If you have any questions about the study please contact the lead investigator, Dr Nicola Starkey, tel 07 8379230. Email: nicola.starkey@waikato.ac.nz

The study has been approved by the Health and Disability Ethics Committee reference 18/CEN/81.

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

You have been invited to participate in this study because you recently visited Waikato Emergency Department with a child/adolescent who had a concussion or an upper limb injury.

If you choose to take part, your participation will be for 3 months only. There will be four assessments in total – within four days of the injury, and then two weeks, 1 month and three months after the injury. Each assessment will be carried out a place and time that is convenient for you (e.g., your home) and will take 30-60 minutes.

During the assessments we will ask you and your child some questions about their symptoms, how they are feeling, their sleep, quality of life and usual day to day activities (e.g., sport and hobbies). We will also ask some questions about your general wellbeing. Your child/adolescent will be asked to complete some short memory tasks and we will check their balance (most people find the tasks enjoyable). You are welcome to stay with your child during these activities.

We want to finish collecting data for this study by December 2019.

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

Taking part in this study will take some of your time and require you (and your child) to complete some questionnaires and computer-based tasks. There are no known risk caused by this study, however you may feel uncomfortable or embarrassed by some of the questions. You and your child do not have to answer any questions you do not wish to do so.

Your (or your child's) usual medical care will not be affected in any way by participating in the study, or withdrawing from the study at any stage. Your (and your child's) participation in this study will be stopped should any harmful effects appear or if a doctor feels it is not in your best interests to continue. Similarly your doctor may at any time provide you (or your child) with any other treatment he/she considers necessary.

This study will be of benefit to the wider population. There is no guarantee that you will benefit directly from being involved in this study. However, if your child has had a concussion, you will be given an opportunity to discuss this with a researcher. The results obtained from your participation may help others with this condition in the future.

WHO PAYS FOR THE STUDY?

There should be no direct costs to you in taking part in this study

A $20 voucher will be provided to each family after completion of each assessment in acknowledgment of your contribution to this research (total of $80 per family). Assessments will be completed at your own home or other accessible location. If for some reason you need to travel for the assessment, your mileage or costs will be reimbursed.

WHAT IF SOMETHING GOES WRONG?

It is unlikely that you will be at risk of harm from taking part in this study. If something goes wrong please contact the lead investigator as soon as possible on 07 8379230.

If you were injured in this study, which is unlikely, you would be eligible **to apply** for compensation from ACC just as you would be if you were injured in an accident at work or at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery. If you have private health or life insurance, you may wish to check with your insurer that taking part in this study won't affect your cover.

WHAT ARE MY RIGHTS?

The study files and all other information that you and your child provide will remain strictly confidential, unless information is revealed that indicates you, your child or someone else is at risk.

No material that could personally identify you will be used in any reports or discussions about this study.

Your (and your child's) participation is entirely voluntary and you will be able to withdraw from the study at any time without experiencing any disadvantage.

If any information that may be of benefit to you or child emerges during the study we will contact you to let you know.

WHAT HAPPENS AFTER THE STUDY OR IF I CHANGE MY MIND?

Upon completion of the study the records will be stored for 21 years in a locked cabinet at University of Waikato by the lead investigator (Professor Nicola Starkey). All computer records will be password protected. Any identifying information will not be shared outside of the research team without seeking your/ your child's permission

After 21 years all electronic information will be deleted and paper forms will be shredded and destroyed with the University confidential waste.
After we have looked at all the data we will send you a summary of results if you would like to receive them.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Professor Nicola Starkey, lead investigator,
Telephone number: 07 8379230
Email: nicola.starkey@waikato.ac.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

For Māori health support please contact :

Te Puna Oranga (Waikato DHB Māori Health Unit),
Hockin Building, Level 1, Pembroke St, P.O.Box 934, Hamilton.
Ph: 07 834 3644. Fax: 07 834 3619.

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS
Email: hdecs@moh.govt.nz

Please keep this for your information.
Thank you for interest in this study

Registration Number:	Participant Initials:	Date of Birth:

Adult Participant Information Sheet

Study title:	**Concussion Recovery in Children and Adolescents: A pilot study**		
Locality:	**Waikato**	Ethics committee ref.:	18/CEN/81
Lead investigator:	**Professor Nicola Starkey**	Contact phone number:	**07 8379230**

You are invited to take part in a study on symptoms that children and young people (aged 5-17 years) experience after concussion or after an injury to their shoulders, arms hand or fingers. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Information sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is 6 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

WHAT IS THE PURPOSE OF THE STUDY?

Concussion is one of the most common injuries in children and adolescents. Most young people recover quickly from concussion but some have symptoms that last a lot longer. We want to find out how long it usually takes for children and adolescents to recover from concussion and to identify factors that are important in recovery.

We want to recruit children and adolescents (5-17 years) with concussion and compare their symptoms to those with injuries to their upper limbs (shoulders, arms, hand and fingers) so

that we can find out about the types of symptoms that are associated with concussion specifically rather than an injury in general.

As well as finding out about the effects of concussion and upper limb injuries we would like your feedback on the study; which things we did well and how we could improve what we do for future participants

The study is supported by a grant from the University of Waikato Medium Strategic Investment Fund. If you have any questions about the study please contact the lead investigator, Dr Nicola Starkey, tel 07 8379230. Email: nicola.starkey@waikato.ac.nz

The study has been approved by the Health and Disability Ethics Committee reference 18/CEN/81.

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

You have been invited to participate in this study because you recently visited Waikato Emergency Department with a concussion or an upper limb injury.

If you choose to take part, your participation will be for 3 months only. There will be four assessments in total – within four days of the injury, and then two weeks, 1 month and three months after the injury. Each assessment will be carried out a place and time that is convenient for you (e.g., your home) and will take 30-60 minutes.

During the assessments we will ask you (and you parent, with your permission) some questions about your symptoms, how you are feeling, your sleep, quality of life and usual day to day activities (e.g., sport and hobbies). You will also be asked to complete some short memory tasks and we will check your balance (most people find the tasks enjoyable). You are welcome to have your parent / guardian with you during the assessment.

