Exploring Identity Adjustment following Adolescent Acquired Brain Injury from the Perspectives of Adolescents and Their Parents

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Thesis Portfolio Abstract

Aim: This thesis explored a systemic understanding of psychosocial outcomes in young people with brain injury (BI) by examining psychosocial adjustment within a family context.

Design: First, a systematic review (SR) examined and appraised the evidence base for psychosocial outcomes from parent-involved interventions post child and adolescent traumatic brain injury (TBI). Psychosocial outcomes pertaining to the young person (YP), the parent, and the dyad/family were synthesised. Secondly, an empirical paper (EP) was presented. Six semi structured interviews were conducted with adolescents with BI and six synchronous interviews with their mothers. Grounded theory methodology was applied to elucidate the process of identity adjustment post adolescent TBI within this dyadic context.

Findings: The potential for parent-involved interventions to impact dyadic outcomes post injury was demonstrated in the SR, but significant issues regarding bias were found. Suggestions were made on ways to better consider research with dyadic populations to more robustly research and capture outcomes. In the EP, themes of continuity and change were described for the dyad. The accounts given by young people with BI focused mainly on their own social peer relationships, as the context for their experience of identity adjustment. This was in the context of mothers describing extensive involvement in many other aspects of their child's life, as they engaged in dilemmas over how to support their child's adjustment. The child's identity adjustment was understood as a predominantly socially determined process, while relational processes with mum were often a lived yet unspoken narrative.

Conclusion: The two papers taken in tandem illustrated the role of the parent in effecting adolescent adjustment in terms of a range of psychosocial outcomes (SR) and in terms of identity adjustment (EP) post BI. Highlighted is the need for parents to be adequately supported, given their potential to support YP adjustment. A second issue highlighted is the risk of others failing to see, attend to or understand the YPs experiences post BI.

Contents

Acknowledgments

I would like to thank my family for their support as I have completed my doctoral studies; especially my sister Aoife who has been a constant and unwavering source of support and love. I also wish to thank my chosen family in Norfolk, which my dear friends Aine and Taylor have come to be. Thank you for everything you have both done for me and Shea as I have navigated through this process.

I wish to extend deep gratitude to my thesis supervisor, Fergus, who has guided me through this process with patience, expertise, curiosity and responsiveness. Thanks also to Paul Fisher, Suzanna Watson, and the team at CCPNR for their respective supports.

I would like to extend a special acknowledgment to the six adolescents and their respective mothers who so kindly shared their time and so bravely shared their experiences with me. I have felt honoured to be given the privilege and trust to capture and share your stories.

Finally, I would like to thank my son for helping me to keep everything in perspective and for lighting up my world in all of the ways.

I love you Shea.

Introduction to the Thesis Portfolio

This thesis portfolio has been completed in partial fulfilment of the researchers Doctorate in Clinical Psychology at the University of East Anglia. The work has a focus of psychosocial adjustment (generally) and identity adjustment (specifically) post brain injury in young people, within the systemic context of family and the parent-child dyad. The question this thesis is seeking to answer, is how do we understand the space between young people post brain injury (BI) and their parents, and how might we best support the young person and the dyad towards psychosocial adjustment.

Chapter One: This chapter details a literature review, in the form of a narrative synthesis, which assesses the current evidence base of parent-involved interventions for brain injury in young people and synopsises outcomes for young people, parents and dyadic/family outcomes.

Chapter Two: This is a succinct bridging chapter, outlining the association between the two pieces of work.

Chapter Three: This chapter presents the empirical study, a grounded theory exploring adolescent identity adjustment post BI in a systemic context.

Chapter Four: This chapter complements and adds to the EP, further exploring grounded theory methodology, clarifying researcher philosophical position and discussing some key elements for consideration following conducting the EP.

Chapter Five: This chapter summarises and critically evaluates the findings of the thesis portfolio. Personal reflections are shared and clinical implications leading on from this work are outlined.

Chapter 1

Systematic review paper prepared for submission to: Neuropsychological Rehabilitation

Author Guidelines available in Appendix A.

The research reported is original work which was carried out under the supervision of Fergus Gracey (Primary Supervisor) and Paul Fisher (Secondary Supervisor). I am the lead author of this paper which is prepared for journal submission.

Adolescent brain injury: A systematic review of the psychosocial outcomes of parent involved interventions for young people with BI and their parents and families.

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Abstract

Objective- Acquired brain injury (ABI) carries significant burden across individual, societal and economic domains and is the primary reason for morbidity in young people (Catroppa et al., 2017). This systematic review (PROSPERO Registration: CRD42019137125) evaluates the evidence base on the efficacy of parent-involved interventions in effecting young person (0-19 years), parent and dyadic/family psychosocial outcomes.

Methods- A systematic search and review of the literature was undertaken. Eligible studies were any parent involved intervention aimed at benefitting the young person (YP) by targeting formally measured psychosocial outcomes related to the YP, parent or dyad. A critical review was undertaken of all papers meeting inclusion criteria: the papers were assessed for reporting quality in accordance with CONSORT guidelines, and a Cochrane Risk of Bias assessment was conducted. A narrative synthesis is presented.

Results- Results indicated mixed findings in relation to the efficacy of parent involved interventions in relation to young person, parent and dyadic/family outcomes. Some interventions had better evidence as efficacious (SSTP&ACT for all 3 domains, FPS for YP outcomes, I-InTERACT for dyadic outcomes). However, concerns were present in relation to significant bias risks across the breadth of the evidence base, and there was a lack of consideration of dyadic issues throughout many studies. YPs were far less often responsible for assessing outcomes (and of most relevance, youth outcomes) than their parents, which raises a possibility that the data may not accurately reflect the young person’s subjective experience.

Discussion- Whilst study results appear promising for specific interventions, high bias ratings indicate results should be interpreted with caution. Arguments remain for inclusion of parents / family in child ABI interventions, but further high-quality randomised controlled trials randomised controlled trials are required**.**

Key words: *child, adolescence, psychosocial, parent-involved interventions*

Introduction

Acquired brain injury (ABI) is the primary reason for morbidity for children and adolescents and can lead to ongoing psychosocial difficulties in many areas including emotional functioning, behaviour and relationships (Catroppa et al., 2017). Psychosocial difficulties have been demonstrated after even mild brain injury in childhood (Limond, 2009); and childhood brain injury (BI) can lead to ongoing adverse effects on adolescent psychosocial development (Mc Kinley et al., 2010).

ABI also impacts parent factors associated with child outcomes, with evidence demonstrating ‘bidirectional effects of child and parenting function in the context of chronic illness" (Law et al., 2019). Parents of children with chronic illness can be more prone to experiencing psychological distress such as anxiety and depression, as well as poorly adaptive parenting responses and family functioning (Law et al., 2019) while the primary caregivers ability to adjust and cope is positively associated with recovery outcomes for individuals with TBI (Rotondi, 2007). Such findings demonstrate a reciprocal relational aspect to brain injury adjustment.

Family context is recognised in relational perspectives as key in the impact of brain injury and rehabilitation (Sanders et al., 2013). Clinically, family interventions for paediatric BI are a key treatment approach (Wade, 2006). A key role for family was highlighted in a review by Ross et al. (2011) of neuropsychological interventions for psychosocial problems in childhood ABI; it was found that 75% of included studies involved family, and that in general improvement in a range of psychosocial outcomes was identified. Brown et al. (2012) concluded that parenting interventions may positively impact child and parent outcomes, but recognised a dearth of studies in this area.

One key set of authors in the area (Wade et al., 2018) have conducted a meta-analysis of family problem solving approaches and found that efficacy was moderated by different factors (age of injury, social competence) in relation to behavioural child outcomes, indicating that this approach to paediatric BI may be more or less effective depending of characteristics of participants and outcomes targeted. However, this did not explore other child outcomes or any parent/dyad outcomes; and this also leaves a gap in the literature in relation to other parent involved interventions other than online family problem solving (OFPST). A broad systematic review (SR) exploring all treatments for BI recently detailed family treatments within this remit (Laatsch et al., 2019) which adds useful synopsis of the literature (up to end of 2017). However, this review did not seek to answer the trio of questions posed in this SR (in relation to the YP, parent, and dyad), with a lack of synthesis to support this. A recent Cochrane review of relevance (Law et al., 2019), goes some way to exploring these questions, within a review of psychological interventions for parents of young people (children and adolescents) with chronic illness (and within this TBI interventions). However, in seeking to identify the most robust clinical evidence, only three studies met inclusion criteria. As such, the review could only conclude findings on two out of the five domains explored, which demonstrated efficacy (parenting behaviour, child mental health) but within the context of minimal studies and poor evidence base generally. On the other three areas (parent mental health, child behaviour, family functioning), no conclusions could be drawn. Given the paucity of research and their lack of robust findings for TBI in their review, it is arguable that a lower threshold of inclusion criteria and a more probing style approach to a systematic review could yield meaningful findings that are being missed when threshold for inclusion are so high to achieve exceptional quality standards for the review. A review with lower threshold of inclusion will allow assessment of the status of the research, identifying areas that may require specific attention in future research in this area.

