# Exploring Family Experience of Acquired Brain Injury in Childhood: Parent and Child Perspectives

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## Abstract

The purpose of this thesis is to explore the lived experience of children and their parents after a child's Acquired Brain Injury (ABI). A systematic review was conducted which synthesised results from 15 qualitative studies involving children's perspectives of their ABI. Results revealed three core areas of importance for children when describing their experiences: 'Sense of Self', 'Relationships' and 'Coping and Support'. These contained further subthemes, including: facing disability; who am I; social world; change in family dynamics; reframing and acceptance; being understood. An empirical paper explored narratives of parents of children with ABI. Findings suggested that parents made sense of life after ABI using two narrative threads: 'trauma' and 'journey'. Both narrative threads represented continuous, dynamic processes which require personal changes and changed perspectives. Findings from both the systematic review and empirical study are critically evaluated in a final discussion chapter.

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## Acknowledgments

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Thank you to everyone in the research and clinical teams for support with recruitment and insightful contributions. Thank you in particular to my supervisor, Dr Fergus Gracey, who is not only a credit to the field but also one of the kindest people I’ve ever worked with.

I am so privileged to have a wonderful family and friends who inspire me and look after me unfailingly. Thank you.

This includes those I lost during the doctorate: my dear Granddad and my beloved ‘Uncy’.

## Chapter 1. Introduction to the Thesis

Acquired Brain Injury (ABI) refers to damage to the brain that occurs after birth and which is not related to congenital disorders, developmental disabilities, or processes that progressively damage the brain (Teasell et al., 2007). It is a significant cause of disability and mortality for young people in first world countries. In the UK, approximately 200,000 children a year will acquire a brain injury, with around 5% of these being classed as severe (Langlois, Rutland-Brown, & Wald, 2006; Neurological Alliance 2003). Some of the commonest causes of ABI amongst children include head trauma (Traumatic Brain Injury or TBI), ischemic and haemorrhagic stroke, meningitis, encephalitis, and brain tumour (Chevignard, 2012).

Following ABI, young people can experience emotional, cognitive and behavioural changes and have ongoing physical health needs (Braine & Smith, 2013), all of which can affect quality of life for both children and their caregivers. The impact of ABI on a child’s development can vary significantly depending on the age at which it occurs, for example, more severe injuries at younger ages are associated with worse outcomes (Anderson, Catroppa, Morse, Haritou & Rosenfeld, 2005). However, there may also be critical periods at other stages throughout development which increase vulnerability to poorer outcomes (Crowe, Catroppa, Babl & Rosenfeld, 2012). Therefore, rehabilitation can be a lengthy process complicated by ongoing child development, meaning that the nature or impact of an individuals’ injuries may only become apparent at various milestones, for example starting secondary-level education. Parents and caregivers provide the environment, social context, and majority of long-term care for children post ABI (Degeneffe, 2001). Therefore, ABI also has protracted impact on wider family and network.

There has been a growing interest in clinical psychology practice and research towards inclusive, person-centred approaches to rehabilitation and understanding of illness events (Joseph & Linley, 2008). This has included moving away from researcher-led focus on deficit and loss towards a more holistic understanding of illness as biographical change for individuals, incorporating themes of coping, identity adjustment and even growth (Picoraro, Womer, Kazak, & Feudtner, 2014). While we know much of the functional impact of ABI on young people and its challenges for families, gaps still exist in the literature around how these changes are experienced and managed by individuals in families, from the perspectives of both children and caregivers.

Parents are closely involved with their child's rehabilitation and therefore they often speak on behalf of or alongside young people in studies which explore the child's experience. As such, a comprehensive picture of child experience of ABI is not easily accessible in the current literature.

In addition to this, while studies have covered parent experience alongside their child's, most have focused on its challenges and losses. For example, the quantitative literature suggests that parents and carers of a child with ABI are more likely to be affected by psychological difficulties such as stress, anxiety, depression and even post-traumatic stress disorder (PTSD) (Hawley, Ward, Magnay, & Long, 2003; Labrell et al., 2018). Less is known, however, about processes of adjustment, and coping, or how challenges are faced over time. Parent wellbeing impacts family functioning (Ergh, Rapport, Coleman, & Hanks, 2002), which in turn affects how children adjust after their injury (Labrell et al., 2018). While the literature has explored adverse consequences for parents after ABI, e.g. increased stress and burden, less is known about how and why they are impacted in this way, or how they make sense of and adjust to these experiences (Roscigno & Swanson, 2011; Wongvatunyu & Porter, 2005).

Deeper insights into family experience of ABI could help services provide complete psychosocial care to children with ABI and their families (Picoraro et al., 2014). In previous studies, parents reported that healthcare practitioners who only focused on loss and injury were unhelpful (Roscigno & Swanson, 2011). Additionally, young people and parents have reported experiencing post-traumatic growth after ABI, for example positive changes including increased resilience or stronger relationships (Di Battista, Godfrey, Soo, Catroppa, & Anderson, 2014). This suggests parents and children may have more nuanced, complex narratives around their experience which exceeds the current picture of ABI as a collection of deficits and losses in the literature.

The aim of this thesis is therefore to collect and examine qualitative accounts of lived experience of families and children with paediatric ABI in order to expand upon concepts which feel pertinent to individuals, not just grief and loss, but also perhaps hope, growth, meaning-making, and discovery. Further, these stories might tell us about the conditions needed for individuals to access such narratives, and the mechanisms of change and transition for families after child BI. Understanding this could allow healthcare staff to offer more collaborative or humanising forms of support (Todres, Galvin, & Holloway, 2009).

The first piece of work presented is a systematic review focusing on qualitative accounts of lived experience of ABI from the perspective of children and adolescents. Then an empirical paper will be presented which explores parent narratives of life after their child’s ABI. Finally, a discussion and critical review chapter will discuss the findings of the thesis as a whole and its implications for theory, practice and future research.

# Chapter 2: Systematic Review prepared for submission to Disability and Rehabilitation

The research reported is original work which was carried out under the supervision of Fergus Gracey (Primary Supervisor), Kiki Mastroyannopoulos (Secondary Supervisor), Charlie Whiffin (Field Supervisor) and Alison Perkins (Field Supervisor). I am the lead author of this paper which is prepared for journal submission.

# What is the Lived Experience of Acquired Brain Injury for Children and Young People? A Systematic Review of the Qualitative Literature

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## Abstract

**Aim:** The aim of this review is to synthesise the qualitative literature on lived experience for children and young people with an Acquired Brain Injury (ABI). Two previous reviews focused on experiences of education and identity change respectively. Given the child's voice is often lacking in literature, a broader synthesis of studies exploring lived subjective experience is warranted.

**Question:** What is the lived experience of children after ABI from the perspective of child participants?

**Method:** Studies were eligible if samples consisted predominantly of children or adolescents with moderate to severe ABI and if qualitative methodology was used to explore perspectives and lived experience. Electronic searches for studies published up to March 2023 were undertaken using PsychInfo, Cinahl, Embase and Medline databases. Searches were conducted in March 2023. All studies were rated for quality using CASP and categorised in terms of the weight they contributed to analysis (core, central or peripheral). Data extraction was completed by the primary author and 50% of the identified studies were checked for quality by a second reviewer (AS). Findings were analysed using thematic synthesis.

**Results:** Fifteen studies met inclusion criteria, two of which were also reviews. Three overarching themes were identified: 'Sense of Self', 'Relationships' and 'Coping and Support'. Within these were further subthemes, including: facing disability; who am I; the social world; change in family dynamics; reframing and acceptance; being understood.

**Discussion:** Only seven of the fifteen articles (six separate studies total) which met inclusion criteria were identified as 'core' studies which focused solely on child perspective, suggesting the child's voice may still be lacking in the literature. However, patterns of meaning were identified across studies which will help shape person-centred rehabilitation practice which includes the young person’s perspective.

**Registration:** The protocol for this review was listed on PROSPERO (reference no: CRD42023389986) in January 2023.

# Exploring Family Experience of Acquired Brain Injury in Childhood

## Introduction

Acquired brain injury (ABI) is a major cause of disability for young people, often resulting in ‘unseen’ long-term difficulties, such as problems with cognition, communication and emotions, or behavioural and personality changes. Children themselves may experience a shift in their identity and sense of self as a result of changes after ABI (Roscigno & Swanson, 2011).

However, researchers rarely seek the perspectives of children regarding their subjective experiences of ABI. In the current knowledge-base, adults are the primary reporters of experience and often speak on behalf of, or alongside children (Mah, Gladstone, King, Reed, & Hartman, 2020). Additionally, studies which examine both child and parent reports of the child’s experience have shown significant differences between parent and child scores on measures (Ross, McMillan, Kelly, Sumpter, & Dorris, 2011; Silberg, Tal-Jacobi, Levav, Brezner, & Rassovsky, 2015).

Quantitative studies which do include self-reports from children have provided some insight into aspects of child experience. Findings from studies measuring Quality of Life (QoL) outcomes suggest changes after brain injury have an impact on QoL across numerous domains including the emotional, social and educational (Anderson et al., 2012; Limond, Dorris, & McMillan, 2009; O’Keeffe, Ganesan, King, & Murphy, 2012). Children with ABI may score lower on self-esteem measures than non-injured peers (Hawley, 2012; Pastore et al., 2015), higher on measures of depression symptoms (Viguier, Dellatolas, Gasquet, Martin, & Choquet, 2001) and lower on self-efficacy questionnaires (Gagnon, Swaine, Friedman, & Forget, 2005).

However, with the majority of research conducted from a positivist position, researchers (Mah, 2019; Hemmell, 2001) have argued that studies to date have been driven by the values and priorities of researchers or adult caregivers rather than led by the perspectives and voices of the children experiencing brain injury. Relying on quantitative instruments may limit understanding of the full experience of ABI for children and young people; without qualitative research which incorporates the voice or lived experience of the child, we may know something of the *what* is experienced but less of the *how*.

Two reviews have been conducted previously which were limited to specific aspects of experience for young people with ABI. Mealings et al. (2012) conducted a systematic review of qualitative papers exploring students' (age range 14-29) perspectives of returning to education after ABI. The review found eight papers which highlighted themes around difficulties returning to school, not only cognitively but also psychosocially, for example fears of rejection or being misunderstood. The review also highlighted a central theme of identity across studies, suggesting the concept of the self influenced other factors when returning to school (Mealings, Douglas, & Olver, 2012). A 2020 mapping review (Kakonge, Charron, Vedder, Wormald, & Turkstra, 2022) also identified eleven papers which featured themes of identity with young people with ABI, a topic which is less easily captured in quantitative studies. Results suggested young people are likely to experience an important 'who am I?' stage after ABI requiring reappraisal of the self and which may be affected by parental attitudes, alliances with clinicians and social participation. However, the mapping review highlighted gaps in the literature regarding how young people 'construct and reconstruct' identity after ABI (Kakonge et al., 2022).

The adult literature features several systematic reviews including subjective experience of ABI for people over the age of 18 (Caplan et al., 2016; D'Cruz, Douglas, &

Serry, 2019; Sansonetti, Fleming, Patterson, & Lannin, 2022). Findings have highlighted the importance of reconstructing or making sense of changes to the self, which may be done in incremental processes at milestones in rehabilitation and is often in tandem with social processes, for example by appraising the responses and reactions of others to the ‘new self’ (Villa, Causer, & Riley, 2021). Reviews also emphasised the need for individuals to be understood and validated by others, which may be helped by improving knowledge around identity processes after ABI (D’Cruz et al., 2019; Villa et al., 2021). The results have value in developing person-centred rehabilitative care which includes individuals’ voices and is aligned with patients’ focus and priorities. The child population has unique characteristics, for example school participation, ongoing developmental stages, a heightened importance on peer relationships and dependency on caregivers (Kakonge et al., 2022). Therefore, its own inquiry is warranted.

No synthesis of the broader qualitative literature around young peoples’ subjective lived experience currently exists. In the current ABI knowledge-base, there is a gap in the literature where the child’s voice is fragmented across different topics of focus such as educational experiences or transitions out of hospital. Therefore, an updated systematic review, covering a broader range of qualitative focus could consolidate the child’s voice in literature and shed light on further concepts which may be important to young people with ABI. This will aid the improvement of clinical practice for children with ABI and may also highlight gaps in research and rehabilitation practices where the child’s voice is still absent.

## Research question

What is the lived experience of Acquired Brain Injury (ABI) for children and adolescents from their perspective?

## Methods

### Protocol and Registration

The protocol for this review was listed on PROSPERO (reference no: CRD42023389986) in January 2023. The Cochrane database and Prospero were searched for reviews in progress with similar themes, however none were identified. Searches were conducted in March 2023.

### Eligibility Criteria

***Studies.*** Studies were either peer-reviewed or unpublished research papers meeting the requirements of doctoral-level theses. Studies were only included which were written or translated into English. No date range was applied. Secondary research material, for example other literature reviews, were also considered if all other eligibility criteria were met. Other researchers' interpretations can provide valuable qualitative contributions which can be helpful for contextualising and interpreting findings, as well as capturing broader issues than the specific focus of the review.

***Participants.*** Studies involving children and young people of school-attending age (5-18 years old) who have sustained a Brain Injury classified as either moderate to severe on the Glasgow Coma Scale (Turner-Stokes & Wade, 2004) or Clinically Significant as defined by Turner-Stokes (Turner-Stokes & Wade, 2004). Studies were excluded if they focused solely on children whose injuries were within the 'mild' range, e.g. concussion, as needs may differ significantly. Studies were also excluded where more than 40% of participants passed above 19 years.

***Outcomes.*** Studies were included if outcomes described the child's lived experience directly according to the following definition: 'Personal knowledge about the world gained through direct, first-hand involvement in everyday events rather than through representations constructed by other people.’ (Oxford Reference, 2023). For example, studies which examined the child’s perspective or experience of themselves and their brain injury, and as described either directly by themselves in interviews, focus groups or by other qualitative means (e.g. art-based methods). Studies were excluded if a) they focused solely on parent or family members’ experience/perspectives; b) focused solely on quantifying medical or physical outcomes with an absence of qualitative data or child perspective around lived experience (e.g. how many children score highly for depression); c) study did not directly describe lived experience of having a brain injury, e.g. studies which described experiences of interventions only.

### Information Sources

Systematic literature searches were completed individually using PsychInfo, Cinahl, Embase and Medline databases up to March 2023. Reference lists from identified studies were also reviewed for additional publications which did not appear in the initial search.

### Search Strategy

Search terms were categorised into four topic areas: children and adolescents, acquired brain injury, experience/perspectives and qualitative methods. Terms were searched for in Titles and Abstracts (keyword search). The full electronic search is included in Appendix B.

### Selection Process

Records identified in database searches were manually screened via Titles and Abstracts for keywords and relevance; duplicates were also removed manually. Full text screening was then conducted on the remaining articles. Data extraction and quality ratings were entered into Excel for screening.

### Data Collection Process

The data were extracted according to CRD's guidelines on systematic reviews in healthcare, including study and participants characteristics and a summary of the key themes (Centre for Reviews and Dissemination; CRD, 2009). Additional data relating to the focus of the study (e.g. education) and severity of brain injury were also extracted. Extraction was completed by the primary author and 50% of extracted data were checked for reliability by a second reviewer (AS). Uncertainties were resolved through a third reviewer (FG).

### Quality Assessment

The Critical Appraisal Skills Programme (Critical Appraisal Skills Programme, 2018) tool was used to assess quality of the papers reviewed (Appendix C), with each given a rating out of 10. Most papers achieved a rating of 'good' quality: this was based on the CASP guidelines that papers which do not answer 'yes' to the first three questions are of either moderate or poor quality. The guidelines do not specify further around categorisations of quality, therefore most researchers using the tool apply their own parameters. In this study, 'good' quality referred to papers which answered 'yes' to the first three questions, 'moderate' referred to those which answered 'no' to one or two of the first three questions and 'poor' answered 'no' to all three. The full table of ratings can be viewed in Appendix D. The second reviewer (AS) quality-checked 50% of the sample.

Papers were also rated for relevance, resonance and rigour using a classification system which organised papers according to how closely they addressed the question of the review under 'core', 'central' or 'peripheral' as outlined in Table 1 below (Whiffin, Gracey,

& Ellis-Hill, 2021). All papers categorised as ‘core’ and ‘central’ to the research question were also rated ‘good’ against the CASP checklist for quality. Secondary research was treated as ‘peripheral’ as this was used mainly for providing contextual information to guide analysis as appropriate.

**Table 1.**

*Classification of papers as core, central and peripheral*

| | |
|---|---|
| **Core** | Relevance – Research question explicitly aligned to the review question<br>Resonance – Findings are rich, complex and evocative and make a meaningful and insightful contribution to advancing the evidence base<br>Rigour – methodologically congruent and appropriately applies qualitative methods |
| **Central** | As above but may fail to meet one or more of the criteria in its fullest sense |
| **Peripheral** | Relevance – Research findings relevant but research question not completely aligned to the meta-synthesis question<br>Resonance – Findings superficial, thin or expected, do not advance the evidence base in a meaningful way<br>Rigour – There may be questions about the methodological congruence of the study and if methods were appropriately applied |

*Table used from Whiffin et al. (2021).*

### Synthesis methods

A thematic synthesis was used to explore children’s experiences of ABI within qualitative research. Thomas and Harden (2008) describe the approach as an appropriate qualitative method for addressing questions relating to perceptions and experiences in reviews (Thomas & Harden, 2008). This is a flexible and descriptive method which can be applied across a range of theoretical and epistemological positions (D’Cruz et al., 2019) and which allows researchers to organise and report data in descriptive themes. Analysis involves three steps: 1) developing codes inductively from the results section of the first article, transferring codes from succeeding articles and adding new codes as needed, 2) developing descriptive themes that are representative of groups of identified codes, and which align closely to the literature being synthesized, 3) developing analytical themes whereby reviewers apply their own interpretations of findings (Rajala et al., 2022; Thomas & Harden, 2008).

# Results

## Study Selection

Database searches identified 359 studies, and after eligibility screening 31 were retained for review. A further 16 were excluded based on the following reasons: age range (more than 40% of sample outside age range of inclusion criteria) (n=4), qualitative data reported separately in another paper (n=1), full text unavailable (n=4), qualitative data did not describe lived experience according to the definition for inclusion (n=2), stakeholders were services (n=1), qualitative data referred to intervention or services only (n=2), only mild ABI described (n=1), or no qualitative data (n=1). The number of papers screened and reviewed are outlined in the PRISMA flowchart below (Figure 1).

Fifteen articles were included in the final synthesis. Six studies used grounded theory methodology, three used interpretative phenomenological analysis (IPA), one used non-specific phenomenological analysis, three used non-specific qualitative analyses, one was a systematic review and one was a mapping review.

All studies except the reviews used semi-structured interviews or focus groups in their methods. In two instances, two papers belonged to the same study (Mealings & Douglas, 2010; Mealings, Douglas, & Olver, 2017) and (Ilmer et al., 2014; Krenz et al., 2021). The total number of participants included in the articles was 145, excluding the systematic and mapping reviews, ranging from 3 to 39 participants per study. The key characteristics from the studies included are reported in Table 2 and an extended version of the table can be viewed in Appendix E.