We want to finish collecting data for this study by December 2019.

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

Taking part in this study will take some of your time and require you to complete some questionnaires and computer-based tasks. There are no known risk caused by this study, however you may feel uncomfortable or embarrassed by some of the questions. You do not have to answer any questions you do not wish to do so.

Your usual medical care will not be affected in any way by participating in the study, or withdrawing from the study at any stage. Your participation in this study will be stopped should any harmful effects appear or if a doctor feels it is not in your best interests to continue. Similarly your doctor may at any time provide you with any other treatment he/she considers necessary.

This study will be of benefit to the wider population. There is no guarantee that you will benefit directly from being involved in this study. However, you will be given an opportunity to discuss your injury with a researcher. The results obtained from your participation may help others with this condition in the future.

WHO PAYS FOR THE STUDY?

There should be no direct costs to you in taking part in this study

A $20 voucher will be provided to your family after completion of each assessment in acknowledgment of your contribution to this research (total of $80 per family). Assessments will be completed at your own home or other accessible location. If for some reason you need to travel for the assessment, your mileage or costs will be reimbursed.

WHAT IF SOMETHING GOES WRONG?

It is unlikely that you will be at risk of harm from taking part in this study. If something goes wrong please contact the lead investigator as soon as possible on 07 8379230.

If you were injured in this study, which is unlikely, you would be eligible **to apply** for compensation from ACC just as you would be if you were injured in an accident at work or at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery. If you have private health or life insurance, you may wish to check with your insurer that taking part in this study won't affect your cover.

WHAT ARE MY RIGHTS?

The study files and all other information that you provide will remain strictly confidential, unless information is revealed that indicates you or someone else is at risk.

No material that could personally identify you will be used in any reports or discussions about this study.

Your participation is entirely voluntary and you will be able to withdraw from the study at any time without experiencing any disadvantage.

If any information that may be of benefit to you emerges during the study we will contact you to let you know.

WHAT HAPPENS AFTER THE STUDY OR IF I CHANGE MY MIND?

Upon completion of the study the records will be stored for 21 years in a locked cabinet at University of Waikato by the lead investigator (Professor Nicola Starkey). All computer records will be password protected. Any identifying information will not be shared outside of the research team without seeking your permission.

After 21 years all electronic information will be deleted and paper forms will be shredded and destroyed with the University confidential waste.

After we have looked at all the data we will send you a summary of results if you would like to receive them.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Professor Nicola Starkey, lead investigator,
Telephone number: 07 8379230
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If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

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You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS
Email: hdecs@moh.govt.nz

Please keep this for your information.
Thank you for interest in this study

Registration Number:	Participant Initials:	Date of Birth:

Participant (13 – 15 years) Information Sheet

Study title:	**Concussion Recovery in Children and Adolescents: A pilot study**		
Locality:	**Waikato**	Ethics committee ref.:	18/CEN/81
Lead investigator:	**Professor Nicola Starkey**	Contact phone number:	**07 8379230**

You are invited to take part in a study on symptoms that children and young people (aged 5-17 years) experience after concussion or after an injury to their shoulders, arms hand or fingers. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time. We will also be asking your parent/caregiver to take part in the study.

This Information sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Assent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Assent Form to keep.

This document is 6 pages long, including the Assent Form. Please make sure you have read and understood all the pages.

WHAT IS THE PURPOSE OF THE STUDY?

Concussion is one of the most common injuries in children and adolescents. Most young people recover quickly from concussion but some have symptoms that last a lot longer. We want to find out how long it usually takes for children and adolescents to recover from concussion and to identify factors that are important in recovery.

We want to recruit children and adolescents (5-17 years) with concussion and compare their symptoms to those with injuries to their upper limbs (shoulders, arms, hand and fingers) so

that we can find out about the types of symptoms that are associated with concussion specifically rather than an injury in general.

As well as finding out about the effects of concussion and upper limb injuries we would like your feedback on the study; which things we did well and how we could improve what we do for future participants

The study is supported by a grant from the University of Waikato Medium Strategic Investment Fund. If you have any questions about the study please contact the lead investigator, Dr Nicola Starkey, tel 07 8379230. Email: nicola.starkey@waikato.ac.nz

The study has been approved by the Health and Disability Ethics Committee reference 18/CEN/81.

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

You have been invited to participate in this study because you recently visited Waikato Emergency Department with a concussion or an upper limb injury.

If you choose to take part, your participation will be for 3 months only. There will be four assessments in total – within four days of the injury, and then two weeks, 1 month and three months after the injury. Each assessment will be carried out a place and time that is convenient for you (e.g., your home) and will take 30-60 minutes.

During the assessments we will ask you (and you parent) some questions about your symptoms, how you are feeling, your sleep, quality of life and usual day to day activities (e.g., sport and hobbies). You will also be asked to complete some short memory tasks and we will check your balance (most people find the tasks enjoyable). Your parent / guardian can be with you during the assessment.

We want to finish collecting data for this study by December 2019.

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

Taking part in this study will take some of your time and require you to complete some questionnaires and computer-based tasks. There are no known risk caused by this study, however you may feel uncomfortable or embarrassed by some of the questions. You do not have to answer any questions you do not wish to do so.

Your usual medical care will not be affected in any way by participating in the study, or withdrawing from the study at any stage. Your participation in this study will be stopped should any harmful effects appear or if a doctor feels it is not in your best interests to continue. Similarly your doctor may at any time provide you with any other treatment he/she considers necessary.

This study will be of benefit to the wider population. There is no guarantee that you will benefit directly from being involved in this study. However, you will be given an opportunity to discuss your injury with a researcher. The results obtained from your participation may help others with this condition in the future.

WHO PAYS FOR THE STUDY?

There should be no direct costs to you in taking part in this study

A $20 voucher will be provided to each family after completion of each assessment in acknowledgment of your contribution to this research (total of $80 per family). Assessments will be completed at your own home or other accessible location.

WHAT IF SOMETHING GOES WRONG?

It is unlikely that you will be at risk of harm from taking part in this study. If something goes wrong please contact the lead investigator as soon as possible on 07 8379230.