Family involved interventions are a core therapeutic approach but are not greatly founded in the evidence base in relation to psychosocial outcomes, despite the reciprocal relational aspect to ABI adjustment for young people with brain injury and their families. A greater understanding of the psychosocial outcomes of parent involved interventions for young people within the family system will be of clinical value for professionals working in the area of paediatric BI, ensuring effective practice to meet psychosocial needs of young people and their parents post injury. A wider range of studies need to be identified to create some more robust conclusions on the effectiveness of family interventions for young people with BI (Ross et al., 2011). However, given the context outlined in a recent Cochrane Review of relevance (Law et al., 2019), the current review seeks- with a broader criteria for inclusion, and wider scope of brain injury- to build on previous research and expand the research base further by exploring the psychosocial outcomes of parent involved interventions for young people (adolescents and children) with brain injury (BI) and their parents.

This review will focus on three questions:

What is the evidence that parent-involved interventions are more effective than control/comparator groups in improving psychosocial outcomes for (1) children and adolescents with BI, (2) parents of children and adolescents with BI and (3) for the dyad (parent/child) and/or family of children and adolescents with BI?

Materials and Methods

Protocol and Registration

The protocol for this review was listed on PROSPERO (the international prospective register of systematic reviews, CRD42019137125) in June 2019, and developed with reference to guidance on systematic review (The Cochrane Handbook for Systematic Reviews of Interventions, 2018).

Eligibility Criteria

Inclusion criteria

Types of studies. RCTs and controlled studies assessing intervention against control or comparator groups, and pre-post study designs were included. Any papers that included duplicate outcome data from another paper already included in the review were excluded, as were single n cases.

Types of participants. There were two sets of participants included.

1) Parents of children and adolescents aged 0-19 years (adolescence as defined by the World Health Organisation) with BI; and who had participated in parent involved intervention for BI. (Parents are operationally defined in this paper as parent/primary caregiver/caregiver/guardian or any definition pertaining to person holding or sharing main responsibility for caring for the child.)
2) Children with ABI whose parents had participated in a parent involved intervention for BI.

Types of intervention. All parent involved interventions for childhood and adolescent BI were acceptable. Any parent involved interventions designed with the intention to support young person with BI (directly or indirectly) were included. Thus, interventions targeting only parents' psychological outcomes (e.g. personal therapy) without being designed with child outcomes in mind were excluded; while interventions aimed to improve outcomes such as parental coping and adjustments, and family adjustment, were considered eligible. Where intervention solely provided educational materials, it was excluded.

Types of outcome measures. Papers were screened for psychosocial outcomes measures. These outcome measures could be self, parent or clinician report. Studies that only reported on non-psychosocial outcomes were excluded.

Information Sources

CENTRAL, the Cochrane database of systematic reviews was initially searched to clarify there was no new or recent review of the topic. This uncovered a relevant review by Law and colleagues (2019) - as previously discussed. Systematic literature searches were created and run individually on PsychInfo, Cinahl, Embase and Medline databases. Databases had been chosen based on the search strategies identified by similar reviews (Brown et al., 2012; Ross et a1., 2011). The search covered research from conception of database in each case until the time the search was carried out, on 23rd June 2019.

Search and study selection

Searches were conducted in abstract and were categorised into three topic areas: acquired brain injury, parent involved interventions and child/adolescent. Exploded Medical Subject Headings (MeSH terms), where relevant, were used for each topic area to ensure a wide-reaching search. Full search terms are provided in Appendix D. Results were filtered for peer reviewed journals in English, using human subjects. Studies meeting criteria for inclusion were to be included in the review.

Data Collection Process and Data Items

A data extraction form was developed- This was populated with data on study design, characteristics of all participants, details of intervention and comparator groups, and recorded psychosocial outcomes for YPs with BI and/or parents. Any queries regarding inclusion were discussed and clarified amongst the research team.

Assessment of Risk of Bias in and across included studies

As outlined in the PRISMA statement (Moher et al., 2009), risk of bias was evaluated using standardised criteria, adapted dependent on the nature of the studies included using the Cochrane Collaboration Risk of Bias Tool (Higgins, Altman & Stern, 2011, Appendix F). Risk of Bias was conducted for each paper included, and an overview of the bias across the cumulative evidence was generated. Non-randomised studies which did not use comparators were assessed using an adapted version of the same tool (Lukens and Silverman, 2014).

Reporting standards- appraisal of included articles

The reporting quality of articles was appraised using a tool based upon the Consolidated Standards of Reporting Trials (CONSORT) guidelines, with some TBI additional items (Ross et al., 2011). This tool is designed to facilitate the understanding and interpreting of trials through high quality and transparent reporting of trials (http://www.consort-statement.org). Given, the current study assessed many different articles which were all related under larger umbrellas of research (Table 1), assessing articles at an individual level felt necessary, to assess each paper on its own merits. Papers were rated as high (>75%), moderate (50-75%) or low (under 50%) quality of reporting.

Synthesis of results

To enable a meaningful review, given the heterogeneity of outcome measure types and domains and intervention content; a narrative synthesis approach was taken. To Cochrane Handbook for Systematic Reviews of Interventions (2018) was consulted, supplemented by Popay et al.'s (2006) narrative synthesis guidance.

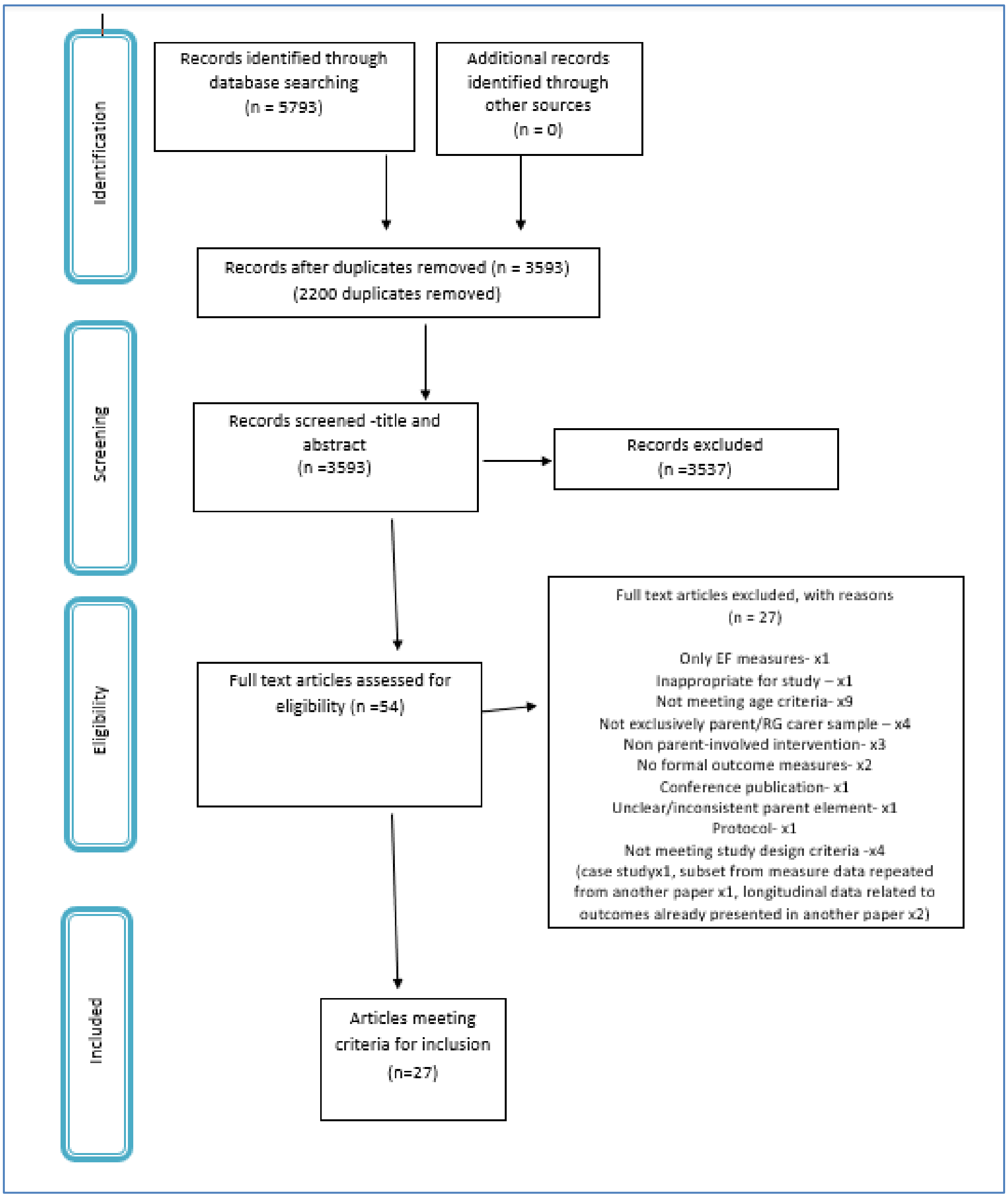
Results

Outcome of Search Process

The systematic search identified 5793 articles. Following the removal of duplicates (n=2200), 3593 articles remained for consideration. Papers were then reviewed at a title/abstract level to assess eligibility against criteria. Following the removal of papers deemed ineligible (n= 3537), 54 articles remained for consideration. The primary author conducted a review of remaining articles at the full text level, to assess eligibility for inclusion in the final selection. 27 articles were then omitted, leaving a final total of 27 papers for including in the review. A second reviewer (KE) independently conducted a full text screening of over a quarter of the same selection (27%), to assess inter-rater reliability, with an initial concordance across reviewers of 93%, rising to 100% after discussion between raters. This final number of papers for inclusion remained at 27. The PRISMA flowchart demonstrating this process is depicted below (Figure 1).