**Table 2**

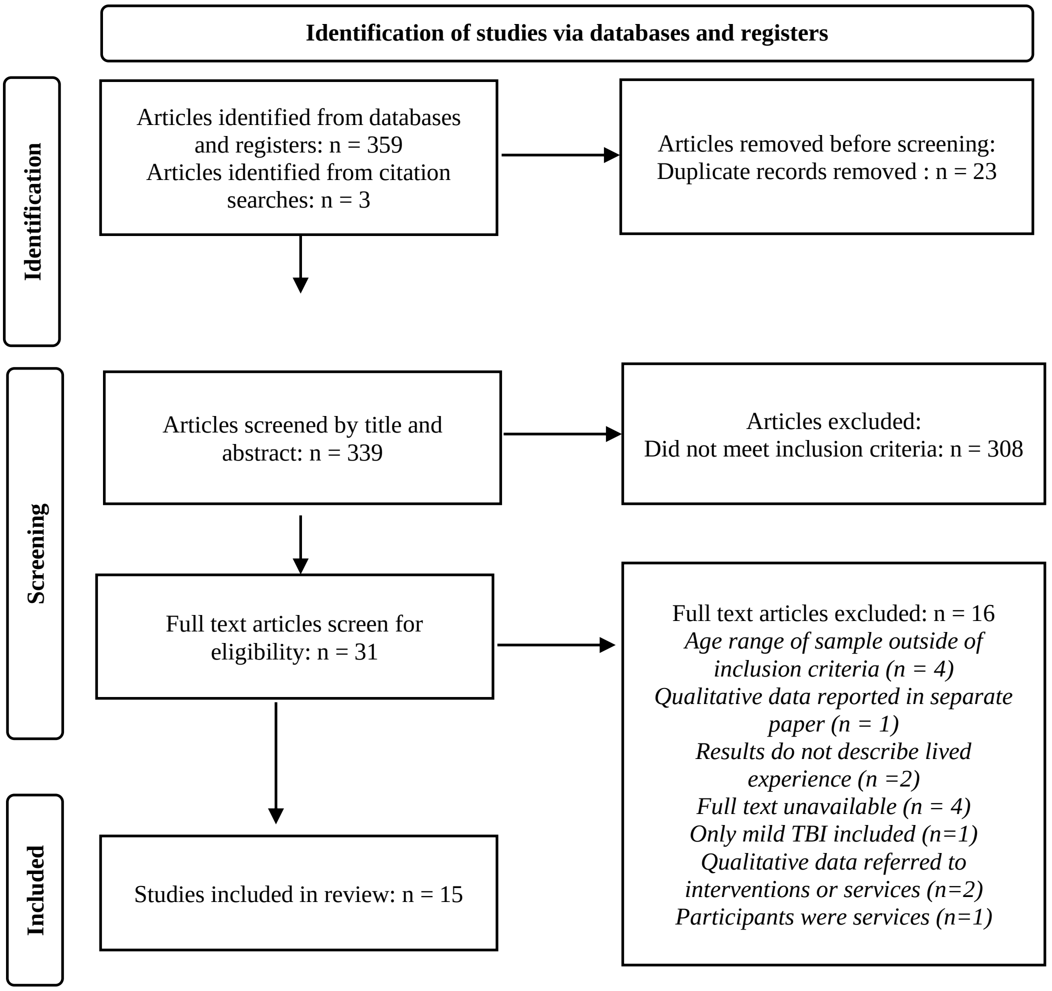
*Key Characteristics of Studies*

| Author/s and Date | Data Collection Methods | Analysis | Study focus | Participant Type | Sample size (child only) | Age range |
|---|---|---|---|---|---|---|
| Mealings, Douglas, & Olver, 2017 | Semi-structured interviews | Grounded theory | Education participation | YP with severe TBI | 3 | 13-17 |
| Mealings & Douglas, 2010 | Semi-structured interviews | Grounded theory | Experience of school | YP with severe TBI | 3 | 13-17 |
| Kakonge, Charron, Vedder, Wormald, & Turkstra, 2022 | Mapping review | Thematic synthesis | Identity | Mixed YP and caregivers | - | 14-18 |
| Gauvin-Lepage & Lefebvre, 2010 | Semi-structured interviews | Not stated | Social inclusion | Mixed YP with mod TBI, caregivers & professionals | 3 | 14-15 |
| Buckeridge, Clarke, & Sellers, 2020 | Semi-structured interviews | IPA | Communication, speech and language | YP with mod/severe TBI | 6 | 11-18 |
| Timmermann et al., 2022 | Semi-structured interviews in focus groups | Not stated | Health related Quality of Life | YP with mild/mod/severe TBI and caregivers | 8 with mod/ severe | 5-17 |
| Krenz et al., 2021 | Semi-structured interviews in focus groups | Qualitative informed by Witzel and Reiter | Health related Quality of Life | Mixed YP with mild/mod/severe TBI and caregivers | 19 | 5 to 17 |
| Hartman, Tibbles, Paniccia, & Lindsay, 2015 | Systematic review and data extraction | Thematic synthesis | Transition from hospital to school | Mixed YP with mod/severe ABI and caregivers | - | 6 to 20 |
| Di Battista, Godfrey, Soo, Catroppa, & Anderson, 2014 | Semi-structured interviews | IPA | Phenomenology of life after a TBI | YP with mod/severe TBI | 10 | 13 to 19 |
| Williams, 2020 | Semi-structured interviews | IPA | Lifeworld of young person after TBI | Mixed YP with mod/severe TBI and caregivers | 3 | 11 to 13 |
| Glennon, Watson, Fisher, & Gracey, 2022 | Semi-structured interviews | Grounded theory | Identity adjustment | Mixed YP with mod/severe TBI and caregivers | 6 | 15 to 18 |

| | | | | | | |
|---|---|---|---|---|---|---|
| Bogan, Livingstone, Parry-Jones, Buston & Wood, 1997 | Semi-structured interviews | General qualitative using NUD.IST software | Long-term outcomes | YP with mild/mod/severe TBI | 31 | 13 to 20 |
| Rodset, 2008 | Semi-structured interviews | Phenomenological but non-specific | Return to school | YP with severe TBI | 6 | Mean age 15 |
| Sharp, Bye, Llewellyn & Cusick, 2005 | Semi-structured interviews | Grounded theory | Return to school | YP with severe TBI | 8 | 14 to 17 |
| Roscigno, Swanson, Vavilala & Solchany, 2011 | Semi-structured interviews | Descriptive phenomenological | Child perspective of ABI | YP with mod/severe TBI | 39 | 6 to 18 |

**Figure 1**

*PRISMA Flowchart*



All studies were evaluated for quality using the CASP Qualitative Checklist (Critical Appraisal Skills Program, 2018) available online (accessed March 2023). All articles were deemed to be of ‘moderate’ to ‘good’ quality. Articles were also categorised according to resonance, relevance and rigour against the review question (Table 1). Seven articles were identified as ‘core’ (two of these were from the same study), one as ‘central’ and six as ‘peripheral’. Quality ratings can be viewed in Appendix D.

## Participant characteristics

Participant age ranged from 5-18 years. Exact age parameters were not always reported. Studies took place in the UK (n=4), Germany (n=2), Australia (n=5), Canada (n=2), Norway (n=1) and the USA (n=1). Nine studies focused only on adolescents between the ages of 13-19 and all others were mixed. None of the studies focused specifically on younger children, e.g. under age 13.

### Main findings

The synthesis aimed to explore patterns of meaning and ‘build a picture’ (Thomas & Harden, 2008) of findings which described the lived experience of children with ABI across qualitative studies. Three overarching and interrelated themes emerged during the synthesis: 1) Sense of Self, 2) Relationships and 3) Coping and Support. While the themes overlap and each impact one another, they have been separated thus to represent how topics were categorised in most studies. For example, the ‘Sense of Self’ domain broadly refers to young people describing changes to their selves including their feelings about functional or physical changes. ‘Relationships’ broadly describes how young people spoke about the responses of others to their post-injury selves, as well as describing relationship changes. ‘Coping and Support’ combines young peoples’ descriptions of ‘what helped’ – whether that be changes made by themselves or others. Each of these domains contained descriptive subthemes which will be outlined in the following subsections.

### Sense of Self

Making sense of changes to the self and identity was a recurrent theme across studies and focus areas. This area was categorised into two additional descriptive themes, 1) facing disability and 2) who am I?

***Facing Disability.*** When describing experience of ABI, young people detailed difficult feelings when facing internal and external changes to the self. Most of the immediate changes mentioned by young people were functional, for example new cognitive and physical difficulties since the injury, and restrictions on participation as a result (e.g. no contact sports; adapted curriculum).

Participants frequently described their various difficulties as frustrating or demoralising. One participant said: *"Knowing I could do something beforehand, before me accident and then knowing I couldn't do it now… just messed with my head"*(Mealings & Douglas, 2010). Activities or thought processes which had once been easier were now a struggle, and this often lead to a loss of confidence in the self and particularly how the self might be perceived by others, or fears of rejection: "*I used to be more confident I guess... like I kind of more now like not include myself in things... like if I get involved then people won't like me…"* (Di Battista et al., 2014). Feeling less able to communicate and express oneself (as a result of deficits) was felt as shameful and with a sense of being inferior, characterised by one participant thus: *"...you kind of think… oh not good enough I don't function as like as you know a talking person*" (Buckeridge, Clarke, & Sellers, 2020). Similarly, needing more support or being singled out by teachers in school was felt as embarrassing. Altogether, differences between the individual and their peers were frequently experienced as alienating.

Restricted activities compounded a sense of frustration as well as boredom and anger, emphasised here by one participant who had to wait before riding his bike again: *"Oh God. Very sad! I can't go on it to after Christmas. Next year."* (Williams, 2020). Some participants experienced a sense of loss and grieved their pre-injury lives or had feelings of longing for 'normality' and how life was before the injury: *"...'cos in the before life, ...I had the freedom to ride my bike like to the [service station] with my friends... and I feel like because my brain injury I can't do that anymore and sometimes... I want to just cry..."* (Di Battista et al., 2014).

Because of negative feelings associated with new challenges and deficits, young people often worried about the permanence of their difficulties and how they would be impacted in the future: "*It was frightening as well the sort of not knowing whether this is going to get better, is this permanent, is this kind of normal*." (Buckeridge et al., 2020).

***Who am I?*** As well as new challenges and struggles attached to deficits after ABI, participants noted general personal characteristics, traits or aspects of lifestyle which had changed since their experiences. Participants thus reflected on their identity before and after injury – *who I was* and *who I am now*: *"...I kept comparing myself to the person I used to be. And I was thinking to myself, I'm never going to be this girl again. I'm not going to be the same person."* (Roscigno, Swanson, Vavilala, & Solchany, 2011).

Some participants reflected that living through the injury as a significant life event had changed their perspectives on the world or how they responded in situations, for example one participant said: *"...And like it probably inspired like me to go through school like as far as I did and do what I want and not listen to anyone else and what they say sort of thing*".

Participants described positive changes and growth after their injury. These included additional knowledge and wisdom: *"…every day I would maybe make a new realization about little things, or I would think about things differently…"* (Roscigno et al., 2011); strength and assertiveness: "*…before I wouldn't say nothing. But yeah, [now] I do*." (Williams, 2020); spirituality: *"God saved my life and I feel like I'm more spiritual*" (Roscigno et al., 2011) and independence: "*I had to have complete cognitive rest so I made pancakes… I can make sauces which I invented at the same time so indirectly, it was - it made me more independent*" (Di Battista et al., 2014).

For some participants, the injury had also prompted a reassessment of goals or ideas about the future. While some aspects of reassessment were based on necessity due to new cognitive and physical challenges: "*At the moment I couldn't see myself getting a job … the job I'd like to get, I can't get*" (Mealings & Douglas, 2010), others were perceived as a result of positive changes to the self: *"I straightened up my life a lot*" (Roscigno et al., 2011); "*…all I wanted to do was be become a famous BMX star... but now I want to become a motivational speaker and spread my message to the world*" (Di Battista et al., 2014).

Normality was a salient issue for young people; as well as desiring a return to normality in everyday life, individuals also questioned 'am I normal?': "*Just thought I was some weirdo... I just thought that something was wrong with me..."; "how different I am to everyone else"* (Glennon, Watson, Fisher, & Gracey, 2022). Being 'normal' linked to a desire to fit in with peers, and fear of ostracism: *"…quite a lot of the people in our school with brain injuries have some sort of disability... no one wants to be friends with them... I don't want to be one of them*" (Buckeridge et al., 2020).

The developing sense of self was an ongoing process, as is typical during adolescence. However, individuals with ABI experienced additional meaning-making around development, questioning ‘is this me or the injury’: “*…I don’t know whether that’s just me growing up or me after a car accident?*” (Di Battista et al., 2014). Some sought to actively reject attributing changes to their injury: “*It felt like too much sometimes, like there were excuses to why I did certain things or said certain things… I have certain things in my life that might be affected by it... but it doesn’t mean everything is to do with it*.” (Buckeridge et al., 2020).

### Relationships

The social worlds of children and adolescents were important and closely interlinked with aspects of identity. School in particular was viewed as the key place for resuming friendships and social life after ABI: *“…the whole point of me wanting to go back to school like hang around with my friends*” (Mealings & Douglas, 2010). The Relationships domain was organised into two further descriptive themes: 1) the social world and 2) changes to family dynamics.

***The social world.*** Functional difficulties impacted relationships when they affected individuals’ abilities to communicate with others and express themselves, as described here by one individual experiencing fatigue: “*I remember just kind of being like so tired that I couldn’t respond in the way I wanted to if at all and thinking oh no I’ve kind of ruined it with that person*” (Buckeridge et al., 2020). This included relationships with teachers at school – when teachers didn’t understand their difficulties, singled them out for being different or chastised them for struggling, young people experienced a sense of detachment.

Changes to the individual sometimes meant that they felt others withdrew or treated them differently: “*Yeah, [my friends came over at first] but then they saw me, and they saw* *the way I acted, and then they didn't come over anymore*" (Roscigno et al., 2011) and some were picked on, called names or bullied: "*People call me like lazy*" (Williams, 2020). Some participants attributed the withdrawal of friendship as a result of others being unable to relate to what the young person had experienced: "*hadn't been through stuff*" (Glennon et al., 2022), while others found continuity of friendship was helped by the willingness of friends to understand their ABI: "*They know I had a brain tumour and that so they're obviously a bit more caring… they're still my friends at the end of the day*" (Buckeridge et al., 2020).

The relationship between identity and relationships in the social world was often cyclical: changes in the self resulted in altered relationships, and these in turn lead to young people feeling even more changed: "*As I was losing more and more people, I felt more and more different*" (Glennon, Watson, Fisher, & Gracey, 2022). Equally, when participants sensed that friendships had resumed the normalcy of pre-injury, their sense of self as 'normal' was also restored.

***Change in family dynamics***. Young people acknowledged changes in family dynamics, especially around restrictions to participation which were often enforced by parents and caregivers. This led to tensions and arguments between family members, exacerbated by the difficult feelings experienced by participants as a result of restrictions: "*I know she's trying to protect me but it's like basically she, she's being a bit too overprotective…It's like, shut up!*" (Williams, 2020).

The protective role of parents was often at odds with participants' sense of themselves as, or desire to be, independent and autonomous: "*She feels like I'm not responsible like I'm just a child", "I've got to try to do stuff by myself"* (Williams, 2020). Roles of young people in the family sometimes changed after ABI, for example if participants were dependent on caregivers for additional needs compared to pre-injury: *"mum has to help me with a lot more,* *she's got to help me with a whole lot more in my life... [like] getting changed..."* (Di Battista et al., 2014).

Participants also spoke of their awareness of the impact their injury had had on other family members: *"[my parents] thought aw he's a goner he's dead he's brain-dead... so I dunno it always plays in their mind aw we could have had a disabled or dead son... ever since then I think they've been very thankful that nothing's happened*"(Di Battista et al., 2014). For some, the injury brought them closer to family: "*I think the accident has changed me… my mom's my best friend. And most people don't actually become friends or are able to talk to their mother 'til they are way older*" (Roscigno et al., 2011). ABI also changed the hierarchy of social relationships; immediate family became the main relationships for some young people due to the nature of recovery and spending more at home, and also if peer friendships had broken down.

### Coping and Support

Young people spoke about how they coped and how others supported them in responses to the changes and new difficulties they faced. This theme is explored in two further subthemes: 1) Reframing and Acceptance and 2) Being Understood.

***Reframing and Acceptance.*** Positive reframing processes for young people featured across studies and across both sense of self and relationship domains. Discrepancies in the self were managed by identifying positive features of their ABI, for example the positive changes to self as previously discussed. As also mentioned, this process supported coping when friendships changed or disintegrated, for example by declaring old friendships incompatible with a new self. Reframing processes attached meaning to individuals' injuries and provided a buffer when previous ideals of self and future were lost, for example, by helping to reassess goals and plans. Positive reframing was an active, conscious choice for some to be optimistic in order to move on with life: "*I'm trying to see it as more of a positive thing than as a negative thing, because seeing it as something that's always holding me back, then I'm always going to be held back for the rest of my life*" (Glennon et al., 2022).

Reframing also facilitated continuity of pre-injury identity, for example as one participant said: "*it [the TBI] sort of concreted my, like my desire to become a doctor*" (Di Battista et al., 2014). This included rationalising or normalising changes in a way which distanced individuals from their injuries, for example by refusing to 'blame' differences on ABI. As one participant expressed, "*everybody sort of has I suppose word finding difficulties, everybody will forget a word*." (Buckeridge et al., 2020).

Young people described processes of acceptance and eventually coming to terms with the things they could not change: *"... what happened, happened ... You can't change that, so may as well just move on with your life, that's about all."* (Mealings & Douglas, 2010). This involved learning to live with their new difficulties and new selves: *"it isn't as much something that you get past, it's more that you learn to live with it."* (Glennon et al., 2022). Acceptance also involved adapting to changes, for example finding new friendships which fit with new selves: *"...I think it was like the social side of things. Like both the online community and kind of starting to make new friends... like maybe this could get better, that kind of thing, I might as well kind of accept it rather than just dwell on it and then feel worse."* (Glennon et al., 2022).

***Being understood.*** Participants made frequent reference to the importance of feeling understood by others and the negative impact of feeling misunderstood. ABI was often described as a 'hidden' or 'invisible' disability (Buckeridge et al., 2020; Roscigno et al., 2011) which gave others the wrong impression or prevented them from getting to know individuals: *“they just don't bother even taking the time to find out who's the face behind the mask”* (Roscigno et al., 2011). This was pertinent at school, when participants’ perceived success and participation often depended on teachers’ understanding of their hidden difficulties:

*“Most of them knew I had a brain tumour so they were considerate about me and like I may need to ask again about something or whatever”* (Buckeridge et al., 2020).

*“I couldn’t remember the work, and all—and the teacher was like, ’You know it; you just can't remember it. Try as hard as you can’. And I was like, ‘I am trying as hard as I can’. And she's like, ‘Just try harder’”* (Roscigno et al., 2011).

Individuals also wanted their thoughts and feelings understood by others: that young people wanted to be treated as ‘normal’ as possible whilst still receiving extra help when required. When participants had positive relationships with professionals and when young people were asked for input around their own support strategies, experiences were described positively (Buckeridge et al., 2020; Mealings & Douglas, 2010). However, participants spoke of feeling negatively about being singled out or treated very differently at school:

*“They didn’t understand what... would help me so they just took me out of some lessons”* (Buckeridge et al., 2020).

*“No I mean I wasn’t singled out ’cause I think they would probably think that was a negative if I was singled out. Like it would make me feel that I was sort of lesser of a person.”* (Buckeridge et al., 2020).

Being understood included healthcare professionals understanding and sharing knowledge about the young person’s difficulties and what to expect after ABI (Bogan, Livingston, Parry-Jones, Buston, & Wood, 1997). Young people wanted professionals to understand more about the lived experience of ABI rather than just focusing functional deficits:

*"I think I should have been told how to deal with it a bit more. More advice on how to deal with it mentally, than just the physical side of it... half the time it's only your mental state that matters, that's all you're suffering"* (Bogan et al., 1997).

## Discussion

### Overview

The aim of this review was to provide a current, in-depth synthesis of the qualitative literature of the lived experience of children with ABI from their own perspectives. Although some of the selected studies included mixed samples (e.g. parent and child perspectives), patterns of meaning and common experience were identified across the articles.

To maintain proximity to the findings described in the studies, results were categorised into three broad themes: sense of self, relationships and coping and support. These represent three overarching domains which appear important to young people when describing how they experience their ABI. However, the boundaries between these domains were blurred and their sub-themes frequently overlapped, for example sense of self impacted relationships, and the quality of relationships impacted how supported young people felt.

***Young people face identity change.*** Facing disability has implications on sense of self – the immediate after effects may be characterised by difficult feelings as young people acknowledge what is lost or now more difficult. As well as physical or functional changes, young people acknowledge differences in their sense of themselves or their character, for example, a loss of confidence or sense of being inferior to others. Positive changes or growth might also be identified, for example newfound wisdom and independence.

Changes to the self can impact children's relationships, particularly peer friendships, in various ways: communicating may feel functionally difficult or participation might be reduced, but others may also respond to or treat young people differently. For example, disability may be stigmatised and lead to social rejection, or changes to the self might mean old relationships no longer work and fade out. Where continuity in relationships is retained, continuity of self may be experienced, whereby young people may be more likely to think of themselves as back to ‘normal’ or their pre-injury selves. Therefore, it appears that individuals’ sense of themselves is not an isolated, internal process but also constructed within, and in response to, their social environments.

The findings build upon Kakonge et al.’s (2022) mapping review of adolescent identity after ABI, which suggested young people seek to reconstruct new adaptive identities after ABI. The mapping review proposed that adolescents use social engagement as a “vehicle” for conceptualising the self, which is backed up in the results of this review which found that processes of both identity formation and relationships impacted upon one another. This concept is also reflected in Glennon et al.’s (2022) paper on adolescent identity change after ABI where findings suggested continuity of identity was sought in the context of peer relationships. Insights indicate the relevance of identity across different domains of life, particularly to adolescents.

***A positive outlook helps young people cope.*** Optimism was important when managing the initial difficult feelings around loss, isolation or changes to participation. Young people described processes of accepting and reframing their experiences or differences in order to help them move on from these feelings. On a practical level this might involve seeking new friendships or restructuring social relationships e.g. spending more time with family. It may also involve reconstructing new ideas around the future e.g. with new goals and aspirations incorporating the new self. Acknowledging the positive changes to self as mentioned may also contribute to this process as part of seeking meaning from difficult experiences.

Di Battista et al. (2014) referred explicitly to themes of post-traumatic growth in the findings of their study exploring coping after adolescent ABI, whereby young people drew meaning from their experiences to cope and reframe expectations of life. The findings of this review support the idea that positive thinking processes are used by young people to manage difficult feelings and assimilate change into their new lives.

***Young people want to be understood, but not treated differently.*** It was important for young people to feel like others understood them, particularly adults such as teachers and healthcare workers. Participants described disability as 'invisible', meaning that others might perceive difficulties on the service but attribute them to other factors, for example laziness in the classroom. Young people wanted their hidden difficulties known in a way that meant they weren't singled out from others, either by being told off or by given 'special treatment'. They also wanted this understanding to be shared with them, for example for professionals to share knowledge of what to expect, or to support young people to understand themselves. However, focusing only on functional difficulties was not always perceived as helpful, participants wanted others to understand their mental health and their experiences of adjustment.

Overall, this review addressed a gap in the literature where children's perspectives were previously splintered across studies with mixed samples or with specific domains of focus. The review provides a picture of the whole lived experience for young people by aggregating data capturing its disparate elements. Further gaps in the literature have become apparent: it is extremely rare that younger children's voice are heard and reported in research studies which mostly use verbal interviews in methodology. Additionally, very few studies have explored the general lived experience or processes of identity, which appears so pertinent to adolescents across their accounts.

### Strengths and limitations

The review was able to extract child and adolescent data from mixed participant papers and revealed common patterns of meaning and experience across studies. Therefore, its results are of value and contribute towards filling a gap in the literature where the child's voice was missing or split over different domains of focus within the ABI knowledge-base. However, adolescents are overrepresented in the data and perspectives of younger children (e.g. under the age of 11) are still lacking in the literature.

The articles included in the review had appropriate methodologies for addressing the research aims and questions. Overall, they were assessed as good to moderately good studies. There are limitations to the CASP tool used for quality appraisal – whilst this is commonly used and endorsed by Cochrane Qualitative and Implementation Methods Group, there is little guidance for users on its application (Long, French, & Brooks, 2020). However, quality ratings of both independent reviewers matched, suggesting quality ratings were applied in broadly the same away.

Only seven of the reviewed articles were categorised as 'core' to the research question in terms of rigour, resonance and relevance, and two of these were from the same study. Of the core studies, only four were explorations of general lived experience of ABI while others had more focused questions, e.g. return to education and experiences of communication. Therefore, although common themes were found across all studies, rich data was limited.