If you were injured in this study, which is unlikely, you would be eligible **to apply** for compensation from ACC just as you would be if you were injured in an accident at work or at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery. If you have private health or life insurance, you may wish to check with your insurer that taking part in this study won't affect your cover.

WHAT ARE MY RIGHTS?

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No material that could personally identify you will be used in any reports or discussions about this study.

Your participation is entirely voluntary and you will be able to withdraw from the study at any time without experiencing any disadvantage.

If any information that may be of benefit to you emerges during the study we will contact you to let you know.

WHAT HAPPENS AFTER THE STUDY OR IF I CHANGE MY MIND?

Upon completion of the study the records will be stored for 21 years in a locked cabinet at University of Waikato by the lead investigator (Professor Nicola Starkey). All computer records will be password protected. Any identifying information will not be shared outside of the research team without seeking your permission.
After 21 years all electronic information will be deleted and paper forms will be shredded and destroyed with the University confidential waste.

After we have looked at all the data we will send you a summary of results if you would like to receive them.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Professor Nicola Starkey, lead investigator,
Telephone number: 07 8379230
Email: nicola.starkey@waikato.ac.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

For Māori health support please contact :

Te Puna Oranga (Waikato DHB Māori Health Unit),
Hockin Building, Level 1, Pembroke St, P.O.Box 934, Hamilton.
Ph: 07 834 3644. Fax: 07 834 3619.

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS
Email: hdecs@moh.govt.nz

Please keep this for your information.
Thank you for interest in this study

Registration Number:	Participant Initials:	Date of Birth:

Participant (8 - 12 years) Information Sheet

Study title:	**Concussion Recovery in Children and Adolescents: A pilot study**		
Locality:	**Waikato**	Ethics committee ref.:	18/CEN/81
Lead investigator:	**Professor Nicola Starkey**	Contact phone number:	**07 8379230**

We want to help people to get better quickly after a bang on the head (concussion). To do this we have to ask children (like you) about any problems you are having (for example feeling sleepy) so that we can see how quickly you get better. We also want to talk to children who have hurt their shoulder, arm or hand so we can find out about their symptoms as well.

We are asking you to take part because you recently banged your head or hurt your shoulder, arm or hand. You can choose if you want to take part (you do not have to). Your parent / caregiver knows that we are asking you to take part and you can talk to them (or us) about it.

WHAT WILL I HAVE TO DO?

A researcher will come and visit you (where you live) and ask you to answer some questions about things you usually do (like sport), how you are feeling and how you are sleeping.
Your parent / guardian can be with you during the assessment. It will take about an hour. You do not need to answer all of the questions if you don't want to (you can stop at any time).

We will visit you four times in the next few months and ask the same questions do that we can see how quickly you get better after your injury.

WHAT HAPPENS IF I TAKE PART?

Answering the questions will take up some of your time. You do not have to answer any questions you do not want to.

We hope to find out about what helps children and young people recover quickly after concussion so that we can help other children in the future.

Your family will receive a $20 voucher after completing each assessment as a thank you for taking part (total of $80 per family).

WHAT HAPPENS TO MY INFORMATION?

Only researchers involved with the study will know your answers to the questions we ask you. We will keep all the information in a locked cupboard or on a secure computer. Your name will not be on any of the reports that we write.

We will keep the information for 21 years. After we have finished talking to all the children and young people we will send you some information about what we found.

CAN I ASK QUESTIONS?

If you have any questions concerns or complaints about the study, please ask your parents/ caregivers or you can contact the person in charge of the study (Nicola):

Nicola Starkey, lead investigator,
Telephone number: 07 8379230
Email: nicola.starkey@waikato.ac.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on*:*

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

For Māori health support please contact:
Te Puna Oranga (Waikato DHB Māori Health Unit),
Hockin Building, Level 1, Pembroke St, P.O.Box 934, Hamilton.
Ph: 07 834 3644. Fax: 07 834 3619.

You can also contact the health and disability ethics committee (HDEC) that approved this study on:
Phone: 0800 4 ETHICS
Email: hdecs@moh.govt.nz

Please keep this for your information.
Thank you for interest in this study

Appendix B- Participant Consent and Assent Forms

Registration Number:	Participant Initials:	Date of Birth:

Parent (Child Over 16) Consent Form

Please tick to indicate you consent to the following

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.	Yes ☐	
I have been given sufficient time to consider whether or not to participate in this study.	Yes ☐	
I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.	Yes ☐	
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.	Yes ☐	
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.	Yes ☐	
I consent to the research staff collecting and processing my information, including information about my child's health.	Yes ☐	
If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.	Yes ☐	No ☐
I consent to my GP or current provider being informed about my participation in the study and of any significant abnormal results obtained during the study.	Yes ☐	No ☐
I agree to an approved auditor appointed by the New Zealand Health and Disability Ethic Committees, or any relevant regulatory authority or their approved representative reviewing my relevant medical records for the sole purpose of checking the accuracy of the information recorded for the study.	Yes ☐	
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.	Yes ☐	

I know who to contact if I have any questions about the study in general.	Yes ☐	
I understand my responsibilities as a study participant.	Yes ☐	
I wish to receive a summary of the results from the study.	Yes ☐	No ☐

Declaration by participant:
I hereby consent to take part in this study.

Participant's name: _____

Signature: _____ Date: _____

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: _____

Signature: _____ Date: _____

Registration Number:	Participant Initials:	Date of Birth:

Parent (Child Under 16) Consent Form

Please tick to indicate you consent to the following

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.	Yes ☐	
I have been given sufficient time to consider whether or not to participate in this study.	Yes ☐	
I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.	Yes ☐	
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.	Yes ☐	
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.	Yes ☐	
I consent to the research staff collecting and processing my information, including information about my child's health.	Yes ☐	
If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.	Yes ☐	No ☐
I consent to my GP or current provider being informed about my participation in the study and of any significant abnormal results obtained during the study.	Yes ☐	No ☐
I agree to an approved auditor appointed by the New Zealand Health and Disability Ethic Committees, or any relevant regulatory authority or their approved representative reviewing my relevant medical records for the sole purpose of checking the accuracy of the information recorded for the study.	Yes ☐	
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.	Yes ☐	

I know who to contact if I have any questions about the study in general.	Yes ☐	
I understand my responsibilities as a study participant.	Yes ☐	
I wish to receive a summary of the results from the study.	Yes ☐	No ☐

Declaration by participant:
I hereby consent to take part in this study.