Figure 1

Flowchart following PRISMA guidelines. Adapted from Moher, Liberati, Tetzlaff and Altam; The PRISMA Group (2009)



Study characteristics

Twenty-seven articles representing fourteen discrete overarching studies were included in the systematic review as the final selection, after study criteria were applied. In the case of eight of the studies, multiple papers originating from the same overarching study had been published. Different articles explored different domains of outcome (e.g. child outcomes, parent outcomes) and/or different outcome measures. Therefore, it was decided to review each paper individually. It is acknowledged that multiple articles generated from one study can create confusion (Law et al., 2019) and may risk altering one's interpretation of findings when presented within a systematic review as separate entities. Therefore, the multiplicities of publications related to each (overarching) study are outlined in Table 1, so that the reader may hold this in mind when considering findings.

Table 1

Overarching studies included in review

Parent study number	Intervention	Design	Papers from same parent study (n)
1.	Online FPS	Pre-post	Wade 2005 *a, b* (2)
2.	FPS	RCT	Wade 2006 *a* (1)
3.	Online FPS	RCT	Wade 2006 *b, c* (2)
4.	TOPS	RCT	Wade 2008 (1)
5.	I-InTERACT	Pre-post	Wade 2009 (1)
6.	BrainSTARS	Pre-post	Dise-Lewis 2009 (1)
7.	TOPS	RCT	Wade 2011, Wade 2012 (2)
8.	I-InTERACT	RCT	Antonini 2014, Raj 2015 (2)
9.	SSTP and Act Group	RCT	Brown 2014, Brown 2015 (2)
10.	CAPS	RCT	Wade 2014 *a, b,* Narad 2015, Wade 2015, Tlustos 2016 (5)
11.	Telephone counselling	RCT	Mortenson 2016 (1)
12.	I-InTERACT	RCT	Wade 2017, Raj 2018, Aguilar 2019 (3)
13.	Family Forward	Sequential, Non-randomised comparison group design	Hickey 2018 *a, b* (2)
14.	TOPS- Family	RCT	Wade 2018, Narad 2019 (2)

In total, twenty-seven papers met inclusion for criteria (Table 5). There were 779 unique child/adolescent participants represented in total. The child sample was 64% male (calculated from 93% of data available) with a mean age of 10.6years. There were 950 unique parent participants represented. Much information was absent on parent/carer age, with an average age of 38.8 years (calculated from 23% of data available). Again, gender data on parents/carers was underreported (absent in 52% of papers), with available data indicating a gender breakdown of 84.5% mothers, 13.9% fathers, and 1.6% other carers (e.g. grandparents).

Risk of Bias

Risk of bias was assessed using the Cochrane Risk of Bias (RoB) tool (Appendix H). This was conducted by the primary author for all included studies, with a subsection of papers (one quarter) independently evaluated by a second reviewer (RP). An initial high concordance rate of 94% rose to 100% following discussion with study supervisor and co-rater on discrepancies in ratings, leading to clarification and agreement across raters.

Risk of bias- Randomised trials

Within the twenty-one papers on randomised trials (Table 2), across all rated items, 56% of domains were considered low risk of bias, 9% were considered unclear, and 35% of domains were rated as at high risk of bias. Random sequence generation was strong throughout. Allocation concealment was less uniformly conducted, (only clearly in 48% of papers). Blinding of participants and personnel was not possible owing to the nature of intervention and so was rated as high risk throughout. Blinding of outcome assessment was challenging to rate. This was not possible in almost all studies as either all or some of the outcome measures were participant rated; and participants were not blind to group assignment. However, the risk of researcher bias was considered limited as a result of the data being participant rated, given participants would have known what intervention they received but not the study hypotheses. Thus, the decision was made to rate as low risk all participant rated measures, where detection bias was felt to be minimised by virtue of this. Most papers were high risk for attrition bias (57%), owing to incomplete data, which is an unacceptably high rating and is problematic for interpretation of results as representative of the entire sample. Reporting bias was found to be present in 24% of papers, which is a problematically high rating and presents concerns over being able to reliably interpret the findings of these papers.

Risk of bias for non-randomised trials

Two non-randomised studies (Table 3) were assessed (Hickey et al, 2018 *ab*). In both cases, a high risk of selection, performance and attrition bias were present. Detection and reporting bias were low risk.

Risk of bias for one group pre-post studies

When considering the four papers related to one group pre-post studies (Table 4), a high risk of selection bias was inherently present by virtue of the sample not being randomised. Performance bias was considered not applicable as a domain, given there was only one arm to the study. Blinding of outcomes was rated as low risk in 75% of studies, but 50% demonstrated high risk of attrition bias and 75% were assessed as at high risk of reporting bias.

Lastly, other bias was considered across all papers as members of the author group had been involved in the design of the intervention being tested for efficacy in all but one study. This was considered between the research team, but was not considered to present risks not already adequately covered within the other tool domains.

Though there is variance in Risk of Bias ratings, they demonstrate an overall high risk of bias across all papers in this review. As such, all findings presented herein must be interpreted with caution, and with individual bias ratings in mind.

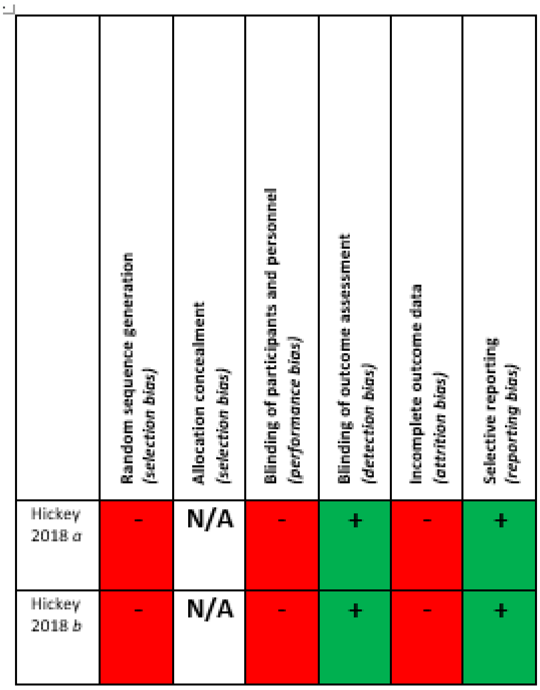
Table 2

Risk of bias for randomised trials

	Random sequence generation *(selection bias)*	Allocation concealment *(selection bias)*	Blinding of participants and personnel *(performance bias)*	Blinding of outcome assessment *(detection bias)*	Incomplete outcome data *(attrition bias)*	Selective reporting *(reporting bias)*
Wade et al 2006 *a*	+	?	-	+	-	+
Wade et al 2006 *c*	+	?	-	+	+	-
Wade et al 2006 *b*	+	?	-	+	?	-
Wade et al 2008	-	-	-	+	+	-
Wade et al 2011	+	-	-	+	+	+
Wade et al 2012	+	?	-	+	-	+
Antonioni et al 2014	+	?	-	+	-	+
Brown et al 2014	+	+	-	+	-	+
Wade et al 2014 *b*	+	+	-	+	+	+
Wade et al 2014 *a*	+	+	-	+	+	-
Brown et al 2015	+	?	-	+	+	-
Narad et al 2015	+	+	-	+	-	+
Raj et al 2015[i]	+	+	-	+	+	-
Wade et al 2015	+	+	-	+	-	+
Mortenson et al 2016	+	?	-	+	-	+
Tlustos et al 2016	+	+	-	+	+	-
Wade et al 2017	+	?	-	+	-	+
Raj et al 2018[ii]	+	?	-	+	-	+
Wade et al 2018	+	+	-	+	-	+
Aguilar et al 2019	+	+	-	-	-	+
Narad et al 2019[iii]	+	?	-	+	-	+

Table 3

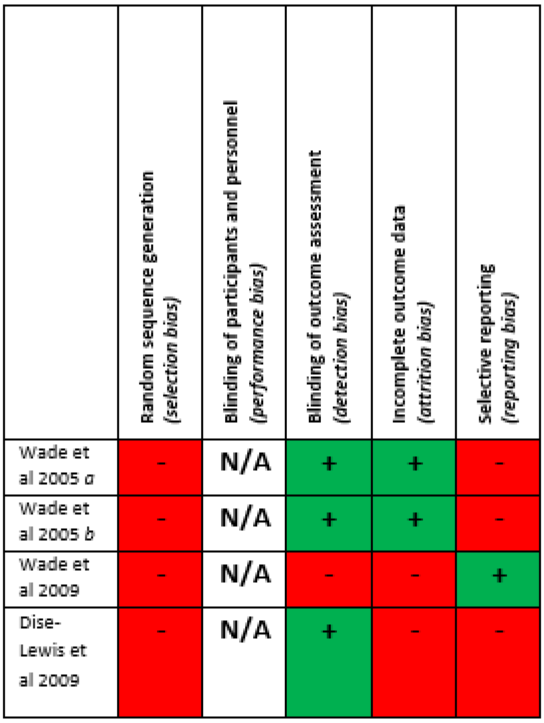
Risk of bias for non-randomised trials



	Random sequence generation *(selection bias)*	Allocation concealment *(selection bias)*	Blinding of participants and personnel *(performance bias)*	Blinding of outcome assessment *(detection bias)*	Incomplete outcome data *(attrition bias)*	Selective reporting *(reporting bias)*
Hickey 2018 *a*	-	N/A	-	+	-	+
Hickey 2018 *b*	-	N/A	-	+	-	+

Table 4

Risk of bias for one group pre-post studies



	Random sequence generation *(selection bias)*	Blinding of participants and personnel *(performance bias)*	Blinding of outcome assessment *(detection bias)*	Incomplete outcome data *(attrition bias)*	Selective reporting *(reporting bias)*
Wade et al 2005 *a*	-	N/A	+	+	-
Wade et al 2005 *b*	-	N/A	+	+	-
Wade et al 2009	-	N/A	-	-	+
Dise-Lewis et al 2009	-	N/A	+	-	-

Quality Appraisal of Included articles

Quality of articles (CONSORT derived tool, Ross et al., 2011) was appraised by the main author for all papers, with a co-rater (RP) appraising 25% of paper to substantiate quality- with high agreement found between ratings (93%) and discrepancies discussed to agree a final score. Most articles were determined to be high quality in their reporting. Sixteen articles were deemed of high quality, seven of moderate quality and four of low quality. Average rating was 73%. Individual ratings are presented in table 5 alongside demographic information, and individual calculations are presented in Appendix I.