A limitation within the search strategy could be the lack of MeSH terms used, meaning that papers may not have been identified if they did not contain search terms in the title and abstract of the paper. However, manual searches of references lists for each of the papers identified any studies which may not have appeared in the initial search; these were then screened against the criteria to ensure that all the relevant papers were included in the review.

A proportion (50%) of the papers were screened by the second independent reviewer (AS) against inclusion/exclusion criteria as well as for quality and the themes extracted. Ideally all papers would have been screened to be sure nothing was missed or inappropriately included, however, the ratings of both independent reviewers matched and were deemed satisfactory.

### Future implications

The high number of mixed or adolescent-only samples suggests that researchers could be doing more to design studies which elevate the child's voice or create conditions for them to express themselves without the need of corroboration from adult parents and professionals. This applies to both adolescents, who were often interviewed alongside parents, and younger children, whose voices were all but missing in analyses of semi-structured interviews. Older children may be more likely to be reflective about their experiences and more easily able to describe detail or depth of meaningful concepts (Roscigno et al., 2011). Research methods for younger children may therefore require more creativity, for example the use of visual or arts-based methods such as photo-elicitation which have been used with children with disabilities (Vänskä, Sipari, & Haataja, 2020) and shadowing methods which have been explored with adults with intellectual disabilities (Van der Weele & Bredewold, 2021).

The findings support Perkins et al.'s (2022) model to guide identity-focused rehabilitation (I-FoRM) after child ABI which builds on the concept that adaptation after ABI is an iterative process between the child and their environment (Perkins, Gracey, Kelly, & Jim, 2022). The foundations of the model include principles based on participatory experiences and interpersonal context to maximise outcomes around adaptation, participation, awareness of needs and integration of new aspects of identity. This thesis reinforces the importance of supporting children to work within relationships and identity construction processes.

Certainly, the knowledge-base would benefit from further enquiry into processes of identity adjustment and social worlds, which appear to be pertinent across studies yet are rarely explored directly in their own right.

## Conclusion

The findings of the review build up a picture of the young person's general lived experience after ABI. This is characterised by a period of making sense of and adapting to a new self, or assessing both continuity and change. Relationships and the social world are a crucial part of young people understanding themselves and how others respond to them. Young people may adapt by restructuring relationships if continuity of old ones is not possible. Positive reframing and optimism are important to young people when managing these changes.

The results however speak mainly for adolescent populations: researchers must adapt qualitative methodology to elicit rich responses from younger children to understand their worlds and experience. Identity in general is underexplored: this review identifies an opportunity for research to fill a gap in the knowledge-base around a deeper understanding of identity formation for young people after ABI.

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# Chapter 3: Bridging Chapter

The previous chapter provided an in-depth systematic review and synthesis of the qualitative literature exploring how children and young people experience ABI from their own perspectives. Core themes were identified which contribute to a bigger picture of the lived experience of ABI for children and adolescents. The findings addressed a gap in the research literature where the child's voice was either missing or diluted across studies with mixed participant groups (e.g. with parents and professionals) and across a range of different domains.

The synthesis highlighted themes around the importance of feeling understood and supported by others, particularly family members and parents. ABI affects whole families, especially when it is experienced by children and young people dependent on and growing within family contexts. Parent experience and wellbeing can affect how young people experience their own ABI or rehabilitation (Labrell et al., 2018), and therefore warrants its own line of enquiry.

Therefore, the second part of this thesis will examine the parent experience, and in particular will address a gap in knowledge around how parents make sense of, adjust, and cope after their child's ABI. Previous studies have focused on deficits and losses for both children with ABI and their parents. This study will aim to expand upon this by examining parent stories as whole narratives, and in doing so, the researcher hopes to capture the nuance of lived experience for caregivers after child ABI.

# Chapter 4: Empirical Paper prepared for submission to Neuropsychological Rehabilitation

The research reported is original work which was carried out under the supervision of Fergus Gracey (Primary Supervisor), Kiki Mastroyannopoulos (Secondary Supervisor), Charlie Whiffin (Field Supervisor) and Suzanna Watson (Field Supervisor). I am the lead author of this paper which is prepared for journal submission.

# Exploring Parent Experience following Child Brain Injury:

## A Narrative Analysis

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# Exploring Family Experience of Acquired Brain Injury in Childhood

## Abstract

**Aims:** The aim of this study was to gain an understanding of parents' narratives and experiences after their child's Acquired Brain Injury (ABI).

**Methods:** Five parents (four mothers and one father) of four children with clinically significant brain injuries were interviewed individually. A qualitative narrative approach was used to understand parent sense-making and adjustment in relation to their child's brain injury.

**Results:** A between-case analysis revealed two core narrative threads: 1. Trauma and 2. Journey, which each contained different themes or subtypes: 1a. injury event and aftermath, 1b. recovery and growth, 2a. battle and conflict, 2b. searching and 2c. back to recovery.

**Conclusions:** Trauma may be ongoing for parents of children with ABI; this is managed with processes involving acceptance, a positive outlook, gratitude, acknowledging progress and drawing upon personal strengths. Recovery after ABI is viewed as a journey with various battles, milestones, and challenges along the way. Feeling heard and understood as a parent may be key to parents navigating such journeys.

**Keywords:** paediatric, acquired brain injury, adjustment, self-identity, parent

Exploring Family Experience of Acquired Brain Injury in Childhood

## Introduction

A significant portion of those affected by acquired brain injury (ABI) are young people under the age of 18 (Langlois et al., 2006). ABI can present multiple changes to individuals including physical disability and cognitive, behavioural, emotional and personality differences (Anderson, Catroppa, Haritou, Morse, & Rosenfeld, 2005). Thus, ABI can present complex challenges to the families and others involved in the young person's care (World Health Organisation, 2008).

### Family context

Paediatric ABI can cause significant losses to families as well as individuals (Kreutzer, Mills, & Marwitz, 2016). Differences in the individual may be experienced as distressing for families and family life can change significantly, for example increased caring needs and medical appointments, practical changes to the home and financial burden (Anderson et al., 2005; Roscigno & Swanson, 2011). As a result of increased caring burden families can become socially isolated (Brown, Whittingham, Sofronoff, & Boyd, 2013) and quality of life may be impacted significantly (Kratz, Sander, Brickell, Lange, & Carlozzi, 2017).

Primary caregivers hold a major role in their child's recovery after ABI, with parent-led rehabilitation resulting in superior outcomes compared to directly clinician-led programmes (Braga, Da Paz Junior, & Ylvisaker, 2005). Children's appraisals of their own identity and changes following ABI can also be impacted by parent perception (Bohanek, Marin, Fivush, & Duke, 2006; Glennon et al., 2022). However, parents' perceptions and ability to engage with their child's rehabilitation may be impacted by their own psychological wellbeing (Bivona et al., 2020; Brown et al., 2013). Family functioning and wellbeing are therefore linked to improved psychosocial outcomes for children with ABI (V. A. Anderson et al., 2005; Micklewright, King, O'Toole, Henrich, & Floyd, 2012; Yeates, Taylor, Walz, Stancin, & Wade, 2010).

### Parent experience

Historically, research literature has recorded the stress, burden, and reduced quality of life that ABI may present for primary caregivers (Degeneffe, 2001). Parents may find less time for themselves and see increased strain on their relationships (V. A. Anderson et al., 2005). It may be common to experience grief for their loss of 'the child they knew' as well as for their previous life or the future they expected (Pauline & Boss, 2009; Roscigno & Swanson, 2011). It is well documented that parents of children with ABI are more vulnerable to depression, anxiety and PTSD (Hawley, Ward, Magnay, & Long, 2003; Labrell et al., 2018).

Although such narratives of loss and deficit dominate rehab language and research, Roscigno and Swanson (2011) suggest that healthcare workers who focused solely on loss and injury were viewed as unhelpful by parents, who wanted professionals to hold hope. Whiffin (2017) argues that focusing only on what has changed or been lost in the individual is restrictive to care and does not illuminate the complexity of what families experience after ABI, nor how they make sense of this (Anderson, Parmenter, & Mok, 2002). Less is known about other areas of the parent experience of ABI, such as adjustment, coping and sense-making. Further, although the literature suggests parent sense-making impacts that of the child (Bohanek et al., 2006) less is known about how the process of 'making sense' is experienced by parents.

### Parent narratives

One method which has allowed researchers to hear the full range of possible ‘stories’ of experience has been narrative analysis, used with children with critical illness (Manning, Hemingway, & Redsell, 2017) and family members of brain-injured adults (Manning et al., 2017; Pals & McAdams, 2004; Whiffin, Ellis-Hill, Bailey, Jarrett, & Hutchinson, 2017). These studies have suggested narrative can play an important role in making sense-making both for individuals and family members after illness events.

Narrative analysis has been used successfully in the context of health events, for example, approaching illness or injury as ‘biographical disruption’ and examining how that rupture to narrative might be repaired or adapted (Manning et al., 2017; Popp et al., 2014; Simpson, Heath, & Wall, 2014). Research suggests stories can be used as tools for regaining control after illness events, helping people making sense of situations or organising information in a meaningful way (Simpson et al., 2014). Narrative captures change or transformation over the passage of time, which is appropriate for the exploration of the potential ‘deconstruction and reconstruction’ of identities which can happen for family members of adults with ABI (Whiffin et al., 2017) and potential resolution or adaptation after loss (Bingley, Thomas, Brown, Reeve, & Payne, 2008).

Research with parents of children with serious illnesses suggests narratives are nuanced and can include themes of transformation or positive outcomes such as increased resilience, strengthened relationships and personal growth (Picoraro et al., 2014; Popp, Robinson, Britner, & Blank, 2014). However, parents of children with ABI and its unique challenges have not been examined in this context. In the neuropsychological literature, family members of adults with ABI have used narrative to describe experiences of identity change themselves (Whiffin et al., 2017), though the nuances of these changes are yet to be explored and even less is known about parents specifically.

A fuller understanding of parent experience could offer insight into parent focus, mechanisms of change and the context of parental adjustment, allowing clinicians to provide more person-centred and collaborative support (Roscigno & Swanson, 2011; Verhaeghe, Defloor, & Grypdonck, 2005; Whiffin et al., 2017).

### Research Questions

The study aimed to address the following question: what stories do parents tell to make sense of their own and their family's experiences following their child's injury?

## Methods

### Design

A narrative approach was used for the study; this is an explorative, qualitative method using participants' stories as the raw data. In addition to content and themes, analysis also considers structure, chronology, use of metaphor, what purpose or function the story might hold and the context in which it is told (Webster & Mertova, 2007).

Epistemologically and ontologically, narrative analysis aligns with the contextual and constructivist paradigms, whereby reality is understood as socially constructed, interpreted and 're-storied' by the self through one's own personal belief system (Kugelmann, 2001; Manning et al., 2017). Therefore, the project is not designed to discover what is 'true' or 'false' about participants' stories, but rather to understand parents' social and psychological worlds by analysing the content and meaning of narratives produced in interviews (Manning et al., 2017). Narratives are constructed within social contexts using the language materials available within those contexts; this includes the researcher's own interpretations and co-construction of the narrative.

### Inclusion/Exclusion Criteria

The inclusion criteria were that a) participants must be parents or primary caregivers of a child who has sustained a Clinically Significant Brain Injury (Turner-Stokes & Wade, 2004) after birth, b) the child is of school-attending age (4-17), c) the child has been discharged from hospital for a minimum of nine months and d) caregivers must be over the age of 18 and be able to speak and read English.

The study focused on school-age children rather than including infants or young people over the age of 18 who may have significantly different needs or, in the case of older children, may live outside of the original family unit. A time period of 9 months since hospital discharge was applied so that families had a chance to be at home and live with the consequences and changes before taking part to share their stories.

### Participants

Five parents of four children with ABI (Table 1) were recruited from a community-based paediatric specialist neurorehabilitation service in the National Health Service (NHS) between September-December 2022. Whilst there are no specific guidelines regarding sample size in narrative analysis, qualitative methods in general encourage quality of the data over quantity, with six to 12 interviews generally accepted (Smith, Flowers, & Larkin, 2009). In this study, the primary concern of data collection was to gather rich, detailed accounts from individuals, following guidance from narrative analysis to interview each participant more than once (Rocco, 2003). Sample size was therefore informed using principles of ‘information power’, as conceptualised by Malterud et al. (2016) whereby sample size is based on the richness and relevance of the data collected rather than on an arbitrary number of participants. Six participants were sought for the study as each were to be interviewed twice resulting in a planned 12 interviews. One participant dropped out of the study before the first interview and further participant time constraints meant one person could only be interviewed once. To manage this, the first interview was extended to allow further questions at the end rather than in a second interview. The resulting nine interviews were deemed to be of sufficient richness and depth, yielding a large amount of information per participant, that the research question could be sufficiently answered based on the aforementioned concept of information power.

Data referring to each child's injury were collected from the parents (see Table 1). All children had severe brain injuries, three of which were Traumatic Brain Injuries (TBI). Each child spent a minimum of one week in hospital, with two spending time in an Intensive Care Unit (ICU).

**Table 1**

*Participant and child demographic data*

| Participant Identification Number | Pseudonym | Ethnicity | Gender | Child Pseudonym | Child Gender | Child Age | Type of Injury | Time Since Injury |
|---|---|---|---|---|---|---|---|---|
| 1 | Jenny | White British | Female | Zac | Male | 15 | TBI | 18 months |
| 2 | Rachel | White British | Female | Eva | Female | 6 | Central Nervous System Infection | 4 Years |
| 3 | Chris | White British | Female | Harry | Male | 11 | TBI | 10 months |
| 4 | Andrew | White British | Male | Eva | Female | 6 | Central Nervous System Infection | 4 Years |
| 5 | Alex | White (Other) | Female | Skye | Female | 13 | TBI | 6 years |

## Procedure

Gatekeepers (clinicians) working within the neurorehabilitation service screened and then dispersed information letters to parents known to the team and who met the inclusion criteria. Parents who gave consent for their contact details to be shared were then contacted by the researcher. All participants opted to be interviewed online.

Four parents were interviewed twice, and one parent was interviewed once due to their own time constraints. A small number of participants, with a total of nine interviews between them, allowed for a thorough investigation of the findings.

### Ethical considerations

Ethical approval for the study was sought and gained via the NHS and Health Research Authority (HRA) (Ref: 22/SC/0220). Approval was also granted by the University of East Anglia Faculty of Medicine and Health Sciences Research Ethics Committee. All participants gave informed consent after discussing the project with the researcher. All personal information was anonymised by using pseudonyms and redacting identifiable information from transcripts. Participants received a £10 Amazon gift voucher as a token of appreciation. After the interviews participants were provided with a debrief and opportunity to reflect on the interview process, which included being given a list of local resources for emotional and wellbeing support.

### Data Collection

Following guidance from the narrative approach (Rocco, 2003), two interviews were conducted per participant, resulting in nine interviews total as one person could not complete a second interview. The first interview was unstructured, beginning with an open question inviting participants to talk about their experience and with very few prompts. The second interview focused on expanding parents' narratives based on their first interviews and included themes related to the study aims if these had not previously been covered, for example sense-making around key events, or how transitions in the narrative were managed.

A 'prolonged and in-depth analysis' was undertaken in five stages as informed by Manning et al. (2017) and Crossley (2002). Stage 1: becoming 'immersed' in the data by re-listening to recordings and re-reading transcripts; stage 2: identifying significant elements of participants' personal narratives; stage 3: identifying narrative tone and structure; stage 4:

identifying imagery and themes; stage 5: re-storying the data (Crossley, 2002; Manning et al., 2017).

Data – the ‘stories’ - were treated holistically, meaning the whole accounts were analysed rather than inductively coded into thematic categories as they would be in other approaches, for example grounded theory (Riessman & Quinney, 2005).

A reflexive diary was used throughout data collection and analysis to aid the process of co-construction of the narrative between participant and researcher, and to record further observations on relational or performative aspects of participants’ narratives (Manning et al., 2017). Reflective supervision with two academic supervisors was also used for this purpose. The final analysis was therefore a co-constructed narrative between the participants (‘story-tellers’) and the researcher.

## Results

Analysis of parent stories revealed two core narrative threads: 1. Trauma, with subthemes a.) injury event and aftermath and b.) recovery and growth; and 2. Journey, with subthemes a.) battle and conflict, b.) searching and c.) back to recovery.

### Trauma narratives

***Injury Event and Aftermath.*** Without exception, each participant spent time detailing imagery to represent the event of their child's injury in the first interview. These images characterised the sense of complete disorientation, fear, chaos, and horror which can accompany traumatic events. The event of the injury was told as a discrete story set within each participant's wider narrative and served as the main biographical hinge from which the rest of the account unfolded (e.g. before and after the event). These distinct trauma events had a protracted temporality compared to the rest of the (whole) narrative: the immediate experience of the injuries were frequently described hour by hour, or even minute by minute, reflecting the nature of how trauma is perceived as it occurs (Vicario & Felmingham, 2018).

P1: *And I heard the air ambulance and I knew it was Zac… So he went with the air ambulance, I went in the back of the police car… they said he probably wouldn't survive the night… and then he had a craniotomy and all the bits… for about 5 days I didn't actually know where I was… I could have been in Japan…*

*…that was our fresh start, our new start.*

Trauma was then continuous even after the event (P1, P2, P4, P5) as the impact of the child's brain injury was not always immediately obvious, meaning ongoing discovery of damage or deficits was experienced as children grew and developed. Parents described several moments in which the perception of their worlds and their lives changed, and two parents (P1, P5) described the ongoing emotional impact of this in the aftermath of the injury.

P5: *And the consultant there told us that no, we're not out of the woods yet… And again our worlds fell apart.*

P1: *…even though your anxiety is through the roof, do you know what I mean? Underneath I am a quivering mess.*

For Jenny (P1), her trauma narrative included a process of losing her own identity as she became subsumed by the world of Zac's care and his injury became the central focus of her being.

P1: *…the first couple of weeks [in hospital] I said, "hello I'm Jenny". And then I said, "hello I'm Jenny, I'm Zac's mum". I introduce myself now as "Zac's mum"… my identity's gone…*

***Recovery and Growth.*** All parents used trauma narratives to understand changes to their own selves and lives 'before and after' their children's injuries. These illustrated how disruptive and significant injuries had been to their previous sense of normality or stability. Life as they knew it had changed, requiring alterations to their previous roles and responsibilities, family life, relationships, and personal coping skills. Recovery and growth themes within these narratives explored how parents maintained continuity in their lives or managed the changes and uncertainty their experiences elicited. All parents spoke of the importance of acceptance for coping with the all-encompassing trauma of their child's brain injury. This included acceptance of what had happened, and for some it included acceptance of uncertainty about the future (P2, P4, P5). For some, (P1, P2), acceptance was the only alternative to living in an unending state of overwhelm and devastation after their trauma – to

Rachel (P2) in particular it felt like the only way to survive, as she emphasised by a continual use of 'I have to'.

P2: *And you, I think you have to flip your thinking. There's no point in sitting there feeling sorry for yourself. That she's got a brain injury. We've got to be happy. And I think it's acceptance is the key word got to accept it and move on.*

Most parents described acceptance as a process of recovery involving various steps such as maintaining a positive outlook (P1, P2, P3, P4), maintaining hope for the future (P1, P5), practicing gratitude (P2, P5), and acknowledging progress (P4, P5).

P4: *Again, it's that word: of finding that hope. You know, it's - it's kind of realizing that, regardless of what abilities Eva might have in the future, that there is hope, there is, there is a there is a life path for her, there is a way forward, there's always a way forward. There's always a solution, there's always, there's always something that you can do.*

For Jenny (P1), it was also important to retain continuity of identity for herself in small practical ways, such as by focusing on her work for just a few minutes a day:

P1: *...but it's like you - you've got to sort of keep that little bit back for yourself... So I'll just take the bits that I know that will bring me a little bit of just being 'Jenny' again.*

Where 'life now' was characterised by additional struggles or challenges to wellbeing, some parents (P3, P5, P4) also used narratives to explore how these were managed in a way which resulted in positive outcomes.

P3: *...being through something like this, makes you very, like weirdly, I just don't care about many things. Like I can cope with almost everything... Yeah, like I'm much more confident about - I mean, I generally am anyway [laughing]. But about if anything bad* *happened, I will be fine. Which I didn't have before, you know, about my family or* - *but I think I'm definitely much stronger now.*

### Journey narratives

All participants' narratives were structured or described in a way which evoked a sense of journey, progression or return. Journeys were characterised through various images and themes such as: battling and conflict, searching, preparing, management and protecting. Unlike Frank's (1999) concept of restitution or quest narratives, whereby narratives may represent quests towards 'overcoming' adverse events and restoring health, only P3's journey was directed towards full recovery. However, each parent's journey narrative was driven by an ongoing sense of duty towards helping their child survive and thrive at any given moment. The nature of paediatric brain injury meant that new challenges were faced and anticipated continuously after the event as the young person developed and as brain changes became apparent at different developmental stages. Therefore, the ultimate 'destination' of the journey was less salient in most narratives (P1, P2, P4, P5) than the journey itself. However, within the larger story there often existed smaller narratives of various 'battles' overcome, conveying a sense of overall advancement.

P1: *So there's been a lot of battles…… You bring your kids up to try and be as safe as you can… and I know what's coming and I do – I , you know, I - I want him to live the best life that he can.*

P2: *And I just want - I want the best for her… So what can we do to make Eva's life better? You know, what services are there, what will support her and help her lead an independent life?*

***Battle and conflict.*** All participants described elements of conflict along their journey, the objective of such conflict being to receive appropriate assessment, treatment, knowledge of how to best support the child, school support and even diagnosis. Professionals and organisations frequently represented obstacles on parents' journeys as gatekeepers of knowledge and practical resources. Conflict arose when parents felt they could not access said resources due to not being heard, believed or respected by professionals, or perceived a lack of communication or lack of knowledge/certainty from professionals.