Participant's name: _____

Signature: _____ Date: _____

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: _____

Signature: _____ Date: _____

Registration Number:	Participant Initials:	Date of Birth:

Adult Participant Consent Form

Please tick to indicate you consent to the following

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.	Yes ☐	
I have been given sufficient time to consider whether or not to participate in this study.	Yes ☐	
I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.	Yes ☐	
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.	Yes ☐	
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.	Yes ☐	
I consent to the research staff collecting and processing my information, including information about my health.	Yes ☐	
If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.	Yes ☐	No ☐
I consent to my GP or current provider being informed about my participation in the study and of any significant abnormal results obtained during the study.	Yes ☐	No ☐
I agree to an approved auditor appointed by the New Zealand Health and Disability Ethic Committees, or any relevant regulatory authority or their approved representative reviewing my relevant medical records for the sole purpose of checking the accuracy of the information recorded for the study.	Yes ☐	
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.	Yes ☐	
I know who to contact if I have any questions about the study in general.	Yes ☐	

I understand my responsibilities as a study participant.	Yes ☐	
I wish to receive a summary of the results from the study.	Yes ☐	No ☐
I agree for you to contact my parent to obtain further information about my injury and symptoms Please provide the name and contact details (phone and email address) for your parent:	Yes ☐	

Declaration by participant:
I hereby consent to take part in this study.

Participant's name: _____

Signature: _____ Date: _____

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: _____

Signature: _____ Date: _____

Registration Number:	Participant Initials:	Date of Birth:

Participant Assent Form (13-15 years)

Please tick to indicate you agree to the following

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.	Yes ☐	
I have been given sufficient time to consider whether or not to participate in this study.	Yes ☐	
I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.	Yes ☐	
I am satisfied with the answers I have been given regarding the study and I have a copy of this assent form and information sheet.	Yes ☐	
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.	Yes ☐	
I assent to the research staff collecting and processing my information, including information about my health.	Yes ☐	
If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.	Yes ☐	No ☐
I assent to my GP or current provider being informed about my participation in the study and of any significant abnormal results obtained during the study.	Yes ☐	No ☐
I agree to an approved auditor appointed by the New Zealand Health and Disability Ethic Committees, or any relevant regulatory authority or their approved representative reviewing my relevant medical records for the sole purpose of checking the accuracy of the information recorded for the study.	Yes ☐	
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.	Yes ☐	

I know who to contact if I have any questions about the study in general.	Yes ☐	
I understand my responsibilities as a study participant.	Yes ☐	
I wish to receive a summary of the results from the study.	Yes ☐	No ☐

Declaration by participant:
I hereby assent to take part in this study.

Participant's name: _____

Signature: _____ Date: _____

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed assent to participate.

Researcher's name: _____

Signature: _____ Date: _____

Registration Number:	Participant Initials:	Date of Birth:

Participant Assent Form (8-12 years)

Please tick to indicate you agree to the following

I know what the study is about	Yes ☐	
I know that I can choose if I want to take part	Yes ☐	
I can stop or not answer questions at any time	Yes ☐	
I know that I can ask questions as any time	Yes ☐	
I want you to tell me what you find out	Yes ☐	No ☐

Declaration by participant:
I hereby agree to take part in this study.

Participant's name: _____

Signature: _____ Date: _____

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has agreed to participate.

Researcher's name: _____

Signature: _____ Date: _____

Appendix C- Checklist of Risk Factors or When There is an Issue of Concern

CBCL Ages 6-18- At Risk

- 18. Deliberately harms self or attempts suicide
- 57. Physically attacks others
- 91. Talks about killing self

- Inform participant you will need to make a referral to GP
- Refer to GP or emergency service
- Complete Health Referral Form

CBCL Ages 6-18- Issues of Concern

- 6. Bowel movements outside the toilet
- 15. Cruel to animals
- 35. Feels worthless of inferior
- 40. Hears sounds or voices that aren't there
- 59. Plays with own sex parts in public
- 67. Runs away from home
- 70. See things that aren't there
- 72. Sets fires
- 103. Unhappy, sad or depressed
- 105. Uses drugs for nonmedical purposes (don't include alcohol or tobacco)

- Recommend they contact their GP
- Offer to contact GP for them
- Note action taken on Checklist

CBCL Ages 5-6- Issues of Concern

- 14. Cruel to animals
- 55. Plays with own sex parts too much
- 71. Shows little interest with things around him/her
- 75. Smears or plays with bowel movements
- 90. Unhappy, sad or depressed

- Recommend they contact their GP
- Offer to contact GP for them
- Note action taken on Checklist

Child SCAT 5 Red Flags

- Neck pain or tenderness
- Double vision
- Weakness/tingling/burning in arms or legs
- Severe or increasing headache
- Seizure or convulsion
- Loss of consciousness
- Deteriorating conscious sate
- Vomiting
- Increasingly restless, agitated or combative