Table 5

Demographic details for studies included

Study ID	Author, Year	Number of YPs	Age of YPs (range, yrs)	Gender of YPs	Time since Injury, mo	Severity of Injury (mean lowest GCS)	Number of parents	Age of parents (range)	Gender of parents	Quality appraisal of paper (%)
1	**Wade 2005 *a***	n=6	9.4 (6-16yrs)	66% male, 33% female	16	moderate to severe TBI	n=8	Not Reported	Not reported	**Low (46)**
1	**Wade 2005 *b***	n=6	10.5 (5-16yrs)	66% male, 33% female	18.7	moderate to severe TBI	n=8	Not Reported	Not reported	**Low (46)**
2	**Wade 2006 *a***	n=32	10.83 (5-16yrs)	66% male, 33% female	8.8	moderate to severe TBI (GCS 10.97)	n=40	Not Reported	80% mothers 20% fathers	**High (85)**
3	**Wade 2006 *b***	n=46	10.96 (5-16yrs)	58.5% male, 42.5% female	13.7	moderate to severe TBI	n=39	Not Reported	90% mothers 10% fathers	**High (81)**
3	**Wade 2006 *c***	n=46	10.84 (5-16yrs)	62% male, 38% female	13.7	moderate to severe TBI	n=40	Not Reported	90% mothers 10% fathers	**High (81)**
4	**Wade 2008**	n=9	15.04 (11-18yrs)	66% male, 34% female	9.3	moderate to severe TBI	n=12	Not Reported	Not reported	**Moderate (69)**
5	**Wade 2009**	n=9	6.5 (4-9yrs)	78% male, 22% female	12.9	moderate to severe TBI	Not reported (9 families)	Not reported	Not reported (9 families)	**Low (42)**
6	**Dise-Lewis 2009**	n=30	11.1 (4-19yrs)	67% male 33% female	31.2	Mild, moderate, severe TBI 23 severe, 6 moderate, 1 mild complicated (GCS 6)	n=41	Not Reported	Not reported	**Low (38)**
7	**Wade 2011**	n=41	14.3 (11-18yrs)	49% male, 51% female	9.6	moderate to severe TBI	n=41	Not Reported	Not reported	**Moderate (73)**
7	**Wade 2012**	n=41	14.3 (11-18yrs)	49% male, 51% female	9.5	moderate to severe TBI	Not reported (41 families)	41.23 (6.11)	Not reported (41 families)	**High (77)**
8	**Antonini 2014**	n=37	5.4 (3-9yrs)	68% male, 32% female	8.2	moderate to severe TBI	37	Not Reported	Not reported	**Moderate (69)**

Study ID	Author, Year	Number of YPs	Age of YPs (range, yrs)	Gender of YPs	Time since Injury, mo	Severity of Injury (mean lowest GCS)	Number of parents	Age of parents (range)	Gender of parents	Quality appraisal of paper (%)
9	**Brown 2014**	n=59	7 (2-12yrs)	59% male, 41% female	40	(GCS 10.2)	59	39.1	90% mothers 10% fathers	**High (81)**
10	**Wade 2014 *a***	n=132	14.5 (12-17yrs)	Not reported	3.5	(GCS 10.1)	121	42.38	86%mothers, 10% fathers 4% grandparents	**High (77)**
10	**Wade 2014 *b***	n=132	14.5 (12-17 yrs)	Not reported	3.5	(GCS 10.1)	121	42.38	86%mothers, 10% fathers 4% grandparents	**High (88)**
9	**Brown 2015**	n=59	7 (2-12yrs)	59% male, 41% female	40	(GCS 10.2)	n=59	39.1	90% mothers, 10% fathers	**High (85)**
8	**Raj 2015**	n=37	5.4 (3-9yrs)	68% male, 32% female	26.5	(GCS of 12 or less)	n=37	32.7 (7.4)	92% mothers, 5% fathers 3% grandparents	**High (77)**
10	**Narad 2015**	n=132	14.8 (12-17yrs)	43% male, 57% female	3.5	(GCS 10.05)	Not reported	Not reported	86%mothers, 10% fathers 4% grandparents	**High (85)**
10	**Wade 2015**	n=132	14.9 (12-17yrs)	64% male, 36% female	3.5mo (int) and 4.1 mo (control)	moderate to severe TBI (42% severe, 58% moderate)	Not reported	Not reported	Not reported	**High (77)**
10	**Tlustos 2016**	n=132	14.5 12-17yrs)	65% male, 35% female	3.5	moderate to severe TBI (39% severe, 61% moderate)	Not reported	Not reported	Not reported	**High (77)**

Study ID	Author, Year	Number of YPs	Age of YPs (range, yrs)	Gender of YPs	Time since Injury, mo	Severity of Injury (mean lowest GCS)	Number of parents	Age of parents (range)	Gender of parents	Quality appraisal of paper (%)
11	**Mortenson 2016**	n= 66	12.3 (5-16yrs)	70% male, 30% female	Not reported (1 week to 3 months)	moderate to severe TBI	n=66	Not reported	Not reported	**High (77)**
12	**Wade 2017**	n=113	5.4 (3-9yrs)	61% male, 39% female	10.8	moderate to severe TBI (37% severe, 63% moderate)	NR	Not reported	Not reported	**High (85)**
12	**Raj 2018**	n=113	6.3 (3-9yrs)	61% male, 39% female	11.1	moderate to severe TBI	n=148	Not reported	Not reported (74 2 parent families)	**High (92)**
13	**Hickey 2018 *a***	n=47	9.35 (1-18yrs)	62% male, 38% female	Not reported (recently sustained ABI)	Not precisely reported	n=68	Not reported	56% mothers, 38% fathers, 6% carers (other)	**Moderate (62)**
13	**Hickey 2018 *b***	n=47	9.35 (0-18yrs)	62% male, 38% female	Not reported (recently sustained ABI)	Not reported	n=68	Not reported	56% mothers, 38% fathers, 6% carers (other)	**Moderate (50)**
14	**Wade 2018**	n=152	14.9 (11-18yrs)	70% male, 30% female	5.7	Mild,/moderate to severe TBI (44% severe, 66% moderate/mild)	n=152	Not reported	87% mothers, 13% fathers	**High (85)**
14	**Narad 2019**	n= 152	14.9 (11-18yrs)	70.4% male, 29.6% female	18	moderate to severe TBI	n=152	Not reported	Not reported	**Moderate (73)**
12	**Aguilar 2019**	n= 113	5.4 (3-9yrs)	61% male, 39% female	10	moderate to severe TBI (37% severe, 63% moderate)	n-113	Not reported	95% mothers, 5% fathers	**High (88)**

Types of intervention:

A variety of intervention types were used (detailed in Table 6). Most of the studies (n= 20 papers) described online interventions, taking place within the family home. Six of the studies detailed face to face interventions and one study was a telephone intervention. Interventions included in the current review were: Family Problem Solving (FPS), Online Family Problem Solving Therapy (OFPST), I-InTERACT, BrainSTARS, Stepping Stones Triple P & Acceptance & Commitment Therapy (SSTP & ACT), a telephone counselling intervention, and Family Forward. Variants of OFPST (Teen Online Problem Solving (TOPS/ TOPS-F) and Counsellor Assisted Problem Solving (CAPS)) are considered together in this review, as all are variants are slight and all are considered as online problem solving therapy by the author group (Wade et al., 2018)). Interventions are described in detail in Table 6 (Appendix I). Papers related to each intervention are outlined in table 1.