P1: *And I had a huge, huge argument with a surgeon. massive argument. And I was a clear winner, because I was right and he wasn't. And that was something that will always stick in my head… But sometimes I don't always feel like I'm heard. I'm - I'm in the corner, shouting and shouting and shouting… I'm not doing it for my sake, I do it for Zac.*

P5: *In the meetings, so I think - I know my daughter the best, right? ...So, if I sort of gave an opinion of what I thought was going on, they would shut me down very quickly… I'd be very much treated like the parent who didn't know anything… I was made to feel inadequate for what I was saying.*

Other battles along parent journeys included perceiving the child's own struggles or behaviour which were met as daily or recurrent challenges to parents' felt ability to protect and support their child (P2, P4).

P4: *…we can't do the things that we were used to doing. And the things that we want to do for Eva. Because we know that we're gonna be met with… you know issues so… You know we can't walk anywhere with her really cause that seems to be one thing that she has a meltdown. So we pretty much have to drive everywhere, including the school, which is only, you know, a 10 minute walk down the road… So again, that, that that has an effect on day-to-day.*

Battles were viewed as ‘overcome’ if the child received the support sought by the parent and were often viewed as a move forward along the wider journey narrative. Some parents (P1, P2, P4) used imagery of strength or tools they drew upon in battles and conflict which helped them overcome their obstacles or adversaries. These included themes around support from others, personal strengths such as becoming assertive, confident and using their knowledge of, or love for, their child.

> P1*: I think you learn… not to be frightened of who you're talking to because they're not always right. They don't know your child. They might have done that operation 100 times before, but they've only done it once on my son... I am assertive because if you don't speak up, nothing ever changes… I'm very, very vocal now… to try and, you know, manage those situations for him…*
>
> *...I fought like that all the way through because I feel like I'm ready is make enemies… I have to be this great big nuisance. You make people listen.*

***Searching.*** Most participants (P1, P2, P4, P5) used searching or truth-seeking narratives, where objectives were characterised by searching for the ‘right path’ or for a full understanding of their child. For parents, this included seeking knowledge about their child’s condition and development to understand how best to support them and seeking certainty in order to prepare for future challenges. Searching narratives included themes of monitoring changes in the child in an effort to understand whether these had always been part of them or were a result of their brain injury.

P2: *...if we were told she had an acquired brain injury, where would we be now? We’ve missed out on… years of therapeutic involvement to get the best care for her… As she's getting older, the gap between her peers and classmates is getting bigger and bigger. So how long will she be able to stay in a mainstream school, if at all? ...what specialist schools* *are available for children with acquired brain injury in this area? Are we gonna have to move?*

Searching and truth-seeking were not only part of the ‘moving forward’ journey narrative but were also used to understand the context of the injury, how it happened and parents’ roles in events. For some (P1, P5, P4), the act of telling the story itself was part of the process of making sense and monitoring progress on the journey towards understanding.

P4: *I think sometimes just talking through and going through it all… to a lot of people that might seem negative, it might seem like it's going back on the past, but to me… it kind of shows how far we've come… by reflecting on it, you realize how far you've come and where we are now, where Eva’s at now.*

For P5 (Alex), the searching narrative concluded with the realisation that certainty could never be ‘found’:

P5: *I never had any guidance, or we never had any guidance on what to expect and what was normal for her. We just didn't know, and no one could tell us that… And that was probably the biggest thing for me to get my head around. Was to accept her for what she is and deal with what comes up.*

***‘Back to recovery’.*** Chris’ (P3) journey narrative largely charted the process of Harry’s recovery to an almost ‘normal’ pre-injury state. Physical improvements were recounted chronologically, as were signs of continuity in Harry’s personality and identity.

P3: *…when they removed the tube, he in the first sentence, he said, “can I have a tissue?” [laughing]. So then I think I thought he I was like, ‘oh, I think he's fine because I think he wants to spit all the stuff from his mouth’. And then actually, he was quite fast. His recovery was very fast compared to other children…*

Chris was more explicit that the ultimate objective of her journey was for her family to regain its previous normalcy. Challenges to this included uncertainty around Harry’s brain changes and the potential impact of this on his identity and her sense of who he was. However, Chris drew upon Harry’s personal strengths as well as the positive characteristics of her family to represent defiance in the face of challenges.

P3: *…definitely for our family, and for me, shows us how strong we are that we could handle this. We could still, you know, we had everything under control… But knowing Harry, we knew he would be fine. And I think lots of positive thinking helps a lot.*

## Discussion

### Overview

The aim of this study was to explore the stories parents tell to make sense of their own and their family's experiences following their child's injury, in order to capture nuances and context of how parents adjust to life after their child’s ABI. Analysis of nine interviews with five parents revealed two overarching narrative threads which were common across each of the stories: Trauma and Journey. Trauma narratives revealed trauma may be ongoing after the child’s initial injury, and also that parents use coping strategies such as acceptance, positivity, gratitude, acknowledging progress and growth. Journey narratives conveyed life after ABI as a quest to maximise outcomes for their children, characterised by battles and searching elements.

All parents experienced the event of their child’s injury as traumatic, and the event served as a core narrative thread or springboard from which the wider stories unfolded. It is well documented that parents can experience trauma as a result of their child’s ABI (Hawley et al., 2003; Labrell et al., 2018). However, this study reveals how this trauma can provide a new context in which parents live: it changes the direction of life completely and requires action or personal change in order to deal with its consequences. The trauma of a child’s ABI is not a singular event or collection of difficult feelings after which life eventually resumes as normal, but a continuous process of adapting and managing uncertainty. In some cases, the trauma itself may be ongoing as children develop and meet or miss milestones, revealing the impact and extent of their injuries in time.

Trauma narratives began with a detailed description of the ‘main event’ (the child’s immediate injury), using striking imagery to convey its significance in biographical disruption. Within the narratives, participants also used comparisons of ‘before’ and ‘after’ to illustrate its impact on their lives, and trauma narratives unfolded to describe how parents then resolved the ensuing chaos of injury. Where getting ‘back to normal’ was impossible, parents had to accept what had changed. It seemed that acceptance was a way of regaining agency over one's narrative where so much had changed outside parents’ control. For one participant especially, acceptance seemed the only way to survive, lest the pain and trauma become all-consuming. Where the changes parents had to accept were painful, participants managed by practicing gratitude (e.g. ‘at least my child is alive and well’), hope (‘things might get better’) and positive thinking or acknowledging progress (‘now she/he can do x’). In doing so, trauma narratives provided some resolution for parents – where they could not fully restore their child’s pre-injury life, they could restore some sense of stability in the face of change. This echoes some of the findings from Roscigno’s (2011) study on parent experiences of their child’s physical recovery which found that gratitude and positivity helped individuals muster the energy needed to support their children.

Furthermore, trauma narratives were used to create meaning for some people, who identified positive aspects of growth or character development, for example, stronger and closer familial relationships and assertiveness and confidence. Perhaps this process itself was attached to ‘positive thinking’ coping strategies as a device for restoring stability in chaos, or perhaps these positive changes were ‘tools’ for harnessing the ongoing trauma of ABI. Studies on narratives of family members of adults with ABI have also found that people acknowledged closer familial relationships after ABI as a way of positive meaning-making after their trauma (Whiffin, Bailey, Ellis-Hill, Jarrett, & Hutchinson, 2015).

This leads to the second core narrative thread: journey. All parents conveyed the experience of their child’s rehabilitation and life after injury with a sense of progressing or advancing along a ‘path’. With the ongoing nature of the children’s development and uncertainty around the full impact of injury, there was usually no particular ‘destination’ but rather an act of continued ‘questing’ to understand, solicit support and acquire resources to facilitate the child’s present needs. Participants expressed advancement by reflecting on ‘what we went through’ as well as ‘how far’ they had come since the injury, for example acknowledging improvements in functional outcomes or care for the child.

Parents frequently described battles and obstacles on journeys, conveying continuous struggle. A particular battle mentioned was that with services: parents felt misunderstood or rejected by professionals who did not listen or who appeared to gatekeep knowledge and resources, e.g. therapies. When participants did feel understood or perceived battles to be ‘won’, e.g. achieving hard-won therapies, a sense of further progression on the journey was felt and described positively. To manage where participants felt they had to battle, parents used existing or new personal strengths as ‘tools’, for example tenacity and forthrightness.

The findings add to those from a previous study on parents experiences after child ABI (Roscigno & Swanson, 2011): similar themes of importance came up for parents in both studies, for example feeling misunderstood or sensing a lack of information provided by professionals. What this study contributes is that parents view ABI within a trauma narrative, which in itself has continuous or dynamic elements. This is helpful for thinking about interventions to support parents after child ABI which bring a trauma focus and perhaps which support parents to create positive meanings around their experiences to manage.

A second contribution to the knowledge-base is that parents make sense of life after child ABI as a journey towards an unknown destination or outcome. Conceptualising life as a journey suggests positive action as a focus and as a way of managing uncertainty about the future. Journey narratives then serve a purpose of assessing progress and advancement and normalise continuous struggle or searching to understand as children develop. This could be a useful metaphor for professionals to understand when considering the language used in rehabilitation contexts. Reframing recovery and rehabilitation as a journey may align more with how parents make sense of and cope with ABI rather than binary ‘functional vs. dysfunctional’ conceptualisations. This further echoes themes from Roscigno’s (2011) study whereby parents rejected overtly negative predictions about their children’s recovery. Interestingly, Roscigno also uses the term ‘quest’ for parents (e.g. ‘alone on their quest’), though does not comment on this metaphor as a function of sense-making for parents. The concept is highlighted in this study by the narrative analytic focus and could be helpful for clinical practitioners to visualise as an alternative to ‘well/unwell’ contexts.

The findings of this thesis reflect those of a (2021) meta-synthesis of family members’ experiences of adults with ABI, whereby adjustment is characterised as a process in flux, with ‘fragile’ steps taken to move forward in new and unfamiliar territories when ABI has challenged individuals’ previous sense of safety and familiarity (Whiffin et al., 2021). The meta-analysis illuminated the invisible, existential ‘work’ required by family members after adult ABI to make sense of past, present and future using multiple narratives. Findings in this study suggest parents of children use narratives in similar ways, with ABI represented similarly as ‘disruption’ to life as they knew it, and as the beginning of a new trajectory and life path. Viewing this period as a ‘life path’ is not always negative – it may come with new struggles or adversity, but being conceptualised as a journey adds meaning, hope and purpose to what can feel like a life-shattering event.

### Strengths and Limitations

The narrative methodology was appropriate for addressing the aim of this project, capturing nuance and allowing parents to discuss the ‘in-between’ spaces of experiences over time. The methodology also allowed useful metaphors used by parents to emerge, which illuminate differences in the way parents conceptualise their experiences compared to how they perceive professionals' conceptualisations. This is helpful for the agenda to provide more humanistic forms of support in clinical practice which are built upon individuals' own motives and goals rather than a medicalised model focused on 'fixing' what is 'wrong'.

However, it could be argued that the focus of the research question, process and context in which interviews occurred implied 'tell me what was difficult/wrong'. For example, participants' first experiences of recruitment began within clinical services for their children and they were then interviewed by a Trainee Clinical Psychologist who asked: 'tell me the story of your child's brain injury up to now'. Narratives created or told within that context are therefore perhaps impacted by participants' perceptions of the healthcare system, their experience of that particular service, and assumptions about what healthcare workers might want to know in that context.

The sample size was fairly small, especially as one participant could not complete a second interview. This was managed by extending the one interview and incorporating further questions into the same session after the first unstructured account. However, certain elements or narratives were only mentioned by one person, for example Chris' (P3) 'back to recovery' narrative. A larger sample size could therefore enrichen cross-comparison between parents' stories. Further, four out of five participants were mothers which unfortunately perpetuates the overrepresentation of mothers' perspectives in literature exploring parents' experiences (Davison, Charles, Khandpur, & Nelson, 2017).

As this was not a strictly comparative or quantitative study, only basic demographic information pertaining to the participants and their children was collected before the interviews. Therefore there may be unrecorded characteristics which could have influenced parents' experiences, for example socioeconomic status, religion, and family composition such as other dependents in the family. However, the study prioritised the richness of individual perspectives and storytelling, aiming to create as open, unbiased, and authentic an environment as possible in the interviews, rather than seeking to identify a universal truth around experiences.

A strength of the study was the researcher's background and training in clinical psychology: clinical psychologists frequently work with narratives and endeavour to understand people in the context of their life stories, therefore the research process was not unfamiliar. Additionally, reflexivity is viewed as a helpful competency for understanding others and being aware of one's own impact on clinical work (Fisher, Chew, & Leow, 2015). The researcher kept extensive field notes, a diary of personal observations and thoughts and a log of the analysis process for the same reason (Appendix L), which also added to transparency in the methods. This enabled the researcher to check and adjust potential biases, for example, it was useful to be alert to the position of working in mental health which could have impacted interpretations to be 'problem-focused'.

### Implications for future research and practice

Participants in the study were parents of children of a wide range of ages: future studies could benefit from more focused exploration of age groups, particularly differences between experiences of parenting younger children compared to adolescents. Additionally, data were collected while all children were still developing and dependent on parents or living withing the family home: future research could collect narratives at later time points when children are grown – for example, do parents ever reach an ultimate 'destination' on their journeys, and what happens to trauma narratives when children develop into adults – are these ever resolved; how do they change over time?

Life as a journey is a helpful metaphor for healthcare workers to understand as it represents the unique, evolving nature of child ABI which requires continuous adaptive support, akin to joining parents on a ‘quest’. The concept may also provide a more comfortable shared lexicon between parents and professionals which allows room for the hope and positivity parents need to manage uncertainty about their futures. In this sense, narratives may also serve a function of continuity for parents making sense of past, present and future. Narrative or trauma-focused therapeutic work may therefore be beneficial for supporting parents to maximise development of positive narratives incorporating themes of growth (Whiffin et al., 2021).

## Conclusion

This study has contributed useful findings about the way in which parents use narratives to make sense of their children’s brain injury after the event. ABI is not just a singular event which ‘happens to’ people, but an ongoing journey containing a multiplicity of narrative threads including journey metaphors and personal trauma narratives. Parents use these stories to make sense of past, present and future: acknowledging change, adapting to what cannot be changed and journeying towards what can be changed. Parents spoke of the internal and external ‘tools’ or changes made in order to adapt to new and unfamiliar contexts: positivity, gratitude, hope and acknowledging progress. Professionals would benefit from adopting the language of parents to align with their goals, for example by viewing recovery as a ‘journey’ rather than a destination, in order to support parents in holding hope and managing unknown futures.

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# Chapter 5: Discussion and Critical Evaluation

In this chapter, the findings, strengths and limitations from the systematic review and empirical paper will be summarised briefly before moving onto a discussion of where the thesis sits within the wider literature. The chapter will end with the researcher's reflections and a final conclusion.

## Summary of findings

The overarching aim of this thesis was to explore the lived experience and narratives of families of children with acquired brain injuries (ABI). There has been a burgeoning interest in clinical psychology practice in moving away from dominant medical models, which have historically focused on physical deficit and loss, towards more inclusive and person-centred approaches to understanding health (Joseph & Linley, 2008). Rather than zooming in on challenges in an attempt to 'fix' what is 'dysfunctional', some researchers have suggested it may be more helpful to think of illness events as biographical change for individuals (Ellis-Hill, Payne, & Ward, 2008; Picoraro et al., 2014) and in doing so, make room for alternative concepts to emerge such as identity construction and growth.

When speaking of 'emerging concepts', qualitative methods are usually the most appropriate means for capturing themes which may not yet be known or understood by researchers. However, even qualitative research questions may be angled towards medical ideas of dysfunction, or interpreted and reported by researchers in a way which honours these themes over others. This thesis identified two gaps in the knowledge-base to address, the first being a lack of the child's own voice and general perspective of lived experience, and the second being a lack of understanding of processes of adjustment for parents (after their child's ABI). This thesis therefore adds value in two ways, 1. by providing a synthesis of the child’s voice in qualitative research literature; 2. by exploring parent narratives to expand an understanding of life after child ABI.

The systematic review found, firstly, that children and young people are often interviewed alongside parents and caregivers to corroborate their accounts or to provide shared accounts. The few studies which held the child’s voice and perspective at the centre of enquiry were focused on various specific domains, for example, returning to school or experiences of communication. Despite this, a synthesis of these studies extracted data relating directly to children’s perspectives and revealed patterns across the different domains.

A core concept for young people is identity adjustment after ABI. Changes are acknowledged and perhaps grieved, while other changes may be viewed as positive. Young people assess what their changes mean for participation and relationships. Processes of identity adjustment are influenced by young people’s social worlds: how others respond to them, understand them and support them. Peer friendships are viewed as especially important; continuity in friendships led to a sense of continuity in identity and vice versa. Another core theme was around coping and support – young people want to be trusted and treated as ‘normal’, i.e. neither singled out from their peers nor overprotected. Despite this, young people want to be understood and for this understanding to be shared with them, in turn helping them rebuild a sense of themselves. On an internal level, young people cope using optimism and positive reframing to assimilate their changes into their identities and their lives.

In the empirical paper it was found that parents’ stories were described as journeys after ABI: dynamic processes where parents must manage their own trauma while simultaneously battling for the best outcomes for their children. Findings suggested that trauma is also ongoing rather than a singular event, as the nature of an ABI for a child is that its impact is revealed over time as the young person grows and faces new experiences in the world. This unfolding characteristic of understanding the impact of a child's ABI on their development and personality is unique compared to parents of children with other long-term conditions, who may also share narratives of trauma (Ehlers & Clark, 2000), including themes of ongoing loss (Smith, 2015).

To manage the journey, parents must manage uncertainty itself, which is perhaps why life after the ABI is characterised as a 'journey', with the eventual destination or outcome unknown. Therefore, parents also practice acceptance, and other ways of managing include remaining positive, hopeful, grateful and reflecting on the journey's 'progress'. Parents may also make personal changes to the self to adapt, for example by becoming more assertive or letting go of less meaningful relationships in life. Parents may perceive this as growth, for example a realisation of what is most important to them in life, and the development of new strength in their convictions.

These findings expand upon themes found in a previous systematic review of the qualitative literature on parent experience of child ABI by Tyerman et al. (2017) which highlighted themes of increased closeness with family members and isolation from others (including professionals) who were perceived not to understand their struggles. The review also found themes of parents seeking understanding across the literature, particularly in response to managing the uncertainty surrounding their child's development and recovery. This study builds upon these findings, for example that parents conceptualise seeking as a continuous, dynamic process part of a wider 'journey', and that positive change may be identified (i.e. close familial relationships) in order to make sense of trauma and maintain narrative continuity.

Themes of continuous ‘adjustment’ and uncertainty were also found in Yehene et al.’s grounded theory study of emotional loss in parents of children, which reflects the narrative of moving forward and momentum found in this study. Yehene found that the themes overlapped and blurred; this study perhaps provides the narrative threads that join them together. For example, conceptualising life a journey incorporates these themes in a holistic way which could allow for helpful shared metaphors to be used between parents and professionals.

## Extended discussion

Both parents and young people talked of the importance of acceptance for moving forward from the difficult feelings around what had been lost or irreversibly changed about life and the child. Within or alongside the process of acceptance were acts of positive thinking or reframing; in particular for young people this seemed an important part of assimilating new aspects of identity, e.g. reconstructing ideas and aspirations about the future to incorporate new strengths or learning after ABI (Roscigno & Swanson, 2011).

The importance of ‘moving on’ for families is a valuable finding which sounds deceptively simple yet illustrates why deficit-focused care may be restrictive, unmatched to individuals’ needs and, ultimately, unhelpful. Families quickly acknowledge what has been lost, but stories and accounts speak of the journey beyond ABI into areas such as meaningful relationships and being understood or heard by others.

The findings build upon studies which have found themes of post-traumatic growth (PTG) for families after paediatric illness (Picoraro et al., 2014) and post-ABI (Di Battista et al., 2014). However, research on PTG is still nascent in the field of child ABI (including with parents) and it could be argued that growth is a response to the unique identity changes that

ABI poses to young people rather than as a direct result of experiencing a trauma. For parents, the link between trauma and positive growth is perhaps easier to claim - parents described changes more explicitly as ways of coping with various battles and obstacles along their journeys. However, parent journeys were also not necessarily always ‘traumatic’, but rather separate narratives representing quests to seek knowledge and resources for their children, therefore changes to the self could also be interpreted more positively and uniquely to the experience of ABI from this perspective.

These themes overlap with broader literature around identity change after ABI, for example, Gracey’s (2009)‘Y-shaped’ model which posits that adaptation to changes after ABI involves processes of ‘resolving social and psychological discrepancies’, including those between the pre-injury and post-injury self. Both parents and children in this thesis described elements of searching for ‘resolution’ within their own identities, for example by using positive reframing to situate themselves within narratives which were personally meaningful, or by identifying strengths as a result of challenges. This reflects the Y-shaped model theory that such adaptive strategies may be used to reduce ‘threat’ – particularly, in this case, for parents whose trauma narratives served the purpose of making sense from chaos. This thesis therefore contributes to an understanding of how family members (in this case parents) may also experience identity changes after an individual’s ABI.

For young people, Ylvisaker (2000) explored the use of metaphor in processes of reconstructing identity after ABI. Individuals may use metaphor to anticipate how they will cope with challenges, for example, ‘waiting for the dust to settle’ (Ylvisaker, 2000). Identity metaphors may then be used to reconstruct positive models of the self, for example using images of strength and power as reflected by the young people describing experiences in this thesis. The use of metaphor was also important to parents in anticipation of difficulties, for example characterising struggles as journeys, battles, and quests.

All these approaches hold the idea that people seek coherence in their identity, and that social context plays an important role in this. This thesis supports the idea that feelings of disconnection or discrepancy in sense of self (e.g. before and after the ABI) can be emotionally challenging, resulting adaptations made by individuals to manage the resulting difficult feelings.