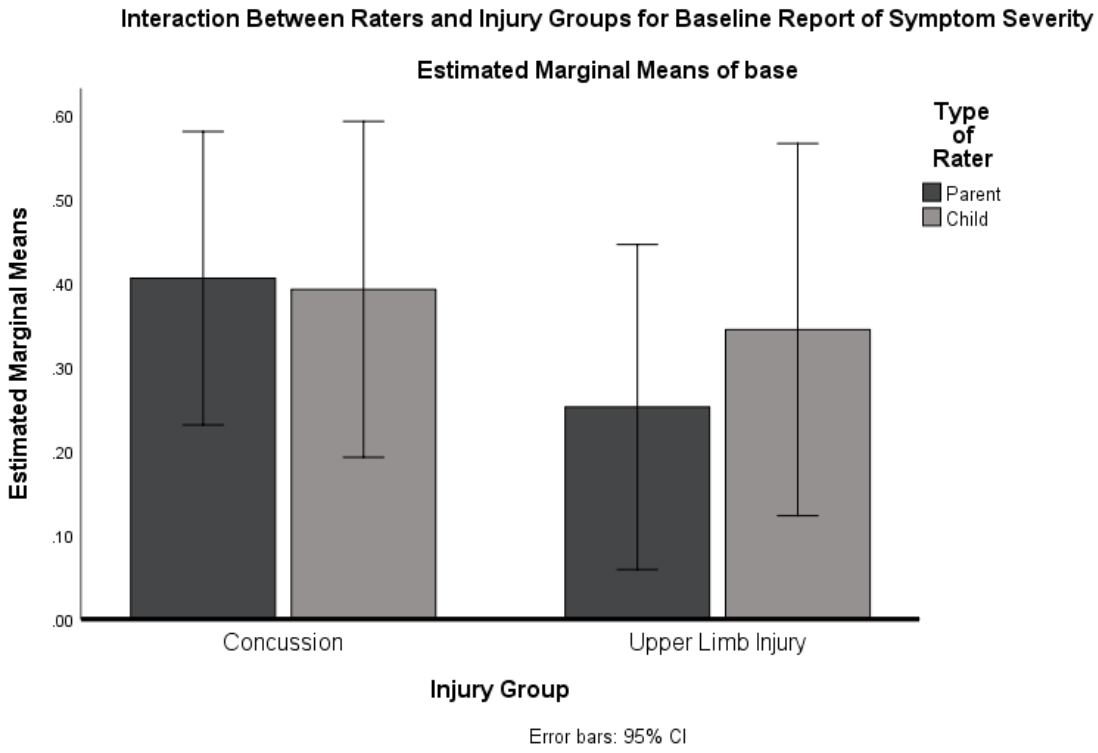
- Recommend they contact their GP
- Offer to contact GP for them
- Note action taken on Checklist

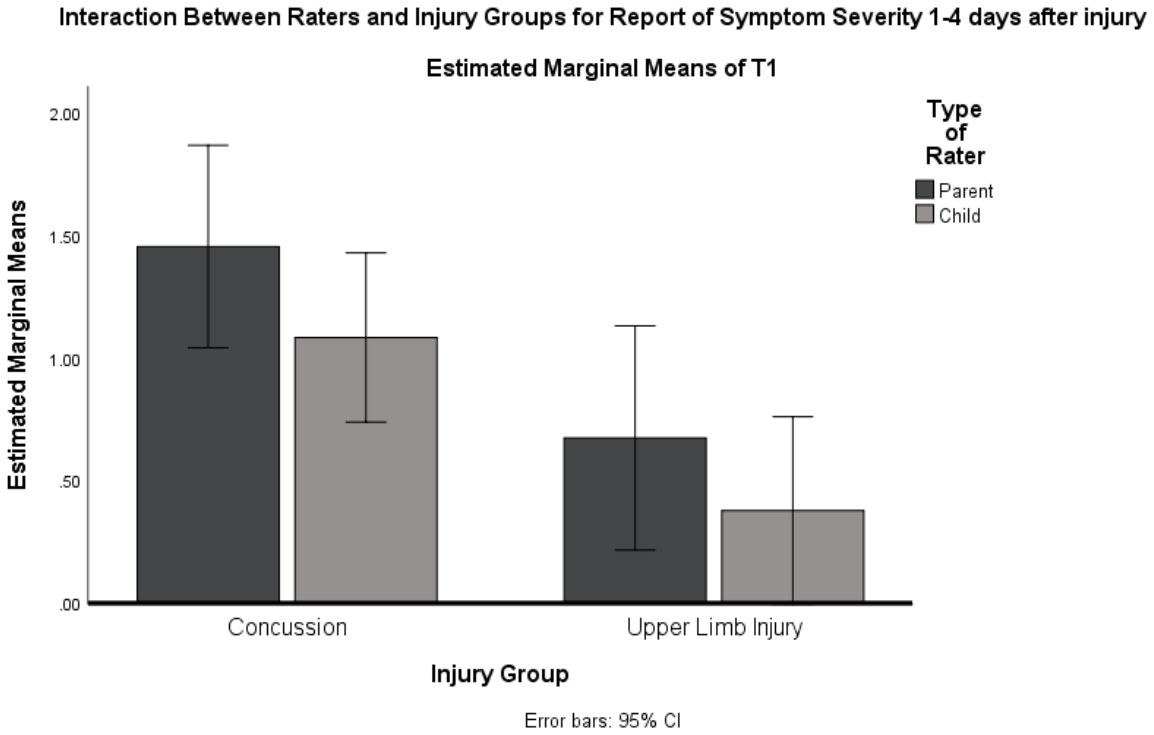
Kessler 10+

- Score 20 or over

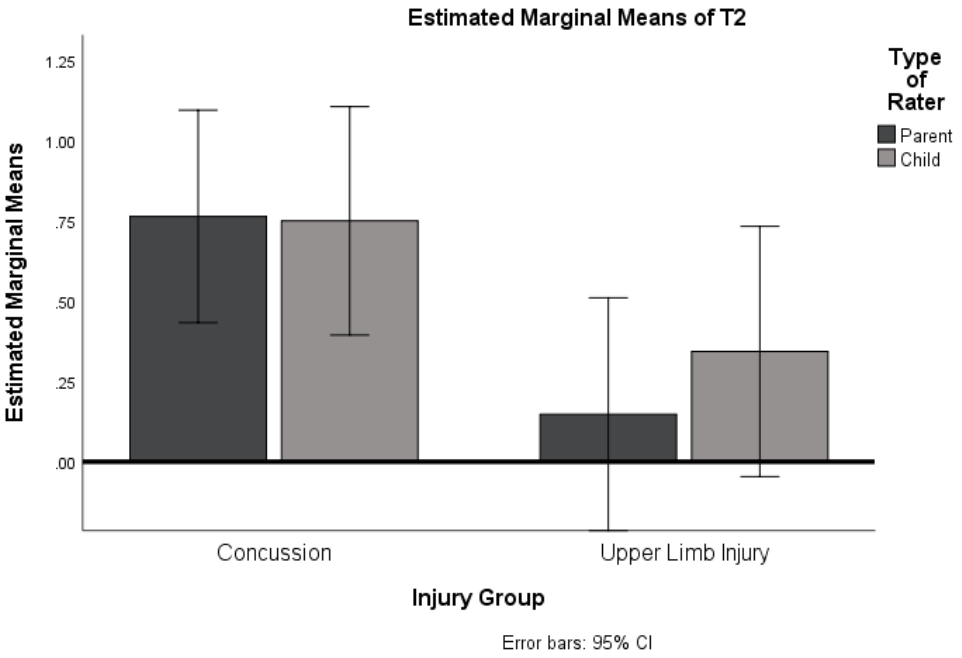
- Recommend they contact their GP
- Offer to contact GP for them
- Note action taken on Checklist