Table 6

Table of interventions . Adapted from elements of the TIDieR checklist; Hoffman et al (2014)

Intervention	Goal	What	Who Provided	How	Where	When and How much
FPS	Face-to-face, family-centred intervention composed of a problem-solving therapy in tandem with education and training in antecedent behavioural management strategies; aimed at improving problem-solving skills and adaptation for children with BI and their caregivers.	Sessions comprised a problem-solving portion and a didactic portion (supported by therapy manual). The intervention was built upon the problem-solving skills framework (D'Zurilla and Nezu, 1990). This outlines a 5 step process of ABCDE: aim (identifying individual or family issues to focus on), brainstorm (generating strategies for achieving aim), choose (a strategy), do it (generating a plan to implement) and evaluate (family members recording outcomes). Psychoeducation on TBI sequelae was provided. Sessions were used to implement the problem-solving process to achieve a family identified aim. Child and parent participated.	Clinical psychology graduate student	Face to face, individual families	At clinic or at family home	7-11 sessions over 6 months
OFPST	A web-based, family-centred, problem-solving intervention aimed at improving child and family adaptation to paediatric TBI. Intervention was comprised of problem-solving treatment in tandem with teaching on antecedent behavioural management strategies; aimed at reducing behavioural consequences of TBI for children with BI and improving outcomes for child and family.	Designed to be analogous to face to face FPS, the intervention (supported by therapy manual) covered the problem-solving skills framework. Web sessions were provided, followed by online videoconferences. Web sessions included didactic content to support self guided learning on strategies for addressing issues (behavioural/ cognitive) that may arise following TBI. This was followed by a therapist videoconference to review work and support implementing the problem-solving process in relation to a family identified goal. Child and parent participated.	Therapist/ clinical psychology doctoral students	Internet	At family home	8-14 weekly/ fortnightly sessions (8 core, 4-6 suppl.)
TOPS *(variant of OFPST)*	A web based, family-centred problem-solving intervention designed to enhance family problem solving and adjustment and support adolescent and family outcomes following paediatric TBI.	A web-based provision of treatment content in tandem with videoconference family therapy sessions (supported by therapy manual. The TOPS intervention expanded upon earlier OFPST, but more emphasis was placed on the adolescents' role in monitoring and adapting behaviours alongside the parents' provision of appropriate behavioural support and scaffolding to support changes. Core sessions focused on the provision of training in relation to problem-solving, communication, and social skills training for all families taking part. Following web session content, families met online with the therapist to review learning and implement the problem-solving process on an identified aim. Child and parent participated.	Bachelors and masters level research coordinators, clinical psychology doctoral students	Internet	At home	10-18, (10 core, 4-8 suppl.)

CAPS *(variant of OFPST)*	Counsellor-Assisted Problem Solving (CAPS) is a web-based, family-centred, problem-solving and communication group derived from OFPST. CAPS aims to improve long-term functional outcomes of adolescents with TBI.	After an initial CAPS session at home to identify family goals for problem-solving, subsequent CAPS sessions were completed online via video conferencing (supported by therapy manual). Each session included a Web-based module that was completed independently and a Skype session with the psychologist to review skills and implement the problem-solving process to address family-identified goals. Child and parent participated.	Clinical psychologist	Internet	At home	7-13 weekly/bi-weekly sessions
I-InTERACT	I-InTERACT is an Internet-based parenting skills program combining features of Parent-Child interaction therapy (PCIT; Eyberg, 1988) with additional training in managing challenging child behaviours, TBI education, stress management and communication. PCIT is an approach to improve behaviours and positively alter the parent child relationship through a model of in vivo coaching for parents of young children.	The intervention (supported by therapy manual) included self-guided web content pertaining to specific skills, alongside a synchronous videoconference session with the therapist. Sessions (following initial face to face session) were comprised of psychoeducation modules and covered learning on antecedent behaviour management, the cognitive and behavioural sequelae of TBI and training in stress and anger management. Participants completed synchronous videoconferencing meetings with a therapist alongside didactic content. Therapists would review work, engage in role-play with participants to support new skills development, and provide coaching and feedback to the parent through an earpiece during in vivo play with the child. In vivo coaching focused on positive parenting skills and the consistent application of non-punitive discipline techniques. Child and parent participated.	Mixture of masters and doctoral level clinical psychologists, and one experienced TBI therapist	Internet	At home	10-14 weekly/bi-weekly sessions (10 core, 4 suppl.)
I-InTERACT Express	Abbreviated version of I-InTERACT which focused exclusively on improving parenting skills through in vivo learning about reinforcement of behaviours counter to problem behaviours.	I-InTERACT Express is an abbreviated version of I-InTERACT focused exclusively on effective parenting (no didactic information about TBI). After an initial home session, remaining sessions were done online. Parents worked through the modules in tandem with receiving coaching on positive parenting skills throughout the intervention. Videoconferences focused skills review and in vivo coaching while implementing parenting skills with the child. Child and parent participated.	Masters and doctoral level clinical psychologists	Internet	At home	7 weekly/bi-weekly sessions (+ 1 booster)
Telephone Counselling Intervention	Intervention consisting of structured telephone follow-up and symptom counselling with parents which was hypothesised to reduce parental reports of paediatric post-concussion symptoms and caregiver anxiety and stress.	On both calls, parents completed a structured interview about their experience of the impact of their child's symptoms on daily functioning, play and education activities. Tailored informed responses were then offered- including clinical guidelines for concussion recovery, symptom management and activity recommendations. Relevant web links and educational materials were offered. Parent participation only.	Occupational Therapist	Phone, Individual	At home	2 telephone calls, 1 at 1 week and 1 at 1 month post-injury

SSTP&ACT	Intervention consisted of a behavioural family intervention, SSTP, combined with an ACT workshop. The two are combined in this intervention with a goal of improving child outcomes, parenting practices, and family functioning following paediatric acquired brain injury (ABI).	The intervention (supported by therapy manual) was delivered in multi-family groups sessions and individual sessions. This consisted of the 2-session ACT (group) program (Whittingham et al., 2010) which built upon an ACT framework and aimed to address experiential avoidance and increase psychological flexibility. Participants also took part in 6 group sessions of an SSTP program (Sanders et al., 2009) and three individual telephone sessions of SSTP. This focused on treating child behavioural and emotional difficulties through supporting improvements in parent skills and knowledge and confidence via a behavioural family intervention, supported with a family workbook. Child and parent participated.	Psychologists and clinical psychology postgraduate students	Face to face, group	Not reported	11 sessions (9 STTP + 2 ACT) over a 10 week period
Family Forward	'Family Forward' aims to normalise family adaptation following paediatric ABI. The intervention used a resiliency model framework hypothesized to optimise family appraisal of a child's acquired brain injury to ensure better adaptation during the inpatient rehabilitation phase of care and early transition home.	The intervention provides trauma psychoeducation and monitors trauma symptoms; encourages members of the family to share their experiences of grief in relation to the injury and changes in the family system following this. The Resiliency Model (Mc Cubbin et al., 1993) provides a conceptual framework for the appraisal work conducted in sessions. Multi-family groups offer a psycho-educational focus and explore different themes of family appraisal including grief responses, stress management and coping. Child and parent participated.	Senior Social Worker	Face to face, group	Hospital	2 family counselling sessions and 1 group session per week-throughout inpatient admission
BrainSTARS	This is a personalised consultative intervention involving educators and parents, and based on a neurodevelopment model of paediatric ABI utilizing a manual as primary curriculum. The intervention aims to improve YP outcomes through educating parents and school personnel on the associations between observed behavioural deficits and underlying neurodevelopmental vulnerabilities: aiming to improve "fit" between the student's capabilities/weaknesses and the expectations/supports in his or her environment.	The intervention comprised of three consultation team meetings involving consultant, parents and school personnel. The BrainSTARS manual was used as the curriculum for the program of consultation. This psycho educational resource provided decision trees to support a symptom-based assessment of problems and outline recommended intervention. The first meeting supported conceptualising of identified areas of education needs for the YP as indicators of weakness in neurodevelopment abilities and to identify key neurodevelopmental abilities on which to focus. The manual was then used to draft a plan of accommodations. Remaining sessions were used to discuss functional progress and review/change plan as needed. Participants were parents and school staff.	Unreported	Face to face, Individual	At school	3 sessions (6-8 weeks between sessions)

Psychosocial outcomes of interventions

Child outcomes

Sixteen studies measured psychosocial outcomes for children (Table 7). Ten articles were appraised as high-quality reporting (High QR), three as moderate (Moderate QR), and three as low (Low QR) - indicating a relatively good quality of reporting. Most outcomes were assessed by parent report only (except for TOPS, and only one coder rated outcome).

Family Problem Solving – FPS

In Wade et al.'s (2006a, High QR) RCT comparing FPS to TAU, parents in the intervention arm rated significant large (partial η2 = 0.17 to 0.21) improvements for the children in relation to internalising symptoms, anxiety/depression and withdrawal.

Online Family Problem Solving – OFPST

Within outcome data, parent, YP and coder ratings were presented, though the outcome data was heavily weighted towards parents' perceptions over dyadic or objective ratings (67% parent rated, 27% child rated, and 7% coder rated).

Online FPS

A small pre-post single group design assessing online family problem solving (Wade et al., 2005a, Low QR) demonstrating mixed results: a non-significant reduction in antisocial behaviours but also, worse self-report rates on depression. A second RCT comparing online FPS to an internet resource comparison (IRC) (Wade et al., 2006b, High QR) found that parents in the FPS group reported significantly better child self-management/compliance at follow up than IRC group, demonstrating moderate effect size (η^2 =.11).

TOPS/F

All 3 TOPS/F papers included both parent and child outcome ratings which are a strength as both dyad perspectives are explored. A Wade 2008 study (Moderate QR) found significant improvements in parent related adolescent internalising symptoms and self-reported adolescent symptoms when total combined sample was analysed (medium ES, *d* = 0.58 and 0.75 respectively). A Wade et al. (2011) RCT (Moderate QR) comparing TOPS to IRC found no significant differences found between the groups on either parent or teen reports of the adolescent's internalizing and externalizing symptoms at follow-up. Lastly, TOPS-F was assessed for efficacy as part of a three-arm trial (Wade et al. 2018, High QR), against TOPS-Teen only and IRC. Here, no differences were found between the groups on either parent or teen reports of the internalising and externalising adolescent symptoms, as rated by either parent or child.