The findings of the thesis could then be interpreted within the Life Thread model by Ellis-Hill (2008), which posits that individuals use narratives to create a sense of coherence and stability after life-altering events, particularly acquired disability (Ellis-Hill et al., 2008). The model uses the metaphor of ‘life threads’ to represent a multiplicity of narratives which any one person can have at once, and which can change dynamically throughout life. These narrative threads are used to create links between and individuals’ ‘past which is known and their future which is unknown’ (Ellis-Hill et al., 2008). Illness events, acquired disability and traumatic experiences can challenge individuals’ sense of predictability and familiarity about the world, therefore ‘breaking’ or ‘fraying’ individuals’ life threads, where others remain to provide a sense of continuity. In this thesis, one participant ‘Jenny’ spoke of the importance of holding onto ‘a piece of herself’. Perhaps this was one of the remaining life threads left in a much-changed landscape, the only thing still connecting her past, present and future. Children, whose ‘self-identity’ threads may be particularly frayed or broken after ABI, may turn to relationships for their sense of continuity, and where friendship threads have also broken, perhaps then use their closeness to family.

The findings of the thesis could also be interpreted within Galvin and Todres’ (2011) framework which suggests a ‘lifeworld-led’ approach to describing health-related conditions in a way which accounts for the complexity and nuance of such experiences, rather than focusing simply on deficit. The lifeworld framework names different categories of ‘wellbeing’ which go beyond rudimentary or binary definitions (such as ill vs. not ill) to describe various felt senses of embodied experiences. One category, for example, is personal identity as an experience of wellbeing: when personal identity feels peaceful, unchallenged and connected to familiarity, one feels a sense of wellbeing (Galvin & Todres, 2011). Perhaps ABI challenges this for both children and parents, but rather than attempting to directly reclaim old selves, identity adjustment could be viewed as an attempt for identity to once again feel peaceful and familiar.

## Critical review

The thesis provided some valuable and novel findings around the parent and child experience of ABI. The systematic review revealed common themes of relevance to children when asked about their lived experience across numerous domains. The findings supported suggestions and insights from a mapping review on adolescent identity after ABI (Kakonge et al., 2022), as identity was a prominent theme across several areas of study focus. Building on these previous findings, the current thesis also identified commonalities between the child and parent experience, such as positive meaning-making and a need to feel understood. The findings therefore support the aim to capture nuance of lived experience rather than a snapshot of what is difficult or dysfunctional. This supports the case towards more humanistic, person-led practice which involves the wider interests of people at the centre.

In the systematic review there was a fairly small number of papers which were identified as ‘core’ to the research question in terms of relevance, rigour and resonance. While a strength is the collection of general ‘themes’ of importance for young people, a deeper interpretation, e.g. example analysing raw data, was not possible. Furthermore, those themes were frequently presented in studies as ‘what is difficult’ and ‘how I cope with it’, suggesting that the direction and interpretation of findings in studies may still be biased towards ‘fixing’ dysfunction after ABI. Therefore, the findings of the review should be treated as helpful as a springboard for future in-depth research such as exploration of identity, but not as a comprehensive picture of lived experience.

Similarly, even with the empirical paper, results may have been impacted by the context in which interviews occurred, e.g. talking to a trainee psychologist affiliated with the clinical service, therefore set within the wider context of healthcare which is still predominantly medicalised. This may have therefore set expectations or affected participants’ sense of what the researcher ‘wanted to hear’ in that setting, for example, a focus on difficulties, deficit or even mental health struggles. Therefore, the methodology presents some limitations for researchers when trying to access more hidden and deeply felt experiences for people.

## Implications for theory and practice

The findings of this thesis further build upon Glennon et al.’s (2022) study which found parents and adolescents shared themes around continuity yet had contrasting ways of managing change. For example, parents (mothers, in Glennon et al.’s case) sought to manage changes from a position of ‘fixing, preparing and protecting’ while young people managed change in relation to their peer relationships (Glennon et al., 2022). Both theses therefore emphasise the need to work within young people’s social contexts, for example with schools and peer groups. A further suggestion is the use of systemic or family therapy to integrate narratives of both children and parents to facilitate understanding – parents’ increased understanding of the goals and motivations of their children could assuage tension around ‘fixing’ or ‘battling’ for them, while also benefitting the young people themselves who have said consistently that being understood is key to their own wellbeing after ABI. This could then provide a safe, person-centred environment for collaborative thinking around adaptation, where instead of being asked ‘what’s difficult for you?’, young people can be asked ‘what is important to you?’. Systemic practices also use social contexts to understand the ‘relational knowledge’ held between people (Ames, 2019). Reflections in a study by Ames (2019) indicate that systemic practices work well for families in clinical rehabilitative settings as they provide flexible and adaptive solutions based on individuals’ changing needs and goals.

Trauma-focused interventions could also be helpful. Both parents and young people described difficult feelings around change which were managed by positive reframing to reorder meaning and value around the ABI. For parents in particular whose trauma may be ongoing, trauma-focused therapeutic work may facilitate processes around acceptance and growth to provide the coping skills and resilience required for journeys into the unknown and anticipation of future difficult events (Nijdam et al., 2018).

Concepts within narrative therapy could be of value in rehabilitation practice, e.g. the process of ‘thickening’ or developing alternative stories to reconstruct new narratives which are more ‘useful’ to individuals when previous ones have been disrupted or no longer match new selves (Weatherhead & Flaherty-Jones, 2011). Narrative therapy involves a ‘collaborative positioning’ of the therapist rather than practitioners taking the stance as gatekeepers to knowledge (Carr, 1998). This could provide an alternative and more helpful relational space between parents and services where professionals are viewed as ‘with’ families on the journey rather than as obstacles to progression.

Following on from the concept of ‘life-worlds’ in the discussion, Ellis-Hill et al. (2021) developed an approach for ‘humanising, life-world led’ caring practice which involves other methods of ‘knowing’ a person which do not simply focus on intellectual, linear ways of thinking, e.g. ‘cause’ and ‘effect’ (Ellis-Hill, Pound, & Galvin, 2022). Life-world practices recognise mutually arising and changing realities rather than a fixed reality which exists to be ‘found’. This approach can then accommodate alternative forms of human knowing, for example ‘embodied knowing’ – the body and physical experiences as a source of knowledge. Such practices may be appropriate for exploring the hidden, felt experiences of identity which go beyond the generalisable, objective and measurable outcomes which inform modern Western healthcare (Ellis-Hill et al., 2022).

## Suggestions for future research

This thesis highlighted a lack of studies focusing just on the lived experiences of young people, and even fewer focusing solely on processes of identity adjustment or the experiences of younger children. Future research methodology may benefit from more creative forms of data collection to allow younger children to express their experiences and narratives, but also to allow all young people additional means for communicating deeper, felt experiences or ‘embodied knowing’. Indeed, these methods could also be appropriate for parents and provide a more collaborative form of research where participants are also researchers and vice versa, therefore strengthening bonds and collaboration between families and services. Ellis-Hill has used this approach in research with adult populations where both individuals with stroke and professionals working on a ward worked together in groups to share stories using arts-based activities (Ellis-Hill et al., 2022). Participants (service-users) reported feeling ‘seen and heard’ during the process, while providers reported feeling an increased sense of confidence in their ability to respond sensitively and meaningfully. Both service-users and providers reported an improved sense of trust between each other and feeling of connectedness, suggesting such methods are humanising for all involved.

**Researcher reflections**

I was first drawn to research in ABI because of an interest in the brain and the apparent magic of neuroplasticity. While these remain fascinating, I now realise they are only part of what ABI means for individuals and their families.

Initially I had been apprehensive that talking to parents about their child's injury would be a saddening experience. However, I soon realised my ignorance. Whilst the accounts certainly moved me, I also felt uplifted after talking to every person who participated.

I reflected on why this might be. Of course we spoke about things which were difficult, but I left those meetings with a sense of human strength in the face of adversity, and familial love above all. Brain injury may have provided a new trajectory for families, but it was not the end of the story. These were stories of hope. Stories which were defined, not by the injury, but by parents' love for their children.

From a research perspective, this also gave me an appreciation of two things: working with stories and working within a social context. Story-telling is how we communicate who and what we are to others, as well as ourselves. Therefore, stories exist within and interact with their social context. The nature of stories is that they are borne to be told and heard; stories exist in relationship. By hearing stories, we understand more of a person within the context of our meeting. It had been an oversimplification to expect people's narratives to be 'sad' – in fact these showed to be rich, multifaceted portraits of who people were.

Lastly, I realised my interests have come full circle from my first degree (fourteen years ago) which was in Fine Art. My undergraduate thesis then was based on Jacques Derrida's 'Acts of Literature' (Derrida, 1992), where I explored the idea of stories as like mirrors in which we view ourselves and our worlds. Stories show us who and what we are. From this perspective, then, as a researcher in Clinical Psychology, what are parents' stories showing me about my world? As researchers, how can we 'hear' what is being told, or shown to us? What do we do about it?

## Conclusion

There are common patterns of meaning, metaphor and themes across studies which explore the lived experience of children and families after ABI. While this is helpful, young people and parents still struggle to feel understood as they navigate new trajectories, new worlds and new selves. Narratives may be an important part of sense-making during this process, but researchers must be aware of the context and conditions under which these are told. Particularly for younger children, alternatives to semi-structured verbal interviews must be sought. Alternative methods in general could allow mutual and changing realities to arise in a dynamic, fluid process.

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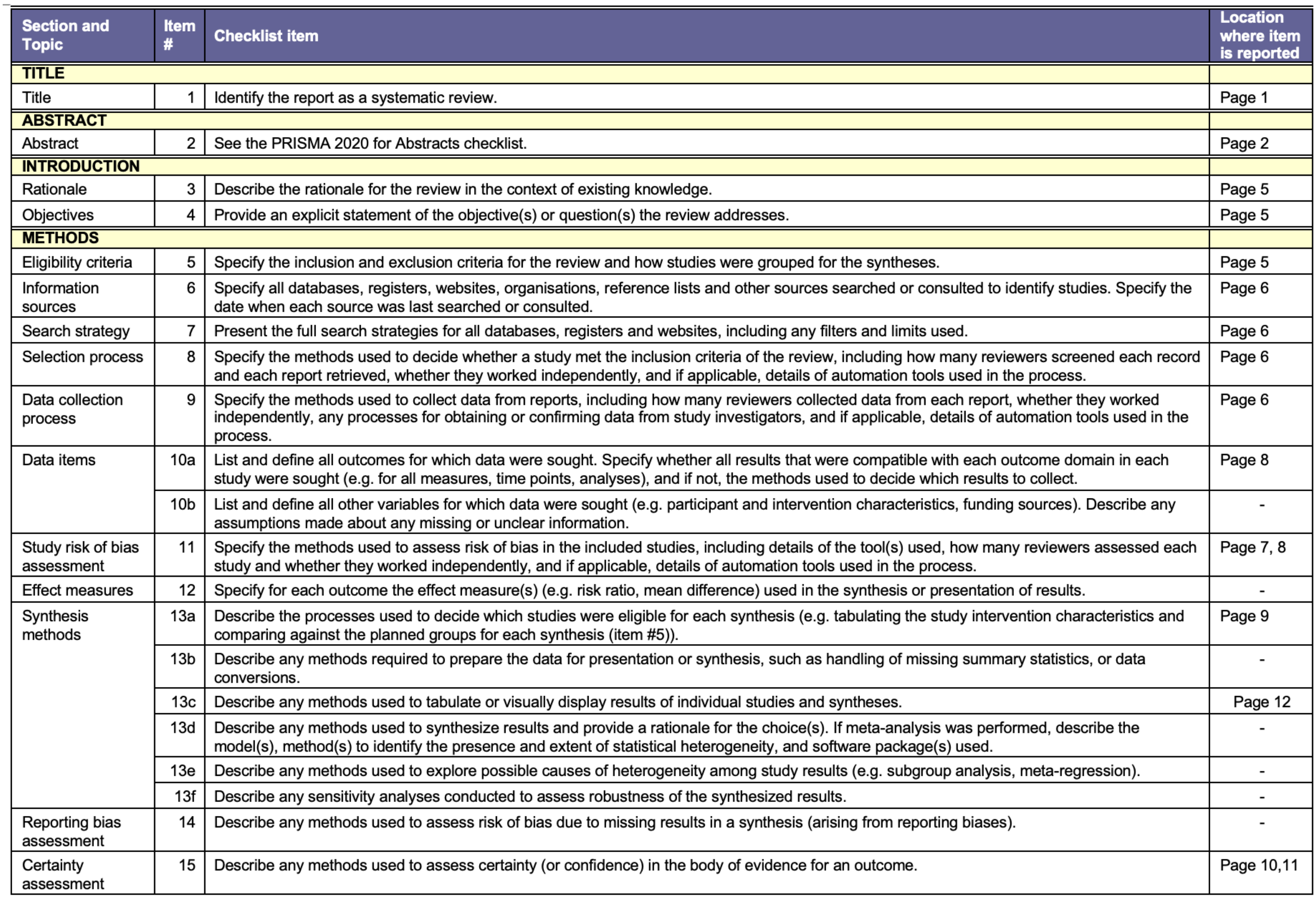
# Appendix A: PRISMA Checklist



| Section and Topic | Item # | Checklist item | Location where item is reported |
|---|---|---|---|
| **TITLE** | | | |
| Title | 1 | Identify the report as a systematic review. | Page 1 |
| **ABSTRACT** | | | |
| Abstract | 2 | See the PRISMA 2020 for Abstracts checklist. | Page 2 |
| **INTRODUCTION** | | | |
| Rationale | 3 | Describe the rationale for the review in the context of existing knowledge. | Page 5 |
| Objectives | 4 | Provide an explicit statement of the objective(s) or question(s) the review addresses. | Page 5 |
| **METHODS** | | | |
| Eligibility criteria | 5 | Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses. | Page 5 |
| Information sources | 6 | Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted. | Page 6 |
| Search strategy | 7 | Present the full search strategies for all databases, registers and websites, including any filters and limits used. | Page 6 |
| Selection process | 8 | Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process. | Page 6 |
| Data collection process | 9 | Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process. | Page 6 |
| Data items | 10a | List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect. | Page 8 |
| | 10b | List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information. | - |
| Study risk of bias assessment | 11 | Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process. | Page 7, 8 |
| Effect measures | 12 | Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results. | - |
| Synthesis methods | 13a | Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)). | Page 9 |
| | 13b | Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions. | - |
| | 13c | Describe any methods used to tabulate or visually display results of individual studies and syntheses. | Page 12 |
| | 13d | Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used. | - |
| | 13e | Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression). | - |
| | 13f | Describe any sensitivity analyses conducted to assess robustness of the synthesized results. | - |
| Reporting bias assessment | 14 | Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases). | - |
| Certainty assessment | 15 | Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome. | Page 10,11 |

| Section and Topic | Item # | Checklist item | Location where item is reported |
|---|---|---|---|
| **RESULTS** | | | |
| Study selection | 16a | Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram. | Page 6 |
| | 16b | Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded. | Page 7 |
| Study characteristics | 17 | Cite each included study and present its characteristics. | Page 9 |
| Risk of bias in studies | 18 | Present assessments of risk of bias for each included study. | Page 10, 11 |
| Results of individual studies | 19 | For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots. | - |
| Results of syntheses | 20a | For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies. | Page 10,11 |
| | 20b | Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect. | - |
| | 20c | Present results of all investigations of possible causes of heterogeneity among study results. | - |
| | 20d | Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results. | - |
| Reporting biases | 21 | Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed. | - |
| Certainty of evidence | 22 | Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed. | Page 10, 11 |
| **DISCUSSION** | | | |
| Discussion | 23a | Provide a general interpretation of the results in the context of other evidence. | Page 17, 18 |
| | 23b | Discuss any limitations of the evidence included in the review. | Page 20, 21 |
| | 23c | Discuss any limitations of the review processes used. | Page 20, 21 |
| | 23d | Discuss implications of the results for practice, policy, and future research. | Page 20 |
| **OTHER INFORMATION** | | | |
| Registration and protocol | 24a | Provide registration information for the review, including register name and registration number, or state that the review was not registered. | Page 5 |
| | 24b | Indicate where the review protocol can be accessed, or state that a protocol was not prepared. | Page 5 |
| | 24c | Describe and explain any amendments to information provided at registration or in the protocol. | - |
| Support | 25 | Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review. | Page 1 |
| Competing interests | 26 | Declare any competing interests of review authors. | Page 1 |
| Availability of data, code and other materials | 27 | Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review. | - |

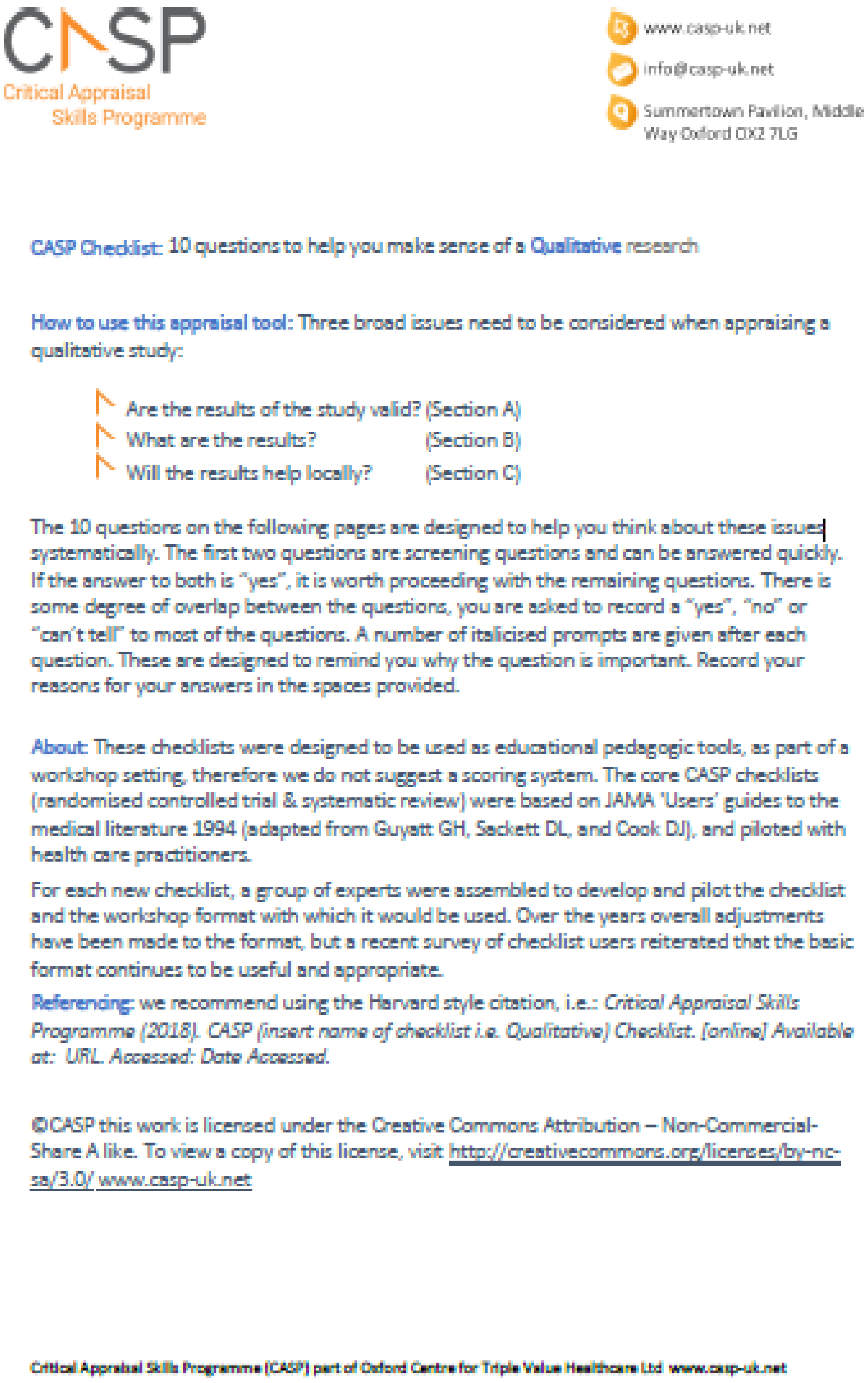
*From:* Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

## Appendix B: Full Search Terms

| **Database** | **Search String** |
|---|---|
| Academic Search Ultimate (EBSCO)<br>MEDLINE (EBSCO)<br>PsycInfo (EBSCO)<br>CINAHL (EBSCO)<br>Scopus | Child* OR paediatric OR pediatric OR youth OR “young people*” OR “young person*” OR adolescen* OR teen* OR student* (Title & Abstract)<br>AND<br>“Brain injur*” OR “head injur*” OR TBI OR ABI OR stroke (Title & Abstract)<br>AND<br>Experien* OR identit* OR percept* OR “sense of self” OR self* OR perceive OR perspective* OR adjust* OR adapt* OR cope OR coping OR view* or "life with" or "living with" or "life after" or "making sense" or "make sense" (Title & Abstract)<br>AND<br>qualitative OR "grounded theory" or "interpretative*" or thematic or theme or interview* or phenomenon* (Title & Abstract)<br>NOT<br>“parental brain*” OR “parent with brain*” (Title & Abstract) |

# Appendix C: CASP Tool



CASP
Critical Appraisal
Skills Programme

www.casp-uk.net
info@casp-uk.net
Summertown Pavilion, Middle Way Oxford OX2 7LG

**CASP Checklist:** 10 questions to help you make sense of a **Qualitative** research

**How to use this appraisal tool:** Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

**About:** These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

**Referencing:** we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

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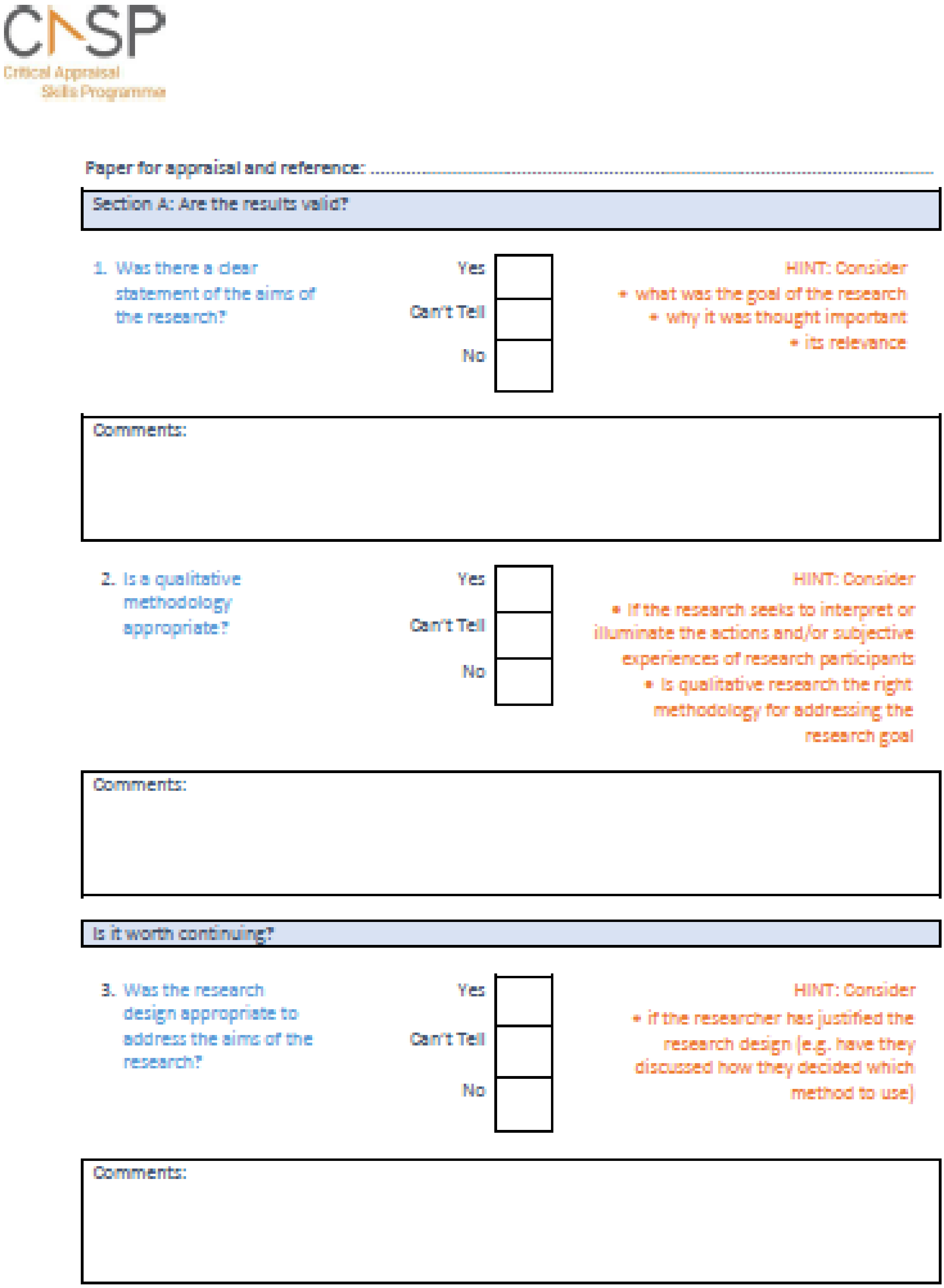
**Critical Appraisal Skills Programme (CASP) part of Oxford Centre for Triple Value Healthcare Ltd www.casp-uk.net**



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Paper for appraisal and reference: ......................................................................................................