Appendix D- Graphs Showing Comparison Reports for Symptom Severity Between Groups and Raters

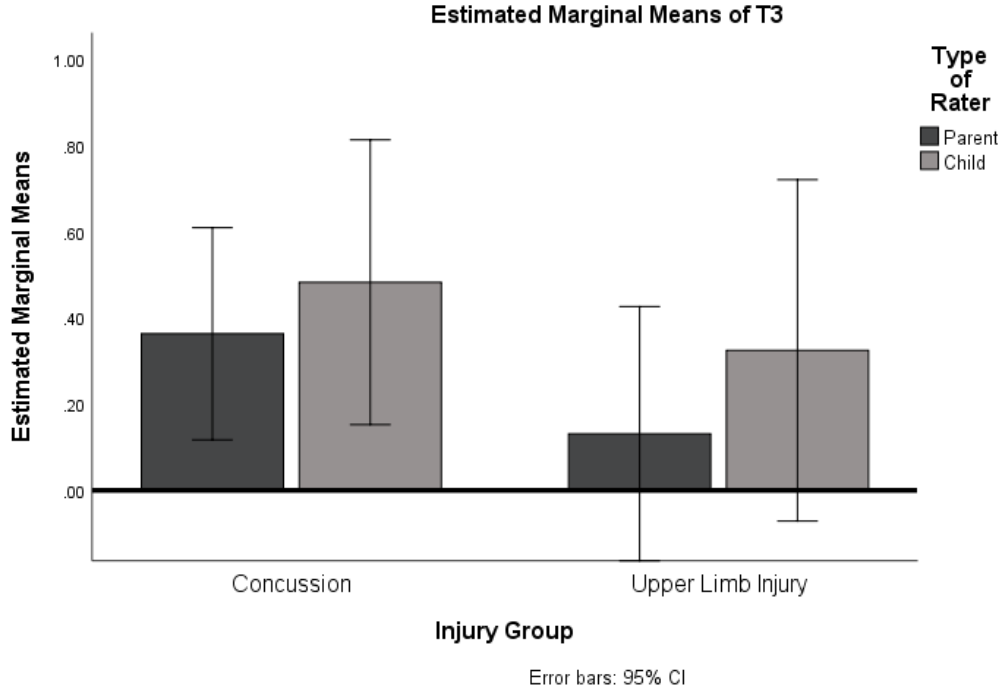




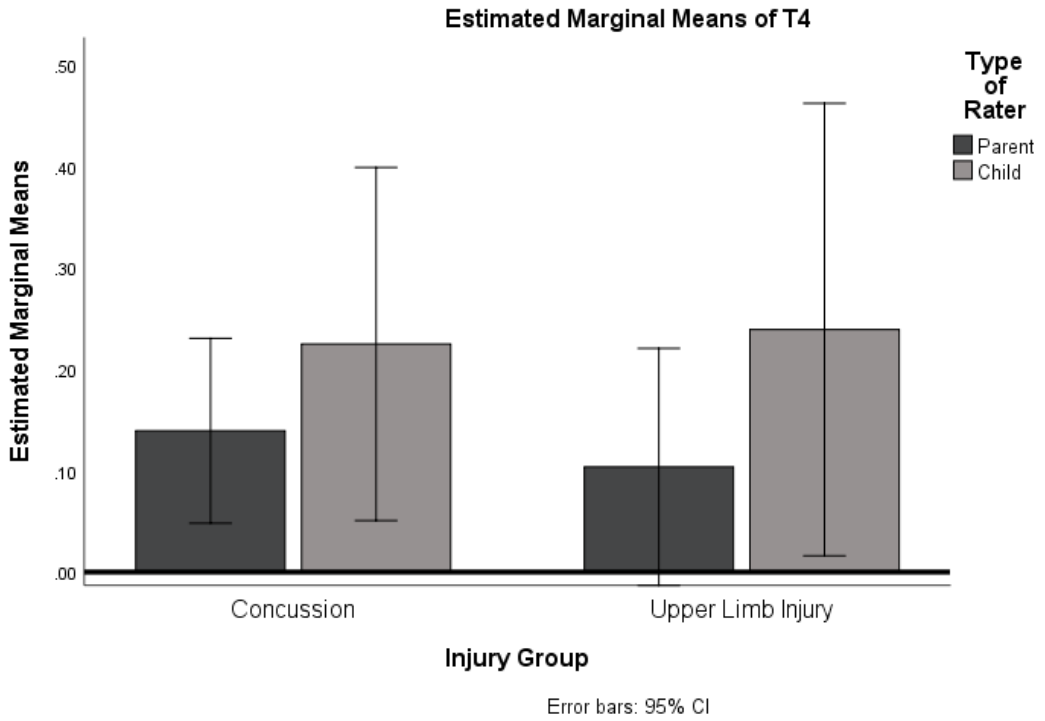
Interaction Between Raters and Injury Groups for Reports of Symptom Severity Two Weeks After Injury



Interaction Between Raters and Injury Groups for Reports of Symptom Severity One Month After Injury



Interaction Between Raters and Injury Groups for Reports of Sympton Severity Three Months After Injury



Appendix E- Upper Limb Injury Mean Scores for Symptom Severity and Symptom Total by Age Range

Table E1

Summary of the Mean Symptom Severity Scores by Age in the Upper Limb Injury Group