CAPS

Three papers detailing CAPS interventions are included. A 2014 (Wade et al. b, High QR) RCT found superior outcomes for CAPS intervention (in comparison to IRC) in improving externalising symptoms, aggression, attention problems and ADHD (medium effect sizes ranging from 0.07 to 0.10) in high school age young people (based upon parent ratings). There were no differences between the groups in relation to younger children. In a 2015 RCT by Wade et al. (CONSORT High), the authors found less impaired adolescent functioning for CAPS in comparison to IRC at final follow up (coder rated). Tlustos et al. (2016, High QR) compared CAPS to IRC and found no main effects for treatment group in relation to the assessed outcomes of social competence, and adolescent behaviour and emotion (all parent rated outcomes). CAPS had more positive effect on HCSBS and BERS-2 than the comparison condition for younger teens with moderate TBI and older teens with severe TBI.

I-InTERACT

An initial efficacy trial (Wade et al., 2009, Low QR) demonstrated a trend for reduction in number of problem behaviours as reported on ECBI (p = .09, large effect size: *d* = 1.12). On a later RCT (Antonioni et al., 2014, Moderate QR), I-InTERACT was compared against IRC. Changes in parent ratings of child behaviour on the CBCL were found to be moderated by income-with those in the low income I-InTERACT group and in the high-income IRC group showing greatest improvements on this measure, indicating I-InTERACT may be most appropriate for low income families. No significant effects in relation to changes on parent ratings of child behaviour on ECBI were found in this study. A three-arm RCT detailed by Wade et al. (2017, High QR) compared I-InTERACT to an abbreviated Express version and to IRC. The Express group demonstrated lower ECBI scores than IRC group at 3 and 6-month time points, but no differences in intensity found between I-InTERACT and IRC at either time point. Aguilar et al. (2019, High QR) reported a main effect for the treatment group on the CBCL- Withdrawn/Depressed subscale at the six month follow up. The Express group had a significantly greater reduction than the IRC, with no other significant group differences found- similar improvements were not detected in the I-InTERACT group.

SSTP & ACT

Brown et al. (2014, High QR) assessed SSTP&ACT efficacy against CAU and found that the intervention demonstrated significant improvements (parent rated) on child behaviour and emotional problems for young people. Changes on the ECBI intensity and problems scales significantly improved for intervention group in comparison to CAU, with medium to large effects respectively (*d* = 0.90, *d* = 0.76). Improvements were also evidenced on emotional subscale of the SDQ (medium effect with *d* = 0.50). Changes on

ECBI were maintained at six month follow up but not on SDQ, with emotional problems returning to baseline.

Structured Telephone Counselling

Mortenson et al. (2016, High QR) assessed efficacy of a post concussive telephone intervention and demonstrated no significant differences between the groups on parent rated outcomes at three months post injury.

School Consultation Program

Dise-Lewis et al. (2009, Low QR) assessed efficacy of a school consultation program, which demonstrated unpromising results. Child behaviour as measured on the BASC indicated no significant improvements.

Summary of child outcomes:

No studies were strongly supported as all papers carried a high risk of bias. All results must be considered with this in mind.

Best supported

The SSTP & ACT intervention evidences efficacy (med-large ES) at improving child behavioural and emotional difficulties. However, emotional changes were not maintained, warranting exploration. FPS also appears a well-supported intervention, showing large improvements on internalising symptoms, anxiety/depression and withdrawal (though a relatively small sample size, Wade et al., 2006a). Though both interventions are promising, findings are tentative as both are standalone studies using parent report only.

Mixed support

Most OFPST variants (five out of eight papers) demonstrated positive effects across a range of psychosocial outcomes. Moderate main effects were demonstrated in relation to improving self-management (FPS- Wade et al., 200b); and internalising symptoms (FPS-Wade et al. 2008). CAPS (Wade et al., 2015) demonstrated main effects in improving adolescent functioning; demonstrated efficacy (Wade et al., 2014b) in relation to externalising and aggressive problems, attention problems and ADHD for older children. CAPS also improved social competence, behaviour and emotion (moderated by age and injury severity; Tlustos et al., 2016). However, three papers showed no improvements post intervention on dyad rated outcome assessments, with poor results demonstrated for TOPS/F. Therapist differences were identified (CAPS = qualified clinical psychologists, TOPS/F = uncontrolled), possibly accounting for differences.

Support for the full I-InTERACT intervention was inconsistent. Despite I-InTERACT demonstrating large reductions in problem behaviours (Wade et al., 2009) in a small sample, and then improving problem behaviours in lower SES families (Antonini et al., 2014); two later papers found an abbreviated Express version to effectively improving child behaviour outcomes while I-InTERACT did not. Inclusion of YPs without clinically significant behaviour problems may have created floor effects impacting results, however.

Minimally or not supported

The telephone counselling and BrainSTARS interventions are not supported.

Table 7

Characteristics of included studies relating to YP psychosocial outcomes

Child Outcomes

Study ID	Author, Year	Intervention (duration)	Design	Contol/ comparator	Psychosocial construct being measured (Outcome measure)	Findings	Quality appraisal of paper
1	**Wade 2005 *a***	Online FPS (12 sessions)	Pre-post	None	**Parent ratings for YP:** Home and Community Social Behaviour (HCSBS). **YP rating for self:** Children's Depression Inventory (CDI)	Parents reported a reduction in antisocial behaviours on the HCSBS–AB , though this difference did not reach the level of statistical significance. CDI ratings worsened over intervention.	**Low (46)**
2	**Wade 2006 *a***	FPS (7-11 sessions)	RCT	TAU	**Parent rating for YP**: Child Behaviour (CBCL)	Parents in the FPS group reported significantly greater improvements in their children in internalizing symptoms, anxiety/depression, and withdrawal than did parents in the comparison group*	**High (85)**
3	**Wade 2006 *b***	Online FPS (8-14 sessions)	RCT	IRC	**Parent rating for YP**: Child Behaviour (CBCL,) Social competence and antisocial behaviour (HCSBS)	FPS group reported significantly better* child self-management/compliance at follow up than IRC group. Trends for greater improvement on CBCL in FPS group, though not significantly different than control arm. Older children and those of lower SES who received FPS showed greatest improvements in self management and behaviour problems, respectively	**High (81)**
4	**Wade 2008**	TOPS with audio (10-16 sessions)	RCT	TOPS minus audio	**Parent rating for YP**: Child Behaviour Checklist (CBCL) **YP rating for self:** Children's Depression Inventory	Significant improvements* were found in parent-reported adolescent internalising behaviours and self-reported adolescent symptoms when the total combined sample was analysed.	**Moderate (69)**
7	**Wade 2011**	TOPS Web based (10-14 sessions)	RCT	IRC	**Parent rating for YP**: Child behaviour (CBCL) **YP rating for self**: Behaviour problems (YSR)	No significant differences found between the groups on either parent or teen reports of the adolescent's internalizing and externalizing symptoms at follow-up as assessed by use of the CBCL and YSR, respectively.	**Moderate (73)**
14	**Wade 2018**	TOPS -Family (10-14 sessions)	RCT	TOPS-TO or IRC	**Parent rating for YP**: Child behaviour- CBCL **YP rating for self:** Child Behaviour- YSR	There were no group differences on the Child Behaviour Checklist (CBCL). Similarly, scores on the Youth Self-Report (YSR) externalizing scale at posttreatment fell within the average range at follow-up and did not differ significantly between groups	**High (85)**
10	**Wade 2014 *b***	CAPS (8-13 onine sessions)	RCT	IRC	**Parent rating for YP**: Child Behaviour (CBCL)	CAPS superior* to IRC in improving externalizing behaviour problems, aggression, attention problems and ADHD in high school age youth. Younger teens did not improve regardless of treatment group.	**High (88)**
10	**Wade 2015**	CAPS (8-13 online sessions)	RCT	IRC	**Coder rating:** CAFAS	Less impaired functioning* for CAPs group than IRC group at final follow up (18 months from baseline).	**High (77)**

Table 7

Characteristics of included studies relating to YP psychosocial outcomes

Study ID	Author, Year	Intervention (duration)	Design	Contol/ comparator	Psychosocial construct being measured (Outcome measure)	Findings	Quality appraisal of paper
10	**Tlustos 2016**	CAPS Web-based	RCT	IRC	**Parent rating for YP**: Social competence (HCSBS-SCS, CBCL-SC) Behaviour and emotion (BERS-2)	No main effects were found for treatment group on any of the social competence measures. CAPS had more positive effect on HCSBS and BERS-2 than the comparison condition* for younger teens with moderate TBI and older teems with severe TBI	**High (77)**
5	**Wade 2009**	I-InTERACT web based (10-14 sessions)	Pre-post	None	**Parent rating for YP**: Child Behaviour (ECBI)	Trend for reductions in number of problem behaviours as reported on ECBI, while intensity of parent identified problem behaviours did not change significantly	**Low (42)**
8	**Antonini 2014**	I-InTERACT web based (10-14 sessions)	RCT	IRC	**Parent rating for YP**: Child Behaviour (CBCL) Behavioural functioning (ECBI)	Changes in parent ratings of child behaviour on the CBCL were moderated by income- with those in the low income InTERACT group** and in the high income IRC group* showing greatest improvements on this measure. No significant effects in relation to changes on parent ratings of child behaviour on ECBI.	**Moderate (69)**
12	**Wade 2017**	I-InTERACT (10-14 sessions) Or I-InTERACT Express (7 session)	RCT	IRC	**Parent rating for YP**: Child Behaviour (ECBI)	The Express group demonstrated lower ECBI scores than IRC group at 3 and 6 month timepoints**, with no differences in intensity found between I-InTERACT and IRC at either timepoint.	**High (85)**
12	**Aguilar 2019**	I-InTERACT (10-14 sessions) Or I-InTERACT Express (7 session)	RCT	IRC	**Parent rating for YP**: Child Behaviour Checklist (CBCL)	There was a main effect* for the treatment group on the CBCL-Withdrawn/Depressed subscale at 6 month follow up. The Express group had a significantly greater reduction* than the IRC, with no other significant group differences found- similar improvements were not detected in the InTERACT group.	**High (88)**
9	**Brown 2014**	SSTP and ACT Group and telephone (11 sessions)	RCT	Control (CAU)	**Parent rating for YP**: Child Behaviour (ECBI) Strengths and Difficulties (SDQ-E)	Significant improvements compared with CAU on parent-reported child behavioural and emotional problems (ECBI**, SDQ-E*), with changes in intervention arm maintained at 6 month follow up for ECBI rating but not SDQ rated emotional problems..	**High (81)**
6	**Dise-Lewis 2009**	Brain STARS Individualised consultation Program	Pre-post	TAU	**Parent rating for YP**: Child Behaviour- BASC	There was no significant change on the Behaviour Assessment System for Children.	**Low (38)**
11	**Mortenson 2016**	Telephone counselling (x2 calls)	RCT	Usual care	**Parent rating for YP**: Post concussion symptoms (PCSI)	No significant difference between the groups on outcomes at 3 months post injury	**High (77)**