**Section A: Are the results valid?**

1. Was there a clear statement of the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

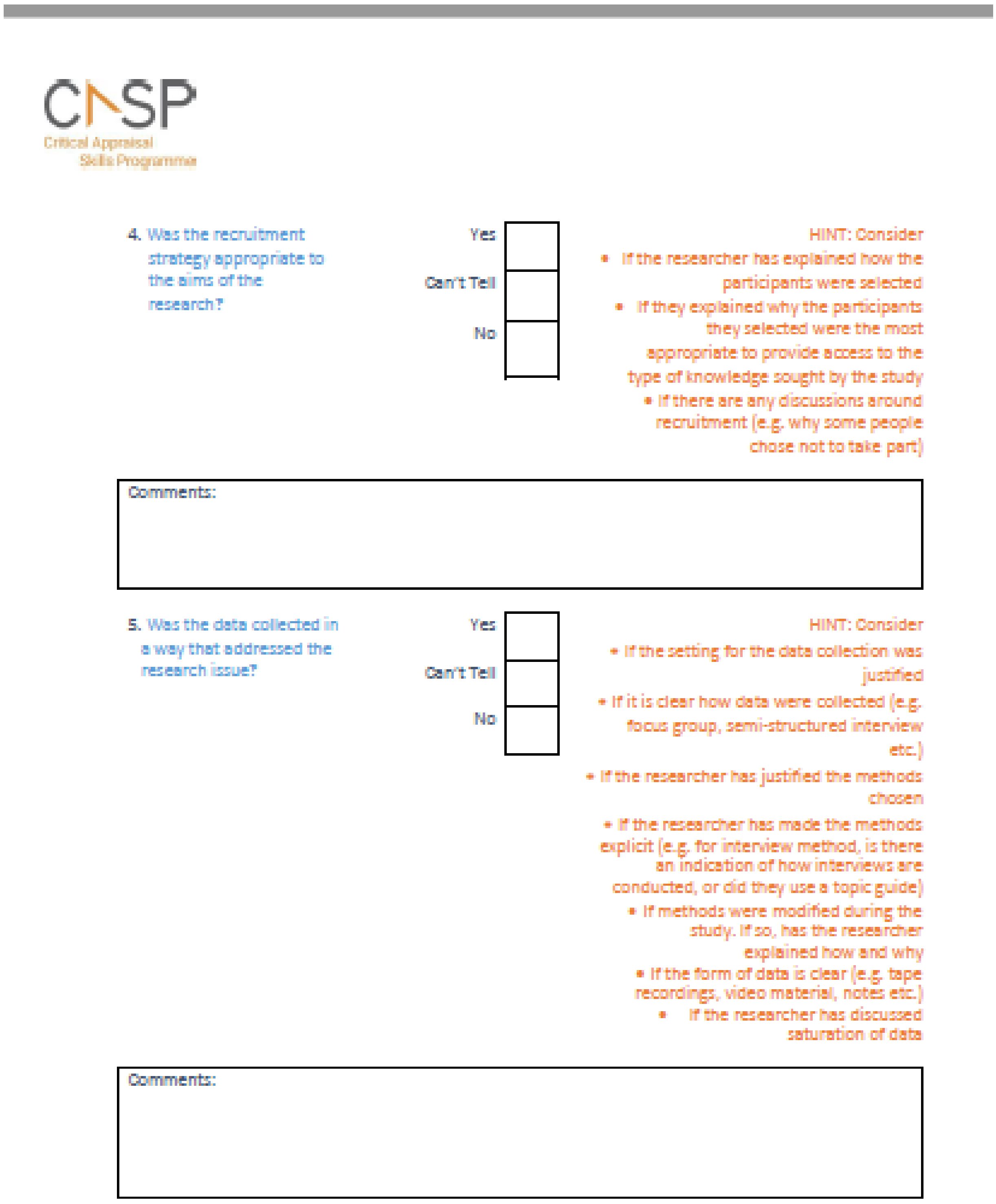
**Is it worth continuing?**

3. Was the research design appropriate to address the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:



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4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

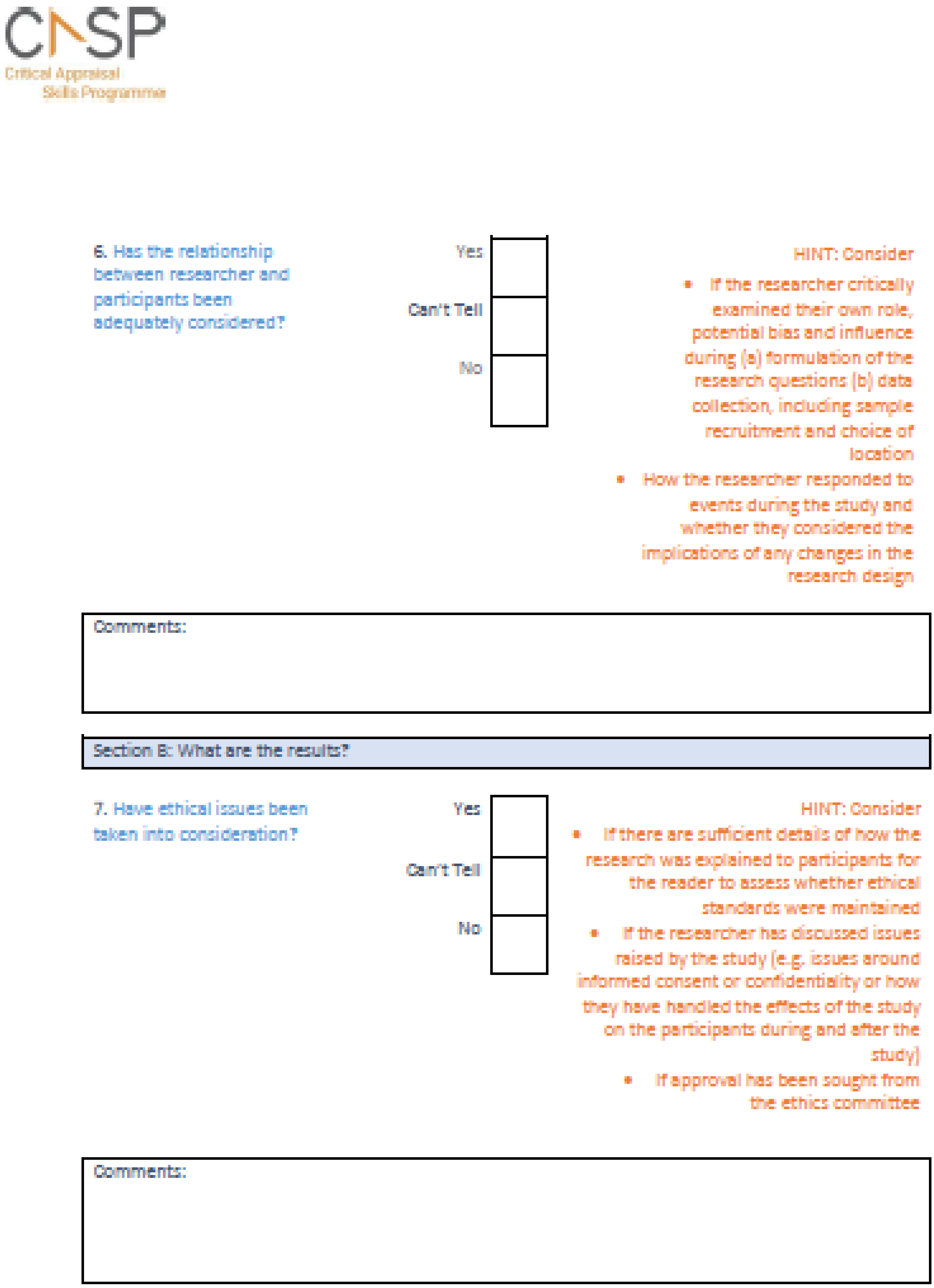
Comments:

5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:



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6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

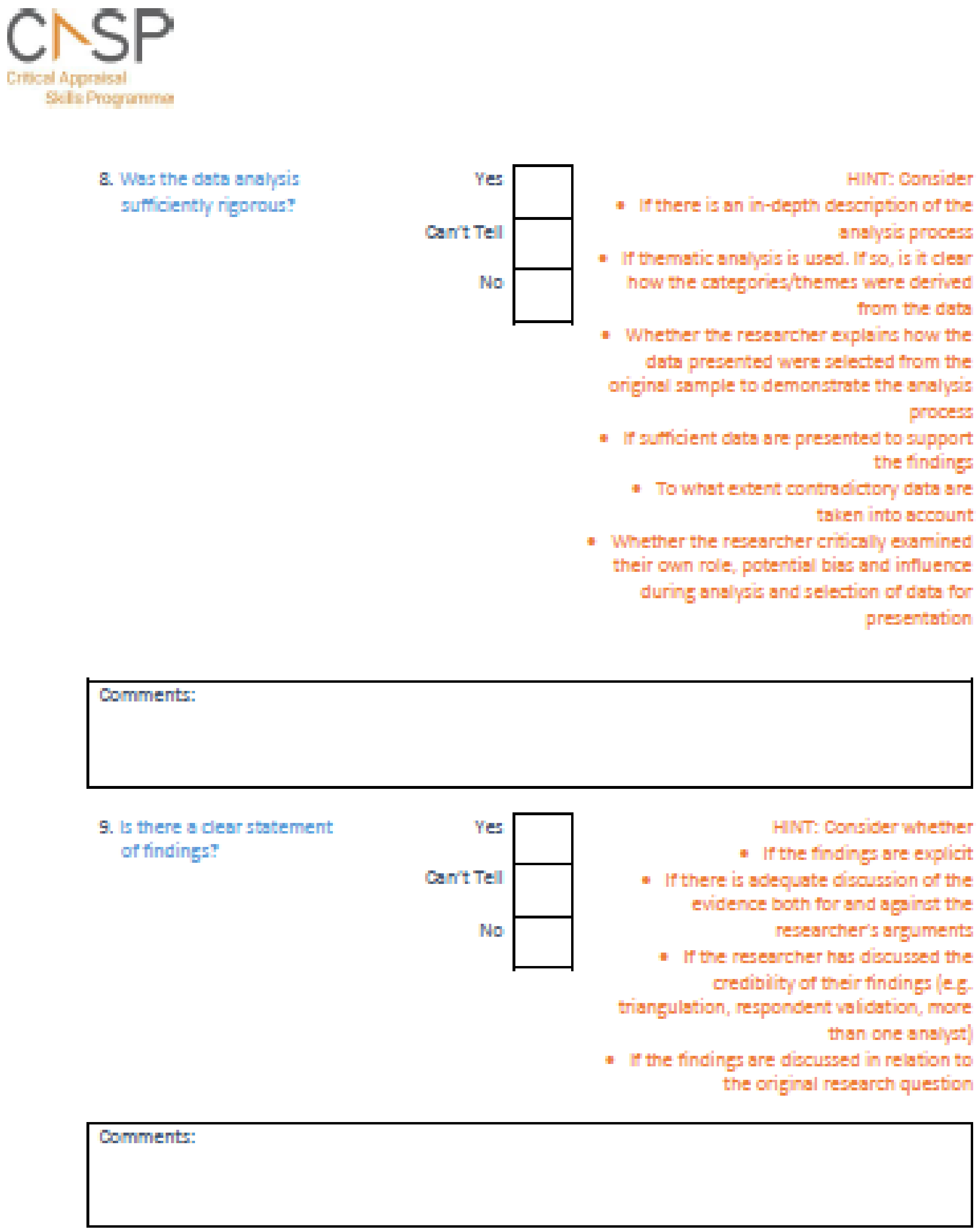
**Section B: What are the results?**

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:



CASP
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Skills Programme

8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

CASP
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**Section C: Will the results help locally?**

| | |
|---|---|
| 10. How valuable is the research? | HINT: Consider<br>• If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature<br>• If they identify new areas where research is necessary<br>• If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used |

Comments:

## Appendix D: CASP Quality Ratings

| | **Core** | | | | | | | **Central** | | | **Peripheral** | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **CASP* questions Yes/Can't Tell/No** | Mealings, Douglas, & Olver, 2017 | Buckeridge, Clarke, & Sellers, 2020 | Di Battista, Godfrey, Soo, Catroppa, & Anderson, 2014 | Williams, 2020 | Glennon, Watson, Fisher, & Gracey, 2022 | Roscigno, Swanson, Vavilala & Solchany, 2011 | Mealings & Douglas, 2010 | Bogan, Livingstone, Parry-Jones, Buston & Wood, 1997 | Gauvin-Lepage & Lefebvre, 2010 | Sharp, Bye, Llewellyn & Cusick, 2005 | Timmermann et al., 2022 | Krenz et al., 2021 | Hartman, Tibbles, Paniccia, & Lindsay, 2015 | Kakonge, Charron, Vedder, Wormald, & Turkstra, 2022 | Rodset, 2008 |
| Was there a clear statement of the aims of the research? | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Is a qualitative methodology appropriate? | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Was the research design appropriate to address the aims of the research? | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | CT | Yes | CT | CT | Yes | Yes | Yes |
| Was the recruitment strategy appropriate to the aims of the research? | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | CT |

| | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Was the data collected in a way that addressed the research issue? | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Has the relationship between researcher and participants been adequately considered? | CT | Yes | CT | Yes | Yes | Yes | CT | No | CT | CT | CT | CT | CT | CT | No |
| Have ethical issues been taken into consideration? | Yes | Yes | Yes | Yes | Yes | CT | Yes | CT | Yes | CT | Yes | Yes | Yes | Yes | CT |
| Was the data analysis sufficiently rigorous? | Yes | Yes | Yes | Yes | Yes | Yes | Yes | CT | No | Yes | Yes | Yes | Yes | Yes | CT |
| Is there a clear statement of findings? | Yes | Yes | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | No | No | Yes | Yes | No |
| How valuable is the research - will the results help locally? | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |

*Key: CASP stands for Critical Appraisal Skills Programme; CT stands for ‘Can’t Tell’

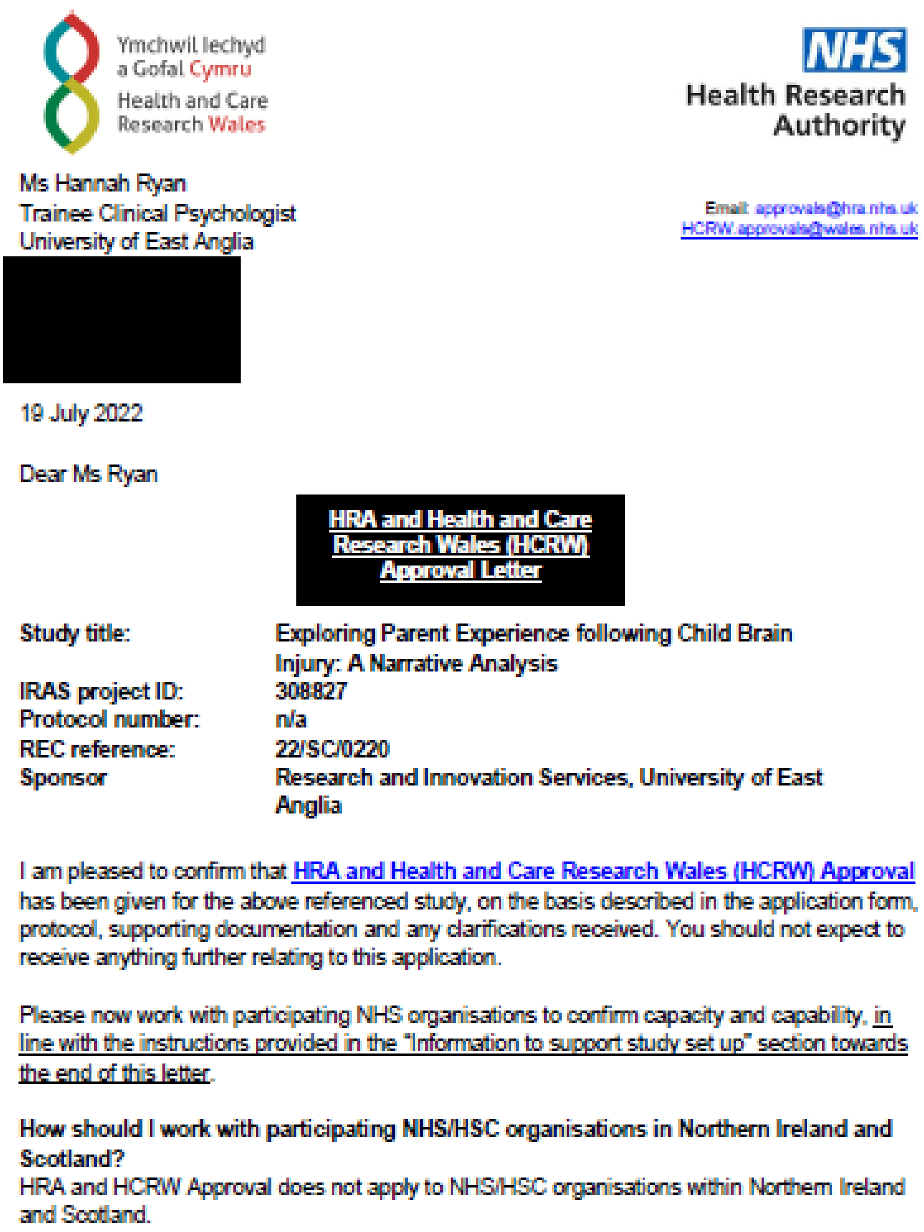
## Appendix E: Extended Table of Study Characteristics