Age Range	Time Point									
	B		T1		T2		T3		T4	
	M	SD	*M*	SD	*M*	SD	*M*	SD	*M*	SD
5-7:11										
parent	2.80	5.22	5.40	6.54	3.33	4.93	4.00	5.66	.00	.00
child	1.20	.84	.20	.45	2.33	2.52	2.00	2.16	1.00	1.42
N	5		5		3		4		4	
8-12:11										
parent	7.18	11.15	17.09	18.00	2.82	3.95	2.89	5.73	4.14	6.39
child	3.81	4.51	.36	.81	3.91	3.45	2.89	3.89	2.71	2.43
N	11		11		11		9		7	
13-17:11										
parent	3.00	4.47	13.50	23.31	3.00	4.15	.00	.00	.00	.00
child	13.67	17.96	17.67	16.62	10.67	19.92	14.67	24.54	10.00	17.32
N	6		6		6		3		3	

Note. M= Mean; SD= standard deviation; *N*= number of respondents; scores are rounded to two decimal places; B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one-month post-injury; T4= three months post-injury.

Table E2

Summary of the Mean Symptom Total Scores by Age in the Upper Limb Injury Group

Age Range	Time Point									
	B		T1		T2		T3		T4	
	M	SD	*M*	SD	*M*	SD	*M*	SD	*M*	SD
5-7:11										
parent	.80	1.30	2.60	3.78	2.33	3.21	2.50	3.00	.00	.00
child	1.20	.84	.60	.89	1.67	1.53	1.50	1.29	.75	.96
N	5		5		3		4		4	
8-12:11										
parent	3.73	4.92	7.45	5.87	2.18	3.28	1.67	3.94	1.86	3.08
child	3.27	3.38	3.45	2.91	2.73	2.15	2.56	3.32	2.43	2.23
N	11		11		11		9		7	
13-17:11										
parent	1.67	1.37	5.17	6.55	2.17	3.13	.00	.00	.00	.00
child	6.50	6.72	7.50	5.79	4.50	6.47	6.33	20.12	4.33	7.51
N	6		6		6		3		3	

Note. M= Mean; SD= standard deviation; *N*= number of respondents; scores are rounded to two decimal places; B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one-month post-injury; T4= three months post-injury.

Appendix F- Upper Limb Injury Correlations Between Parent and Child Rating of Symptom Severity and Symptom Total by Age Range

Table F1

Spearman's Correlation of Upper Limb Injury Parent and Child Ratings of Concussion Symptom Severity Over Time by Age Group

Age Range	Time Point									
	B		T1		T2		T3		T4	
	r_s	p	r_s	p	r_s	p	r_s	p	r_s	p
5-7:11	.177	.776	-.516	.373	-1**	<.001	.105	.895	.	.
8-12:11	.022	.950	.385	.242	.446	.170	.480	.191	.759	.080
13-17:11	.000	1	-.290	.577	.339	.511	.	.	.	.
N										
5-7:11	5		5		3		4		4	
8-12:11	11		11		11		9		6	
13-17:11	6		6		6		3		3	

Note. Child's age is presented in years: months; B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one month post-injury; T4= three months post-injury; **= significant within 0.01; r_s = spearman's rho; p= significance value; *N* = number of respondents; .= unable to be calculated.

Table F2

Spearman's Correlation of Upper Limb Injury Parent and Child Ratings of Concussion Symptom Total Over Time by Age Group

Age Range	Time Point									
	B		T1		T2		T3		T4	
	r_s	p	r_s	p	r_s	p	r_s	p	r_s	p
5-7:11	.177	.776	-.516	.373	-1**	<.001	.105	.895	.	.
8-12:11	.036	.916	.067	.844	.310	.354	.480	.191	.759	.080
13-17:11	.149	.778	-.145	.784	.585	.222	.	.	.	.
N										
5-7:11	5		5		3		4		4	
8-12:11	11		11		11		9		6	
13-17:11	6		6		6		3		3	

Note. Child's age is presented in years: months; B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one month post-injury; T4= three months post-injury; **= significant within 0.01; r_s = spearman's rho; p= significance value; *N* = number of respondents; .= unable to be calculated.

Appendix G- Individual Symptom Frequency Counts and Percentage of Parent and Child Endorsement by Age Range

Table G1

Frequency Counts and Percentage of Endorsement of the PCSI Symptom Headache by Age Ranges in the Concussion Group

Rater and Age Range	Time Point B N	B %	T1 N	T1 %	T2 N	T2 %	T3 N	T3 %	T4 N	T4 %
5-7:11										
Parent	1/5	20	2/5	40	0/3	0	0/3	0	1/3	33.3
Child	1/5	20	3/5	60	0/3	0	0/3	0	1/3	33.3
8-12:11										
Parent	5/12	41.7	11/12	91.7	4/11	36.4	0/11	0	2/11	18.2
Child	1/12	8.3	10/12	83.3	3/11	27.3	2/11	18.2	2/11	18.2
13-17:11										
Parent	5/10	50	10/10	100	6/10	60	3/9	33.3	1/9	11.1
Child	8/10	80	9/10	90	8/10	80	4/9	44.4	2/9	22.2

Note. N = number of respondents who endorsed the symptom as present out of total number of respondents; % = percentage of endorsement; scores are rounded to two decimal places; PCSI= post-concussion symptom inventory; B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one-month post-injury; T4= three months post-injury; Child's age is presented in years: months.

Table G2

Frequency Counts and Percentage of Endorsement of the PCSI Symptom Nausea by Age Ranges in the Concussion Group

Rater and Age Range	Time Point B N	B %	T1 N	T1 %	T2 N	T2 %	T3 N	T3 %	T4 N	T4 %
5-7:11										
Parent	2/5	40	1/5	20	0/3	0	0/3	0	0/3	0
Child	0/5	0	2/5	40	0/3	0	0/3	0	1/3	33.3
8-12:11										
Parent	1/12	8.3	6/12	50	1/11	9.1	1/11	9.1	1/11	9.1
Child	1/12	8.3	7/12	58.3	2/11	18.2	2/11	18.2	2/11	18.2
13-17:11										
Parent	3/10	30	7/10	70	4/10	40	4/9	44.4	1/9	11.1
Child	2/10	20	6/10	60	5/10	50	2/9	22.2	1/9	11.1

Note. N = number of respondents who endorsed the symptom as present out of total number of respondents; % = percentage of endorsement; scores are rounded to two decimal places; PCSI= post-concussion symptom inventory; B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one-month post-injury; T4= three months post-injury; Child's age is presented in years: months.