Child Behaviour Checklist (CBCL), Youth Self Report (YSR), Eyberg Child Behaviour Inventory (ECB)I, Strength and Difficulties Questionnaire- Emotion subscale (SDQ-E), Home and Community Social Behaviour Scale (HCSBS), Behavioural and Emotional Rating Scale- 2nd edition (BERS-2), The Child and Adolescent Functional Assessment Scale (CAFAS), Behavioural Assessment System for Children (BASC), Postconcussion Symptom Inventory (PCSI), Home and Community Social Behaviour Scale- Social Competence Scale (HCSBS-SCS), Child Behaviour Checklist- Social Competence (CBCL-SC).

*Statistical significance p <.05, **Statistical significance p<0.1

Table 8

Characteristics of included studies relating to parent psychosocial outcomes

Parent Outcomes

Study ID	Author, Year	Intervention (duration)	Design	Contol/ comparator	Psychosocial construct being measured (Outcome measure)	Findings	Quality appraisal of paper
1	**Wade 2005 *a***	Web based interventation (12 sessions)	Single group, pre-post treatment	None	**Parent rating for self:** Global psychiatric symptoms and parental distress (SCL-90-R) Depression (CES-D) Anxiety Inventory (AI) Parenting Stress Inventory (PSI)	Parenting stress (PSI), depression (CES-D), and parental distress (SCL-GSI) all declined significantly* from baseline to follow-up. Anxiety also reduced but this difference was not significant.	**Low (46)**
3	**Wade 2006 *c***	Online FPS (8-14 sessions)	RCT	IRC	**Parent rating for self:** Parent distress and psychiatric symptoms (SCL-90-R-GSI) Parental Anxiety (AI) Parental Problem solving (SPSI) Parental depression (CES-D)	FPS group reported significantly less global distress, depressive symptoms and anxiety in comparison to the IRC group*. Significant improvement in problem solving skills also shown for FPS group but differences not significant between the groups at follow up.	**High (81)**
2	**Wade 2006 *a***	FPS (7-11 sessions)	RCT	TAU	**Parent rating for self:** Parent psychological distress (BSI)	ANCOVA analysis revealed no group differences on the BSI–Global Severity Index and anxiety and depression subscales. Examination of group means indicated that both groups reported little change in parental distress from baseline to follow-up.	**High (85)**
4	**Wade 2008**	TOPS with audio (10-16 sessions)	RCT	TOPS minus audio	**Parent rating for self:** Parental distress (SCL-90-R) Parental Depression (CES-D)	Significant changes were found on outcomes of parent depression**. No changes on parental distress post intervention.	**Moderate (69)**
7	**Wade 2012**	TOPS Web based (10-14 sessions)	RCT	IRC	**Parent rating for self:** Parental distress (SCL-90-R-GSI) Parent social problem solving (SPSI-R:S) Parental depression (CES-D)	TOPS found to be effective in improving problem solving and reducing depressive symptoms for certain subsets of caregivers, with income x group interaction effects for both domains.*	**High (77)**
14	**Narad 2019**	TOPS-Family inetrvention (10-14 sessions)	RCT	TOPS-TO or IRC	**Parent rating for self:** Parental depression (CES-D) Parental Psychological Distress (SCL-90-R: GSI)	There was no effect of treatment group on parent-reported distress. Changes in parental depression were evidenced post intervention, and the number of parents moderated the effect of treatment group**: parents from 2-parent households in TOPS-F reported fewer depressive symptoms at follow-up than those in TOPS-TO* and IRC** and single parents in TOPS-F*. There were no treatment group differences in depression among single parents.	**Moderate (73)**
10	**Wade 2014 *a***	CAPS (7-11 sessions)	RCT	IRC	**Parent rating for self:** Parent distress (SCL-90-9-GSI) Parent Self-efficacy (CSES) Parent depression (CES-D)	CAPS participants who completed 5 or more sessions reported greater reduction in depression than IRC group*, however groups did not differ on global distress	**High (77)**

Table 8

Characteristics of included studies relating to parent psychosocial outcomes

Study ID	Author, Year	Intervention (duration)	Design	Contol/ comparator	Psychosocial construct being measured (Outcome measure)	Findings	Quality appraisal of paper
8	**Raj 2015**	I In TERACT Web-based (10-14 sessions)	RCT	IRC	**Parent rating for self:** Parent distress (SCL-90-R:GSI) Parent depression (CES-D) Parenting stress (PSI) Parenting self-eficacy (CSES)	No significant differences between groups in parent depression, parenting stress or caregiver self-efficacy. No group differences reported on parent distress, though post hoc analyses revealed significant* reductions in distress within InTERACT group for parents with lower income in comparison to those in IRC.	**High (77)**
12	**Raj 2018**	I-InTERACT (10-14 sessions)	RCT	Express or IRC	**Parent rating for self:** Parental depression (CES-D) Parental psychological distress (SCL-90-R: GSI) Parenting Stress (PSI) Caregiver self efficacy (CSES)	No main effects of treatment on caregiver distress, parenting stress or parenting efficacy. Greater reductions in CES-D scores for caregivers in I-InTERACT condition compared to controls.	**High (92)**
9	**Brown 2014**	SSTP and ACT Group and telephone (11 sessions)	RCT	Control (CAU)	**Parent rating for self:** Dysfunctional parenting style (The Parenting Scale)	Significant improvements compared with CAU on dysfunctional parenting style, with pre-post decreases in laxness** and over reactivity* for the intervention arm while no significant changes in the CAU group. Changes maintained at follow up.	**High (81)**
9	**Brown 2015**	SSTP and ACT Group intervention (10 sessions)	RCT	Control (CAU)	**Parent rating for self:** Parenting confidence (PTC) Parent adjustment (DASS) Parent relationship (PPC) Psychological flexibility (AAABIQ) Parents thoughts and feelings questionnaire (PTFQ) Relationship Satisfaction betwen parents (RQI)	Significant improvements shown on all measures relative to the CAU group . Significant changes pre to post on confidence**, anxiety*, stress*, couple disagreement*, psychological flexibility**, parent thoughts and feelings**- while no significant changes for CAU group on any of these domains. No difference in change scores on depression or relationship satisfaction in comparison to CAU.	**High (85)**
13	**Hickey 2018 *a***	Family Forward (2 counselling sessions and 1 multi-family group session* per week through admission)	Controlled non -randomised trial	TAU	**Parent rating for self:** Impact of Events (IES-R) Parent experience of child illness (PECI) Illness perception (Brief IPQ)	No significant differences were detected between groups at post-intervention and at follow-up on trauma response (IES-R) For the PECI, no significant differences in trajectories were found post intervention or at 6 month follow up for Uncertainty, Unresolved Sorrow and Anger, Emotional Resources, and Guilt and Worry. No significant group differences were detected between the parent/caregiver reports on the Brief IPQ at post-intervention or follow-up.	**Moderate (62)**

The Symptom Checklist-90-R (SCL-90-R), Center for Epidemiologic Studies Depression Scale (CES-D), Anxiety Inventory (AI), Parenting Stress Index (PSI), SPSI (Social Problem-Solving Inventory), Brief Symptom Inventory (BSI), Social Problem Solving Inventory: Revised- Short (SPSI-R-S), Caregiver Self-Efficacy Scale (CSES), PTC, Depression Anxiety Stress scales (DASS), Parent Problem Checklist (PPC), Acceptance and Action ABI Questionnaire (AABIQ), Impact of Events Scale- Revised (IES-R), Parent Experience of Child Illness (PECI), Brief Illness Perception Questionnaire (Brief IPQ).