| Paper | Pub type | Country | Data Collection Methods | Analysis | Study focus | Participant Type | Sample size (child only) | Age range | Findings/themes |
|---|---|---|---|---|---|---|---|---|---|
| Mealings, Douglas, & Olver, 2017 | Peer-reviewed | Australia | Semi-structured interviews | Grounded theory | Education participation | YP with severe TBI | 3 | 13-17 | Adolescent student sense of self, changes and support |
| Mealings & Douglas, 2010 | Peer-reviewed | Australia | Semi-structured interviews | Grounded theory | Experience of school | YP with severe TBI | 3 | 13-17 | Poor community awareness of TBI, the invisible nature of TBI, getting back to everyday life, planning to return to education, being accepted and adjusting to long-term changes |
| Kakonge, Charron, Vedder, Wormald, & Turkstra, 2022 | Peer-reviewed | Canada | Mapping review | Thematic synthesis | Identity | Mixed YP and caregivers | - | 14-18 | Adolescents post-TBI are likely to: (1) question their identity considering dissonance between the current self and their pre-injury self; and (2) seek new, adaptive meanings and identities |
| Gauvin-Lepage & Lefebvre, 2010 | Peer-reviewed | Canada | Semi-structured interviews | Not stated | Social inclusion | Mixed YP with mod TBI, caregivers & professionals | 3 | 14-15 | Perceptions of adolescents affect personal experiences, the family, friends, the environment and school and may limit social inclusion |
| Buckeridge, Clarke, & Sellers, 2020 | Peer-reviewed | UK | Semi-structured interviews | IPA | Communication/speech and language | YP with mod/severe TBI | 6 | 11-18 | Three main themes: the social world; communication competence; and life in the classroom. |
| Timmermann et al., 2022 | Peer-reviewed | Germany | Semi-structured interviews in focus groups | Not stated | Health related Quality of Life | YP with mild/mod/severe TBI and caregivers | 8 with mod/ severe | 5-17 | TBI group reported a broader range of aspects concerning HRQoL than the comparison groups (e.g., negative emotions such as sadness and shame, reduced self-esteem after TBI, cognitive fatigue) |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Krenz et al., 2021 | Peer-reviewed | Germany | Semi-structured interviews in focus groups | Qualitative' informed by Witzel and Reiter | Health related Quality of Life | Mixed YP with mild/mod/severe TBI and caregivers | 19 | 5-17 | TBI affects various areas of life, for example in the field of cognition, such as memory disorders, attention problems, or physical limitations and pain. These in turn can negatively affect self-esteem, social and family networks. |
| Hartman, Tibbles, Paniccia, & Lindsay, 2015 | Peer-reviewed | Canada | Systematic review and data extraction | Thematic synthesis | Transition from hospital to school | Mixed YP with mod/severe ABI and caregivers | - | 6-20 | a. Six themes emerged: (a) lack of ABI-specific education for families and professionals, (b) communication-related factors as a facilitator and/or barrier to transition, (c) emotional focus, (d) peer relationships, (e) supports, and (f) ABI sequelae in the classroom |
| Di Battista, Godfrey, Soo, Catroppa, & Anderson, 2014 | Peer-reviewed | Australia | Semi-structured interviews | IPA | Phenomenology of life after a TBI | YP with mod/severe TBI | 10 | 13-19 | Family and relationship changes, altered roles, responsibilities, independence, coping and post-traumatic growth |
| Williams, 2020 | Doctoral thesis | UK | Semi-structured interviews | IPA | Lifeworld of young person after TBI | Mixed YP with mod/severe TBI and caregivers | 3 | 11-13 | Impact of restrictions, relational Impact of restrictions and resilience and post-traumatic changes |
| Glennon, Watson, Fisher, & Gracey, 2022 | Peer-reviewed | UK | Semi-structured interviews | Grounded theory | Identity adjustment | Mixed YP with mod/severe TBI and caregivers | 6 | 15-18 | Tension between continuity and change, acknowledging or rejecting discrepancies |
| Bogan, Livingstone, Parry-Jones, Buston & Wood, 1997 | Peer-reviewed | UK | Semi-structured interviews | General qualitative using NUD.IST software | Long-term outcomes | YP with mild/mod/severe TBI | 31 | 13-20 | Challenges fitting back in at school. This was either facilitated or hindered by the extent and quality of support |
| Rodset, 2008 | Peer-reviewed | Norway | Semi-structured interviews | Phenomenological but non-specific | Return to school | YP with severe TBI | 6 | Mean age 15 | Academic difficulties, but social aspects were of more concern. Optimism used to cope. |
| Sharp, Bye, Llewellyn & Cusick, 2005 | Peer-reviewed | Australia | Semi-structured interviews | Grounded theory | Return to school | YP with severe TBI | 8 | 14-17 | Challenges fitting back in at school. This was either facilitated or hindered by the extent and quality of support |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Roscigno, Swanson, Vavilala & Solchany, 2011 | Peer-reviewed | USA | Semi-structured interviews | Descriptive phenomenological | Child perspective of ABI | YP with mod/severe TBI | 39 | 6-18 | Profound sudden changes in ecological environments, not always prepared for the negative responses of others, learned ways to adjust and find positive meaning |

# Appendix F: HRA Ethical Approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

Ms Hannah Ryan
Trainee Clinical Psychologist
University of East Anglia
[redacted]

19 July 2022

Dear Ms Ryan

## HRA and Health and Care Research Wales (HCRW) Approval Letter

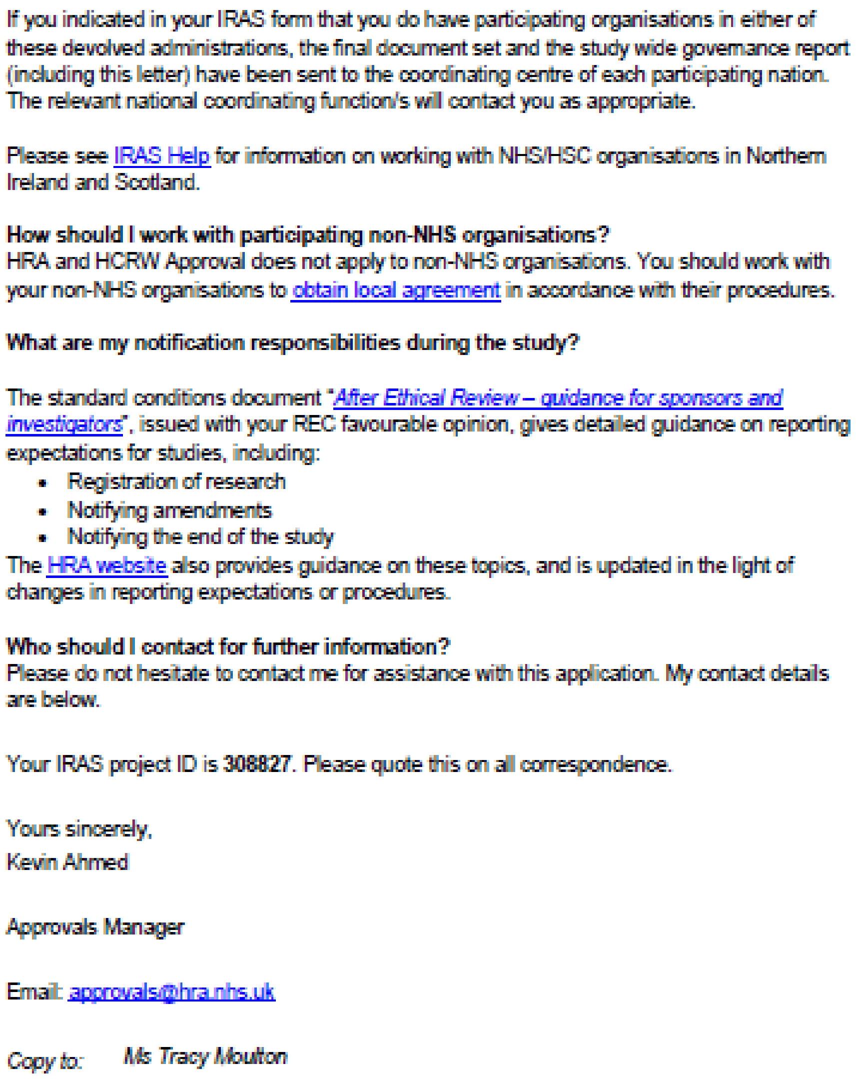
| | |
|---|---|
| **Study title:** | **Exploring Parent Experience following Child Brain Injury: A Narrative Analysis** |
| **IRAS project ID:** | **308827** |
| **Protocol number:** | **n/a** |
| **REC reference:** | **22/SC/0220** |
| **Sponsor** | **Research and Innovation Services, University of East Anglia** |

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

**How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?**

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.



If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

**How should I work with participating non-NHS organisations?**
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

**What are my notification responsibilities during the study?**

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

**Who should I contact for further information?**
Please do not hesitate to contact me for assistance with this application. My contact details are below.

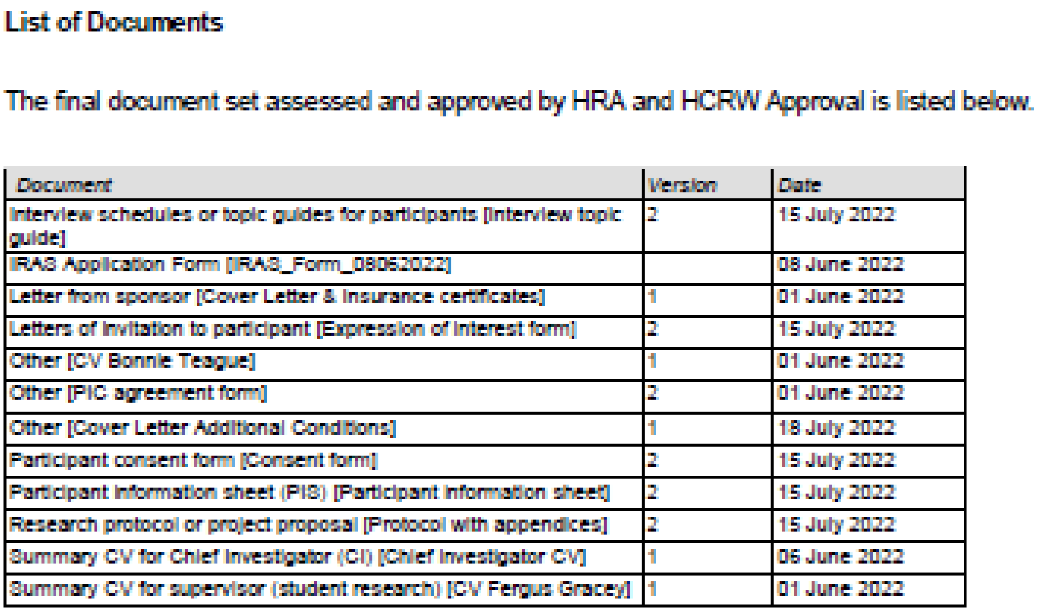
Your IRAS project ID is **308827**. Please quote this on all correspondence.

Yours sincerely,
Kevin Ahmed

Approvals Manager

Email: approvals@hra.nhs.uk

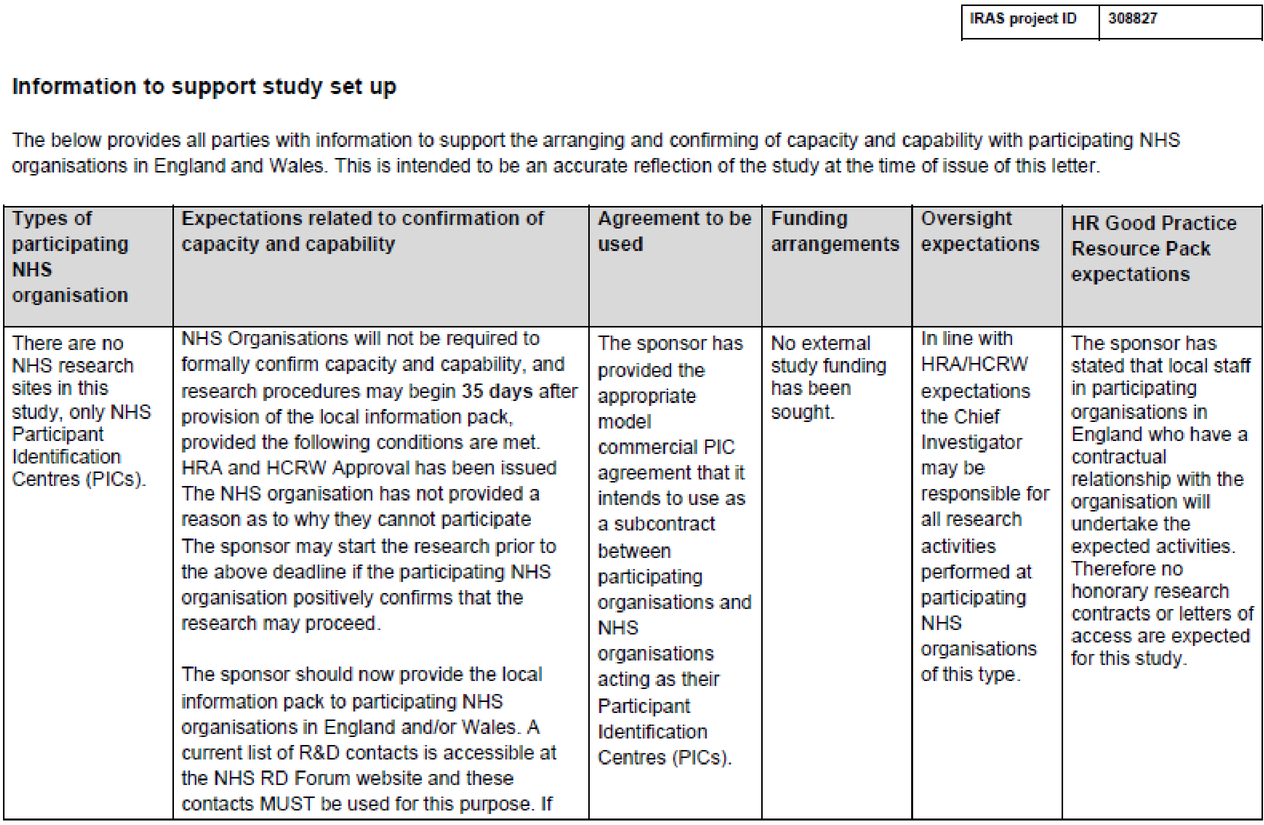
*Copy to:* *Ms Tracy Moulton*



**List of Documents**

The final document set assessed and approved by HRA and HCRW Approval is listed below.

| *Document* | *Version* | *Date* |
|---|---|---|
| Interview schedules or topic guides for participants [Interview topic guide] | 2 | 15 July 2022 |
| IRAS Application Form [IRAS_Form_08062022] |  | 08 June 2022 |
| Letter from sponsor [Cover Letter & Insurance certificates] | 1 | 01 June 2022 |
| Letters of invitation to participant [Expression of interest form] | 2 | 15 July 2022 |
| Other [CV Bonnie Teague] | 1 | 01 June 2022 |
| Other [PIC agreement form] | 2 | 01 June 2022 |
| Other [Cover Letter Additional Conditions] | 1 | 18 July 2022 |
| Participant consent form [Consent form] | 2 | 15 July 2022 |
| Participant information sheet (PIS) [Participant information sheet] | 2 | 15 July 2022 |
| Research protocol or project proposal [Protocol with appendices] | 2 | 15 July 2022 |
| Summary CV for Chief Investigator (CI) [Chief Investigator CV] | 1 | 06 June 2022 |
| Summary CV for supervisor (student research) [CV Fergus Gracey] | 1 | 01 June 2022 |

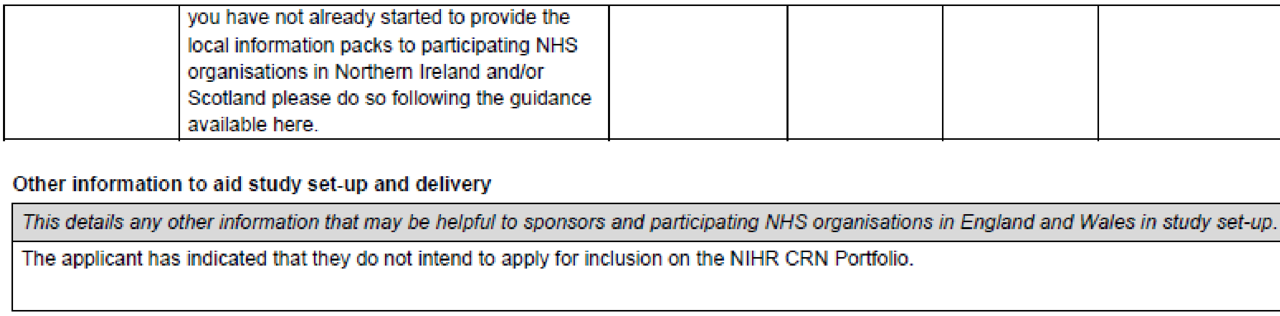


| IRAS project ID | 308827 |
|---|---|

**Information to support study set up**

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

| Types of participating NHS organisation | Expectations related to confirmation of capacity and capability | Agreement to be used | Funding arrangements | Oversight expectations | HR Good Practice Resource Pack expectations |
|---|---|---|---|---|---|
| There are no NHS research sites in this study, only NHS Participant Identification Centres (PICs). | NHS Organisations will not be required to formally confirm capacity and capability, and research procedures may begin **35 days** after provision of the local information pack, provided the following conditions are met.<br>HRA and HCRW Approval has been issued<br>The NHS organisation has not provided a reason as to why they cannot participate<br>The sponsor may start the research prior to the above deadline if the participating NHS organisation positively confirms that the research may proceed.<br>The sponsor should now provide the local information pack to participating NHS organisations in England and/or Wales. A current list of R&D contacts is accessible at the NHS RD Forum website and these contacts MUST be used for this purpose. If you have not already started to provide the local information packs to participating NHS organisations in Northern Ireland and/or Scotland please do so following the guidance available here. | The sponsor has provided the appropriate model commercial PIC agreement that it intends to use as a subcontract between participating organisations and NHS organisations acting as their Participant Identification Centres (PICs). | No external study funding has been sought. | In line with HRA/HCRW expectations the Chief Investigator may be responsible for all research activities performed at participating NHS organisations of this type. | The sponsor has stated that local staff in participating organisations in England who have a contractual relationship with the organisation will undertake the expected activities. Therefore no honorary research contracts or letters of access are expected for this study. |



**Other information to aid study set-up and delivery**

| *This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.* |
|---|
| The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio. |

## Appendix G: Participant Information Sheet

# Research Study

# Exploring Parent Experience following Child Brain Injury

### Summary

My name is Hannah Ryan and I am carrying out research as part of my Doctorate in Clinical Psychology at the University of East Anglia (UEA). The aim of the planned research is to gain a deeper understanding of parents' stories of theirs and their family's experiences after their child has sustained a brain injury. The study has been approved by an NHS ethics committee.

### Purpose of the study

We are doing this research because we know that families can go through different experiences after child brain injury. Although we know about some of the difficulties parents face, we think there is a lot more to learn through listening to parents' stories about what it has been like for them and how they make sense of their experiences.

### What would taking part involve?

If you agree to take part, you will meet with me for two interviews to talk about you and your family's experience of your child's brain injury. You can decide the time and place of the interviews. These could be online or at your home, or at your child's brain injury service. If you wish to answer questions via email, this is also possible and will be kept secure on the University email provider. The two interviews will be at least one week apart. I will audio record the interviews so that these can be transcribed and analysed. Once interviews are all complete, I will look at themes and connections between parents' experiences. The findings will be shared with those who participated in the study in any way, including those who were interviewed as well as the healthcare teams who supported the study. The findings may be published in an academic journal. If you do not wish to take part, this will not impact you or your child's healthcare in any way.

### Are there benefits to taking part?

We are doing this research because we want to understand family experience better in order to help improve services and supports that are offered. Some people find it helpful to contribute to improving understanding of childhood brain injury and the impact on family. There are no financial gains to participating, however as a thank you gesture if you take part you will receive a £10 Amazon voucher. Unfortunately, we cannot offer additional care or solutions for any difficulties you might be experiencing. If you decide to travel to your child's brain injury service for your interview, we won't be able to reimburse costs for travel or parking.

### Are there any risks to taking part?

It is possible that you might talk about experiences which bring up difficult emotions. However, you are able to stop the interview, change the topic or take a break at any time without giving a reason. You do not have to answer any questions you do not feel comfortable to. After the interview you will be given a list of local and national sources of support. If you mention anything during the interview which makes me concerned about your safety or for anyone else's, I have a legal duty to pass this on to the relevant authority. However, I would discuss this with you first.

### How will we use information about you?

In this research study we will use information from you. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules. At the end of the study we will save some of the data in case we need to check it. We will make sure no-one can work out who you are from the reports we write. If you choose to answer questions via email, this information will be protected by an encrypted University email provider.

If the interview takes place in your home or online it is important that no one else in the household can overhear, including children. This is to protect your confidentiality and ensure you can speak freely. If you decide you would like to be interviewed at a clinical site it is important that you are able to attend the interview alone. Once the data has been analysed, it may be shared in an academic journal, conference or other presentations. Anonymous short extracts or quotes from your interviews may be shared as part of this.

**What are your choices about how your information is used?**

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about you.

**Where can you find out more about how your information is used?**

You can find out more about how we use your information at:

- www.hra.nhs.uk/information-about-patients/
- by asking one of the research team: Hannah.ryan@uea.ac.uk
- by contacting the Data Protection Officer, Ellen Paterson at dataprotection@uea.ac.uk or 07824527234

**Are there any other details I need to consider?**

It is encouraged that you speak to your child about your participation in the research. We do not need consent from your children to interview you, as we are not accessing their health records. However, if you wish to give them the opportunity to ask me questions then we can arrange that they attend the first part of your meeting with me. They cannot be present for the main interview.

If both parents/caregivers would like to take part in the study, you can choose whether to be interviewed together or individually.

If you decide to take part and then change your mind, you can withdraw at any time during the interview and for 14 days afterwards. If you do withdraw, your data will be destroyed and will not be used.

**If you are interested in taking part in the study, you are welcome to contact the researcher by email at: Hannah.ryan@uea.ac.uk. Or, you can fill out the Expression of Interest form on the next page and give this back to your clinician.**

## Appendix H: Expression of Interest Form

# Expression of Interest Form

## Exploring Parent Experience following Child Brain Injury

If you are interested in taking part in the study, you are welcome to contact the researcher by email at:

Hannah.ryan@uea.ac.uk

If you are interested in taking part in the study but would prefer the researcher to contact you first, please fill out this form and give it back to your clinician.

By signing this form, I am agreeing to be contacted for research purposes regarding the above study.