Table G3

Frequency Counts and Percentage of Endorsement of the PCSI Symptom Dizziness by Age Ranges in the Concussion Group

Rater and Age Range	Time Point B		T1		T2		T3		T4	
	N	%	N	%	N	%	N	%	N	%
5-7:11										
Parent	1/5	20	1/5	20	0/3	0	0/3	0	0/3	0
Child	0/5	0	2/5	40	0/3	0	0/3	0	0/3	0
8-12:11										
Parent	1/12	8.3	6/12	50	2/11	18.2	1/11	9.1	0/11	0
Child	2/12	16.7	6/12	50	5/11	45.5	1/11	9.1	1/11	9.1
13-17:11										
Parent	2/10	20	7/10	70	4/10	40	1/9	11.1	0/9	0
Child	3/10	30	7/10	70	5/10	50	4/9	44.4	1/9	11.1

Note. N = number of respondents who endorsed the symptom as present out of total number of respondents; % = percentage of endorsement; scores are rounded to two decimal places; PCSI= post-concussion symptom inventory; B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one-month post-injury; T4= three months post-injury; Child's age is presented in years: months.

Table G4

Frequency Counts and Percentage of Endorsement of the PCSI Symptom Irritability by Age Ranges in the Concussion Group

Rater and Age Range	Time Point B		T1		T2		T3		T4	
	N	%	N	%	N	%	N	%	N	%
5-7:11										
Parent	3/5	60	3/5	60	1/3	33.3	1/3	33.3	2/3	66.7
Child	0/5	0	3/5	60	1/3	33.3	0/3	0	0/3	0
8-12:11										
Parent	2/12	16.7	9/12	75	3/11	27.3	6/11	54.5	2/11	18.2
Child	4/12	33.3	5/12	41.7	2/11	18.2	1/11	9.1	2/11	18.2
13-17:11										

Parent	4/10	40	7/10	70	10/10	100	6/9	66.7	2/9	22.2
Child	6/10	60	8/10	80	6/10	60	5/9	55.6	3/9	33.3

Note. N = number of respondents who endorsed the symptom as present out of total number of respondents; % = percentage of endorsement; scores are rounded to two decimal places; PCSI= post-concussion symptom inventory; B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one-month post-injury; T4= three months post-injury; Child's age is presented in years: months.

Table G5

Frequency Counts and Percentage of Endorsement of the PCSI Symptom Difficulty Concentrating by Age Ranges in the Concussion Group

Rater and Age Range	Time Point									
	B		T1		T2		T3		T4	
	N	%	N	%	N	%	N	%	N	%
5-7:11										
Parent	2/5	40	3/5	60	1/3	33.3	0/3	0	1/3	33.3
Child	1/5	20	2/5	40	2/3	66.7	0/3	0	1/3	33.3
8-12:11										
Parent	3/12	25	10/12	83.3	2/11	18.2	2/11	18.2	0/11	0
Child	3/12	25	5	41.7	3/11	27.3	2/11	18.2	2/11	18.2
13-17:11										
Parent	5/10	50	8/10	80	7/10	70	4/9	44.4	0/9	0
Child	7/10	70	9/10	90	7/10	70	5/9	55.6	4/9	44.4

Note. N = number of respondents who endorsed the symptom as present out of total number of respondents; % = percentage of endorsement; scores are rounded to two decimal places; PCSI= post-concussion symptom inventory; B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one-month post-injury; T4= three months post-injury; Child's age is presented in years: months.

Appendix H- Kappa Coefficients for Individual Symptoms by Age in the Concussion Group

Table H1

Kappa Coefficients Showing Agreement Between Parent and Child Ratings of Individual Symptoms by Age

Symptom and Age Range	Time Point									
	B		T1		T2		T3		T4	
	K	p	K	p	K	p	K	p	K	p
Headache										
5-7:11	1*	.025	-.154	.709	.	.	.	.	-.500	.386
8-12:11	.226	.217	-.125	.640	.377	.201	.	.	.389	.197
13-17:11	.400	.114	.	.	.545	.053	.308	.343	.609	.047
Nausea										
5-7:11	.	.	-.364	.361	.	.	.	.	.	.
8-12:11	-.091	.753	.167	.558	.621*	.026	.621*	.026	.138	.621
13-17:11	.211	.490	.783*	.011	.800**	.010	.526	.073	1.00**	.003
Dizziness										
5-7:11	.	1.00	.545	.171	.	.	.	.	.	.
8-12:11	-.125	.640	.667*	.021	.421	.087	1.00**	.001	.	.
13-17:11	.737*	.016	.524	.098	.400	.197	.270	.236	.	.
Irritability										
5-7:11	.	.	-.667	.136	1.00	.083	.	.	.	.
8-12:11	.143	.584	.077	.735	.744*	.011	.154	.338	1.00**	.001
13-17:11	.231	.429	-.316	.301	.	.	.308	.343	.182	.571
Difficulty concentrating										
5-7:11	.545	.171	-.154	.709	-.800	.083	.	.	1.00	.083
8-12:11	.111	.700	-.050	.793	.233	.425	.389	.197	.	.
13-17:11	.200	.490	-.154	.598	.048	.880	.780*	.016	.	.
N										
5-7:11	5		5		3		3		3	
8-12:11	12		12		11		11		11	
13-17:11	10		10		10		9		9	

Note. K= kappa coefficient; p= significance value; *N*= number of respondents; B= baseline; T1= 1-4 days post-injury; T2= two weeks post-injury; T3= one-month post-injury; T4= three months post-injury; N= number of valid cases; . = not computed as parent or child report was constant; *= significant within 0.05; **= significant within 0.01; Child's age is presented in years: months.