My preferred methods of contact are as below:

**Email** ________________________________________

**Text**__________________________________________

**Telephone**_____________________________________

**Other**_________________________________________

| | | |
|---|---|---|
| ____________________ | ____________________ | ____________________ |
| **Name of Participant** | **Date** | **Signature** |
| ____________________ | ____________________ | ____________________ |
| **Name of Person taking consent** | **Date** | **Signature** |

## Appendix I: Consent Form

**Title of Project:**

**Exploring Parent Experience following Child Brain Injury: A Narrative Analysis**

**Name of Researcher: Hannah Ryan**

Initial

1. **I confirm that I have read the information sheet of the above study. I have had time to consider my decision and have my questions answered.** ☐
2. **I understand that taking part is voluntary and I can stop the interview or withdraw for up to 14 days afterwards without giving a reason. I understand that this will not affect my own or my child's healthcare.** ☐
3. **I understand that if the researcher feels concerned for my safety, or the safety of someone else, they have a duty to pass this information onto the relevant authority. I understand that they would discuss this with me first.** ☐
4. **I understand that my personal details will not be shared with anyone outside of the study team.** ☐
5. **I agree for the interview to be audio recorded. I agree that online interviews may also be video recorded.** ☐
6. **I agree for my speech or written text to be quoted anonymously in publications.** ☐

**By signing this declaration, I am agreeing to take part in the above study.**

| | | |
|---|---|---|
| ____________________ | ____________________ | ____________________ |
| **Name of Participant** | **Date** | **Signature** |
| ____________________ | ____________________ | ____________________ |
| **Name of Person taking consent** | **Date** | **Signature** |

# Appendix J: Interview Topic Guides

## Interview 1

### Pre-interview and warm-up questions

- Nice to see/meet you, I'm Hannah/how are you today/were you able to find the room easily [if at clinic base]?
- Are you able to see and hear me ok [if online]? Is there anything we can do before we get started to help you feel comfortable before the interview/would you like a drink of water nearby during the interview/do you know where the loos are if needed [if at clinic base]?
- Can I check that you've been able to read through the information and informed consent sheet/do you have any questions about this before we start?
- You're welcome to take a break or stop at any point; you don't need to give me a reason for this. Today will be guided by you rather than directed by me, but I might ask questions to explore some of the things you have told me. You don't have to answer anything you don't want to and don't need to give a reason for this.
- Is there anything else you'd like to discuss before we start recording? Are you happy for me to begin recording and start the interview?

### Interview

- Can you tell me the story of your experience with your child's brain injury?

Possible prompts, guided by participant's story:

- Earlier you said ____ made you feel ____, could you tell me more about that?
- It seemed like _____ was important, could you tell me a bit more about that?
- I can hear that _____ has been helpful, are you able to describe why?
- You described that _____ changed, how do you make sense of that change?

## Interview 2

### Pre-interview and warm-up questions

- Nice to see you again/how are you today?
- Are you able to see and hear me ok [if online]? Is there anything we can do before we get started to help you feel comfortable before the interview/would you like a drink of water nearby during the interview?
- Last time you started to tell me your story of [child's name] brain injury. Today is an opportunity for you to continue with that if you like or add to what we've spoken about. I might ask some more questions about your story today to make sure I've fully understood your experiences. As with last time, you're welcome to take a break, change topics or stop at any point without giving a reason.
- Would you like to ask any questions before we start? Are you happy for me to begin recording and start the interview?

### Interview

- Following on from our last interview, is there anything which was not discussed last time that you would like to talk about today?
- Last time we spoke, you mentioned ________. Could you tell me more about this?

Possible additional prompts:

- What has life been like for you after your child's brain injury?
- Can you tell me about any changes you have noticed about yourself?
    a. Is there anything surprising or new you have learned about yourself/your family/your child since the BI?
- How have your relationships been affected – with friends/family/at work/others?
- How have your experiences affected how you deal with change/life/challenges now?
- What do you think has contributed to the changes mentioned?
    a. Who or what have you found most helpful/unhelpful?
- What would you say are the most important things you have taken from your experience?

## Appendix K: Participant Debrief Form

Thank you for giving up your time to participate in this study. Please feel welcome to contact me at a later date by email or phone if you have any other questions about this research.

The aim of the study is to gain a better understanding of what it is like for parents and caregivers following their child's brain injury. By looking at themes and patterns in people's stories, we hope to get a bigger picture of family life after brain injury.

If you would like to withdraw from the study, you have 14 days to do so. Withdrawing from the study will not affect your child's care in any way and you don't have to provide a reason if you do decide to withdraw.

I can provide you with a summary of the findings of the study once analysis is complete if you would be interested in this. Please let me know if you would prefer to receive this by email or over the phone.

If you have any concerns about your psychological wellbeing after this interview, please contact your GP or your child's brain injury service. You can also view some further sources of support in the rest of this document.

**Wellbeing Service**

NHS service providing many types of psychological support and advice.

You can refer yourself online or contact using the details below:

[redacted]

**Mind**
Mental health charity offering wellbeing advice and support.
Web: [redacted]

[redacted]

*available 9.30am – 5.30pm, Mon-Fri (closed Bank Holidays)

[redacted]

*available 9 am – 3pm, Mon-Fri (closed Bank Holidays)

**Child Brain Injury Trust**

Providing emotional and practical support, information and learning opportunities for families and professionals affected by childhood acquired brain injury across the UK.

Web: https://childbraininjurytrust.org.uk/

Tel: 01869 341075

**Headway**

Providing support after brain injury
Web: https://www.headway.org.uk/
Tel: 0808 800 2244

## Immediate Support

**First Response Helpline:** NHS service providing immediate mental health support over the phone 24/7
Tel: 0808 196 3494

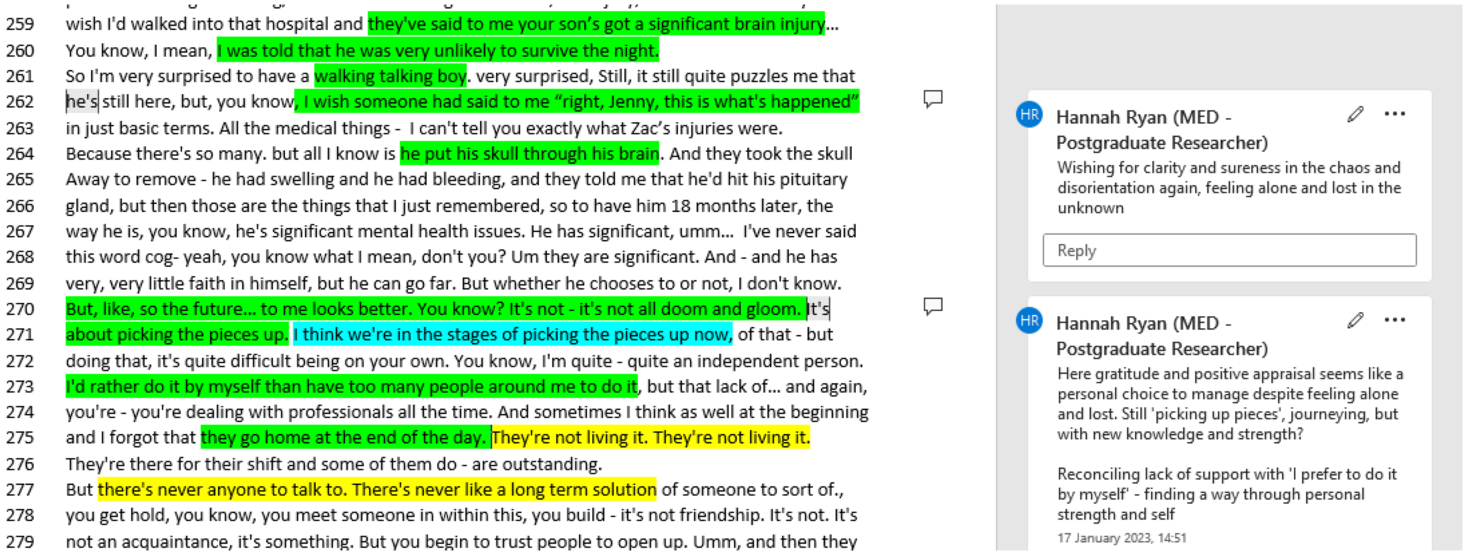
**The Samaritans:** free and confidential support 24 hours a day, every day of the year
Tel: 116 123
https://www.samaritans.org/

**Shout:** free and confidential text support service 24 hours a day, every day of the year

Text: 85258

https://giveusashout.org/

# Appendix L: Example of Initial Noting and Reflexive Diary



wish I'd walked into that hospital and they've said to me your son's got a significant brain injury... You know, I mean, I was told that he was very unlikely to survive the night. So I'm very surprised to have a walking talking boy. very surprised, Still, it still quite puzzles me that he's still here, but, you know, I wish someone had said to me "right, Jenny, this is what's happened" in just basic terms. All the medical things - I can't tell you exactly what Zac's injuries were. Because there's so many. but all I know is he put his skull through his brain. And they took the skull Away to remove - he had swelling and he had bleeding, and they told me that he'd hit his pituitary gland, but then those are the things that I just remembered, so to have him 18 months later, the way he is, you know, he's significant mental health issues. He has significant, umm... I've never said this word cog- yeah, you know what I mean, don't you? Um they are significant. And - and he has very, very little faith in himself, but he can go far. But whether he chooses to or not, I don't know. But, like, so the future... to me looks better. You know? It's not - it's not all doom and gloom. It's about picking the pieces up. I think we're in the stages of picking the pieces up now, of that - but doing that, it's quite difficult being on your own. You know, I'm quite - quite an independent person. I'd rather do it by myself than have too many people around me to do it, but that lack of... and again, you're - you're dealing with professionals all the time. And sometimes I think as well at the beginning and I forgot that they go home at the end of the day. They're not living it. They're not living it. They're there for their shift and some of them do - are outstanding. But there's never anyone to talk to. There's never like a long term solution of someone to sort of., you get hold, you know, you meet someone in within this, you build - it's not friendship. It's not. It's not an acquaintance, it's something. But you begin to trust people to open up. Umm, and then they

HR Hannah Ryan (MED - Postgraduate Researcher)

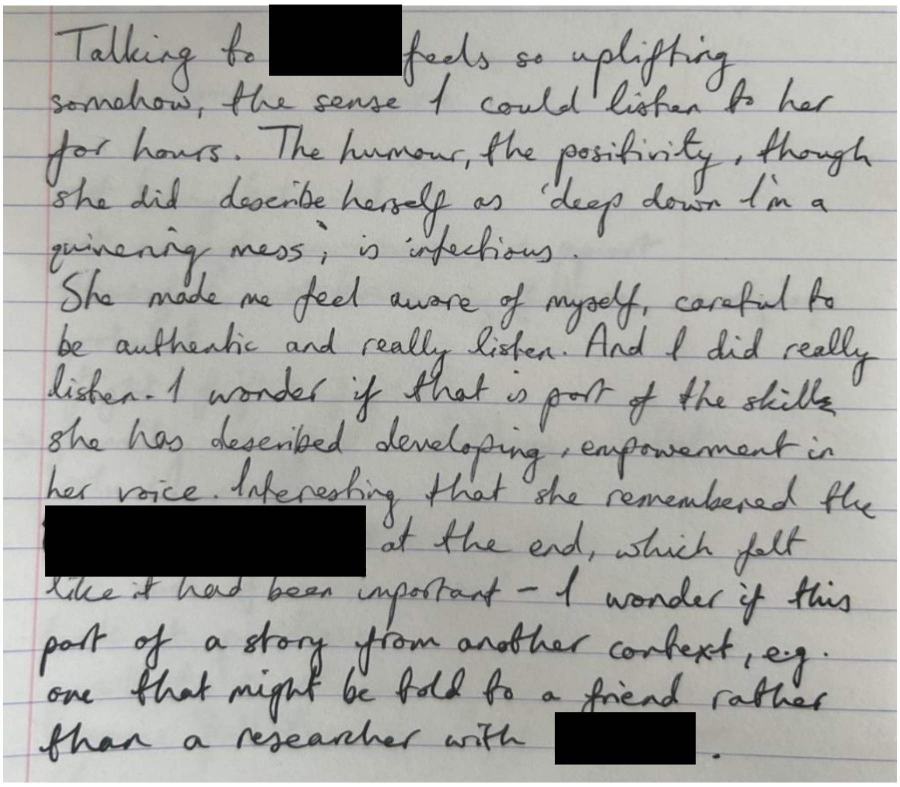
Wishing for clarity and sureness in the chaos and disorientation again, feeling alone and lost in the unknown

HR Hannah Ryan (MED - Postgraduate Researcher)

Here gratitude and positive appraisal seems like a personal choice to manage despite feeling alone and lost. Still 'picking up pieces', journeying, but with new knowledge and strength?

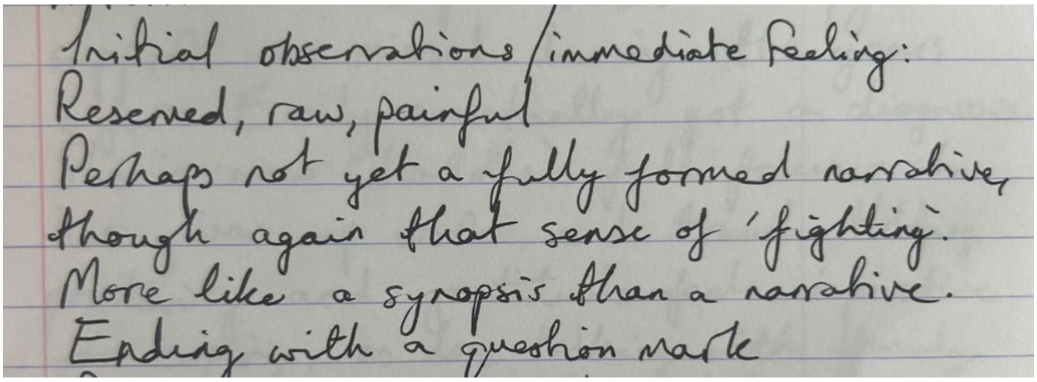
Reconciling lack of support with 'I prefer to do it by myself' - finding a way through personal strength and self

17 January 2023, 14:51

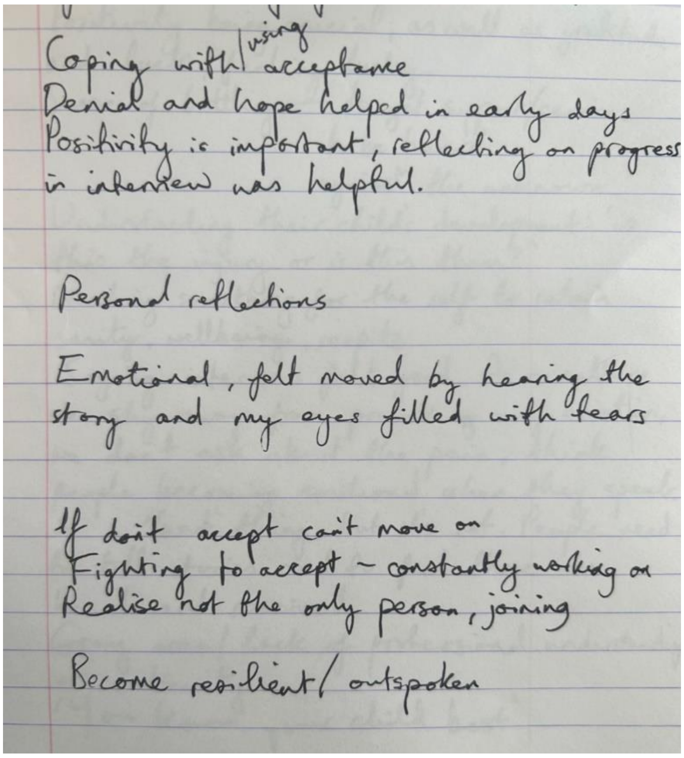


Talking to [redacted] feels so uplifting somehow, the sense I could listen to her for hours. The humour, the positivity, though she did describe herself as 'deep down I'm a quivering mess', is infectious.

She made me feel aware of myself, careful to be authentic and really listen. And I did really listen. I wonder if that is part of the skills she has described developing, empowerment in her voice. Interesting that she remembered the [redacted] at the end, which felt like it had been important – I wonder if this part of a story from another context, e.g. one that might be told to a friend rather than a researcher with [redacted].



Initial observations/immediate feeling:
Reserved, raw, painful
Perhaps not yet a fully formed narrative,
though again that sense of 'fighting'.
More like a synopsis than a narrative.
Ending with a question mark



Coping with/using acceptance
Denial and hope helped in early days
Positivity is important, reflecting on progress
in interview was helpful.

Personal reflections

Emotional, felt moved by hearing the
story and my eyes filled with tears

If don't accept can't move on
Fighting to accept ~ constantly working on
Realise not the only person, joining

Become resilient/ outspoken

## Appendix M: Example Table of Key Events, Imagery and Themes

| **Phase ID** | **Key events** | **Imagery** | **Themes** |
|---|---|---|---|
| Before Zac's injury | Jenny suspecting ADHD<br>Managing Zac's risks<br>Not being heard around ADHD | 'Bouncing Tigger'<br>Doctor putting hand on Jenny's knee<br>'Knowing something' would happen | Not being heard<br>Knowing son<br>Predicting risk |
| The injury and immediately after | Discovery of injury<br>Accompanying Zac to hospital<br>Battling with staff<br>Becoming assertive | Sound of helicopter 'I just knew'<br>Being in 'Japan'<br>Taking mask off to shout at doctor<br>Person with no legs in next bed | The scene<br>Disorientation<br>Chaos<br>Horror<br>Battling |
| Rehab | Negativity of parents (and staff?)<br>Unsuitable rehab environment<br>Choosing to stay together | Only alluded to: 'traumatic', 'as traumatic as the event'<br>Humour: putting a song on for the wheelchair, jokes<br>Smoking, hiding from a parent | Triumph using personal strengths<br>Choosing narrative – positivity<br>Avoiding negativity<br>Continuing battle<br>Knowing child best |
| Present home life | Changes to work<br>Changes to home life | Flat covered in work materials<br>Got to get out will go 'cuckoo' | Retaining own identity |
| Reflections on past and future | | Avoiding negative stories of recovery<br>When Zac moves out/college | Moral message<br>Coping/continuous path<br>Hope<br>Choosing positive narrative |

## Appendix N: Example Narrative Summary

*NOTE: Identifiable details of the story have been omitted*

One evening, when Zac was 14, he went out [redacted]. He told Jenny he was with a friend. Otherwise she wouldn't have let him go. Jenny heard a helicopter and knew instantly that it was for Zac. The next thing she knew, Jenny was in the back of a police car following the air ambulance to the hospital. Zac had [redacted], fracturing his skull right through to the brain.

The next few hours and days were a blur. Jenny and Zac were in a hospital, but had no idea where – it could have been Japan for all she knew. She was told Zac would likely not survive the night. Jenny made calls to family so that they could say their goodbyes.

Zac did survive, but Jenny had already accepted that life was about the change significantly.

In hospital, Jenny was no longer 'Jenny'. She became simply, 'Mum'. No one in the hospital called her by her first name, and eventually she gave up introducing herself.

Again, it felt to Jenny like no one listened to her. Zac was moved around different wards. One rainy afternoon he was moved to an adult trauma ward. Jenny felt he would be better suited to the paediatric ICU, but no one listened. In the bed next to Zac was a woman who had lost her legs. A football match played on the television, and the medics stood around watching it. Jenny begged for Zac to be moved. One doctor wanted to prescribe [redacted] for Zac, but Jenny knew her son. She knew this wouldn't be right for him because [redacted], and begged the doctor not to. It was a battle; Jenny took off her mask to shout. She decided she no longer cared about being likeable, she was no longer intimidated by the hierarchies of medical professionals – Jenny knew her son. The doctors might have seen 1000 types of brain injury, but they did not know Zac as she did. The doctor agreed not to give Zac [redacted], and after that, Jenny felt she had found her voice. From then on, she always spoke up about what she thought was right for Zac.

Zac was discharged from hospital [redacted]. Being just the two of them at home felt like a stark change to being surrounded by medics. Jenny didn't sleep: she watched Zac sleeping to make sure he was breathing. She felt lost and alone.

Eventually, Zac and Jenny were invited to join a rehabilitation centre where they stayed together. [redacted] The rehab centre itself was a huge shock for Jenny. Other children there were much less medically stable than Zac, and they often screamed in pain. Other parents spoke of preparing for their children's deaths. Jenny suspected many of them wondered why she and Zac were there when he could walk, talk and feed himself. She felt distressed by the general air of negativity and trauma. To cope, she stayed with Zac in his room and watched uplifting films. They joked and laughed together, and played a musical theme tune when he tried a new wheelchair for the first time. Jenny kept herself away from other parents who were negative, [redacted]. She refused to read anything negative about brain injury. She felt homesick.

With the help of therapy, Zac was eventually discharged. Jenny found life at home had changed. She had to give up work and focus 20 hours of the day on Zac. Their relationship became intense and intertwined, Jenny's social circle shrank. Jenny found herself confined to her flat. It was a contrast to the freedom and travelling she had before Zac's injury. [redacted]. It was imperative for Jenny, who had lost so much of her identity, to keep a tiny bit back for herself by working. A few moments of the day when she could be Jenny and not just 'mum'. Where she could do something other than 'be a carer'.

But Jenny held hope for the future. She reflected on the strengths she had developed: on her new abilities to be ‘dislikeable’ and assertive, to speak up. She remained determined that the small parts of her day that remained just for her, such as her [redacted], would eventually grow. She reflected on what she had kept: Zac was alive, and things could have been so much worse. She would continue to speak up for him in his care: she knew him best.

But Jenny also wanted to speak up for other parents. Parents who were not heard, who had similar frustrations and battles with medics who did not know their children as they did. Things had to change, and Jenny would continue to battle on the continuous journey.

# Appendix O: Author Guidelines for Submission to Neuropsychological Rehabilitation

## Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements.

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**Structure**

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# Appendix P: Author Guidelines for Submission to Disability and Rehabilitation

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Please note that this journal only publishes manuscripts in English.

Disability and Rehabilitation accepts the following types of articles: Reviews, Research Papers, Case Studies, Perspectives on Rehabilitation, Reports on Rehabilitation in Practice, Education and Training, and Correspondence. Systematic Reviews including meta-syntheses of qualitative research should be submitted as Reviews. All other types of Reviews will normally be considered as Perspectives in Rehabilitation.

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Example 1: Leprosy

o Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.

o Reconstructive surgery is a technique available to this group.

o In a relatively small sample this study shows participation and social functioning improved after surgery.

Example 2: Multiple Sclerosis

o Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).

o People with MS have complex reasons for choosing to exercise or not.

o Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

6. Acknowledgement. Please supply all details required by your funding and grant-awarding bodies as follows: For single agency grants: This work was supported by the under Grant. For multiple agency grants: This work was supported by the under Grant; under Grant; and under Grant.

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