*Statistical significance p <.0.05, **Statistical significance p<0.01

Table 9

Characteristics of included studies relating to dyadic/family psychosocial outcomes

Dyadic/family outcomes

Study ID	Author, Year	Intervention (duration)	Design	Contol/ comparator	Psychosocial construct being measured (Outcome measure)	Findings	Quality appraisal of paper
1	**Wade 2005 *a***	Online FPS (12 sessions)	Pre-post	None	**Parent rating:** Family burden of injury interview (FBII)	Scores for family burden of injury improved significantly pre to post intervention**.	**Low (46)**
2	**Wade 2006 *a***	FPS (7-11 sessions)	RCT	TAU	**Dyad rating:** Parent child interaction (CBQ)	No group differences were observed on the parent or child CBQ	**High (85)**
4	**Wade 2008**	TOPS with audio (10-16 sessions)	RCT	TOPS minus audio	**Dyad rating:** Conflict Behaviour (CBQ) **Parent rating:** Conflicts and disputes (Issues Checklist) Problematic issues (Issues Severity Scale)	Reductions reported in dyad reported parent-adolescent conflict at follow up*; as well as in parent rated number** and severity** of parent-adolescent problem issues.	**Moderate (69)**
7	**Wade 2011**	TOPS Web based (10-14 sessions)	RCT	IRC	**Dyad rating*:** Dyad Conflict (IBQ)	Parents of adolescents in the TOPS group reported significantly** lower levels of parent-teen conflict at follow-up than did those in the IRC group, but there was no difference on adolescent ratings between the groups.	**Moderate (73)**
14	**Narad 2019**	TOPS-Family inetrvention (10-14 sessions)	RCT	TOPS-TO or IRC	**Parent rating:** Family functioning (FAD- GF) Dyad conflict- caregiver report (IBQ) Family cohesiveness- caregiver report (PARQ)	Differential effects were found for 1 and 2 parent households- number of parents moderated treatment effects. Among single parents, TOPS-TO reported better family functioning than TOPS-F* and greater cohesion* and less conflict* than IRC. Among 2-parent families, TOPS-F reported less depression** than IRC and less depression* and greater cohesion* than TOPS-TO.	**Moderate (73)**
10	**Narad 2015**	CAPS Web-based (7-11 sessions)	RCT	IRC	**Dyad rating*:** Family Assessment Device (FAD) Problem solving discussion (PSDRS) **Coder rating:** Iowa Family Interacion (IFIRS)	For each of the three measures of family outcomes, the limited benefits of CAPS were documented only for a subset of teens and were not consistently evident for both parent and teen outcomes. There was a decrease in severity for parent reported conflict for teens with severe TBI, but only at 18 months** (not at 6 months). Teen reported conflict indicated improvement but only with older adolescents. Increased teen-reported family problem solving was trending towards significance post treatment, but only for lower SES teens.	**High (85)**
5	**Wade 2009**	I-InTERACT web based program (10-14 sessions)	Pre-post	None	**Coder rating:** Dyadic Parent-Child Interaction (DPICS)	Significant improvements were evidenced in initial sessions- in all positive parenting behaviours (PPB) and total PPB* and reductions in negative parenting behaviours (questions and total negative behaviours)**- with these maintained at follow up	**Low (42)**
8	**Antonini 2014**	I-InTERACT Web based (10-14 sessions)	RCT	IRC	**Coder rating:** Dyadic Parent-Child Interaction (DPICS)	Significant improvements in observed positive parenting skills in comparison to IRC	**Moderate (69)**

Table 9

Characteristics of included studies relating to dyadic/family psychosocial outcomes

Study ID	Author, Year	Intervention (duration)	Design	Contol/ comparator	Psychosocial construct being measured (Outcome measure)	Findings	Quality appraisal of paper
12	**Wade 2017**	I-InTERACT (10-14 sessions)	RCT	Express or IRC	**Coder rating*:** Dyadic Parent-Child Interaction (DPICS)	Express and I-InTERACT groups displayed significantly **higher levels of positive parenting at follow up. Significant differences* were found between the intervention and IRC in negative parenting behaviour too, with treatment groups showing fewer negative behaviours over time in comparison to IRC. But only the I-InTERACT group demonstrated significant difference at 6 months follow up.	**High (88)**
13	**Hickey 2018 *b***	Family Forward (two counselling sessions and one multi-family group session p/w	Controlled non randomised trial	TAU	**Parent rating*:** Family Assessment Device (FAD-GF) Family Management Measure (FaMM)	No significant differences in family adaptation outcomes (FAD-GF) were detected. The Family Forward group achieved superior outcomes in managing their child's care at home (FAMM) and greater parental satisfaction in focusing on their child's care (FAMM Parent Mutuality scale) post-intervention.	**Moderate (50)**
11	**Mortenson 2016**	Telephone counselling (x2)	RCT	Usual care	**Parent rating*:** Family burden of injury interview (FBII)	No significant difference between the groups on outcomes at 3 months post injury	**High (77)**
9	**Brown 2015**	SSTP and ACT Group (10 sessions)	RCT	Control (CAU)	**Parent rating*:** Family functioning (FAD)	Significant improvements pre to post intervention shown on family functioning.**	**High (85)**

Family Assessment Device (FAD), Family Burden of Injury Interview (FBII), Conflict Behaviour Questionnaire (CBQ), Dyadic Parent-Child Interaction Coding System (DPICS), Interaction Behavior Questionnaire (IBQ), Family Assessment Device – General Functioning Scale (FAD-GF), Parent Adolescent Relationship Questionnaire (PARQ), Problem Solving Discussion Rating Scale (PSDRS), Iowa Family Interaction Rating Scales (IFIRS), Family Management Measure (FaMM), Relationship Quality Index (RQI), Parent Problem Checklist (PPC)

*Statistical significance p <.0.05, **Statistical significance p<0.01

Parent outcomes

Twelve studies demonstrated psychosocial outcomes for parents (Table 8). Eleven of the twelve papers were appraised as moderate (n=4) to high (n=7) quality; so research papers in the area are reasonably strong as a body of work. All outcomes are parent rated.

FPS

Wade et al (2006a, High QR) compared an FPS intervention against treatment as usual, with no group differences found on a psychological distress measure (BSI) and its anxiety and depression subscales; and little change in parental distress from baseline to follow-up in either group.

OFPST

In an RCT by Wade et al (2006c, High QR), comparing an online FPS intervention to a comparator of internet resources, the FPS group reported significantly less global distress, depressive symptoms and anxiety in comparison to the comparator group. Wade et al. (2012, High QR), compared TOPS/F against internet resources, where TOPS was found to be effective in improving problem solving and reducing depressive symptoms for certain subsets of caregivers, with medium to large income x group interaction effects for rational problem solving (RPS, R2 = .41) , positive problem orientation (PPO, R2 = 0.23) and depression CES-D (R2 = 0.33). Parents of lower SES in the TOPS/F group gained the most benefits in comparison to counterparts in other arms: reporting improvements in RPS, significant improvements in PPO and reductions in depressive symptoms. Groups did not differ on parental distress at follow-up. Wade et al.'s 2014a OFPST (High QR) paper assessing CAPS against IRC, found there was a significant difference between the groups on depression, when comparing IRC to participants who had completed 5 of more sessions of the CAPS intervention (medium effect size, *d* = 52). However, groups did not differ on global distress outcomes.

Wade et al. (2005a, Low QR) assessed an FPS online intervention, and found significant reductions in parenting stress, depression and parental distress post intervention. Wade et al.'s (2008 Moderate QR) TOPS study found significant changes pre to post intervention for the combined sample on parent depression (p = 0.01, medium effect size of *d* = 0.8) but no changes on parental distress. In a three-arm RCT (Narad et al., 2019, Moderate QR), TOPS/F was compared against TOPS-Teen only and IRC. There were changes in parental depression, moderated by the number of parents: With parents from 2 parent households in TOPS-Family reporting significantly fewer depressive symptoms post treatment than single parents in the same arm (small effect, *d* =.45), and fewer symptoms than 2 parent households in the TOPS-TO and IRC trial arms (small to medium effect sizes, *d* = .45 - *d* = 0.56).

I-InTERACT

Raj et al.'s (2018, High QR) 3 arm trial (I-InTERACT, Express and IRC) found that caregivers with elevated levels of depression in I-InTERACT experienced greater reductions in depression compared with caregivers in IRC (approaching significance, p = .06, small effect size, η2 = 0.05). However, though I-InTERACT reduced caregiver depression it did not affect other assessed caregiver outcomes: no main effects on caregiver distress, parenting stress or parenting efficacy. Raj et al.'s earlier (2015, High QR) RCT comparing I-InTERACT against IRC found no significant differences between groups in parent depression, parenting stress or caregiver self-efficacy. Differences were found between the groups (large effect size, R2 = 0.50) on distress when SES was considered as a moderator: lower-income parents in the non-intervention group experienced modest increases in parent distress whereas those in the intervention group experienced significant decreases in distress.

SSTP & ACT

Brown et al. 2014 (High QR) reported significant improvements on dysfunctional parenting style in comparison to CAU. A significant, large decrease on laxness pre- to post intervention (*d* = 1.07) and a significant, medium decrease in over reactivity (*d* = 0.66) was evidenced, with no significant changes in the CAU group. Treatment effects were maintained at 6 months. In a second paper (Brown et al., 2015, High QR) the intervention group demonstrated significant improvements pre-post intervention in measures of confidence (large effect, *d* = 0.95), anxiety (small effect, *d* = 0.45), stress, (medium effect, *d* = 0.54) psychological flexibility (medium effect, *d* = 0.77), thoughts and feelings (medium effect, *d* = 0.78), and parent disagreement (medium effect, d = 0.62) (with no changes for CAU). No significant differences in change were found between the groups in relation to depression or parent relationships.

Family Forward

A non-randomised controlled trial (Hickey et al., 2018, Moderate QR) assessed a Family Forward intervention compared against treatment as usual. No differences were found between the groups on outcomes of parental adjustment, illness perception and trauma response. A key weakness of this study was variation between the groups on characterises and time in treatment (as occurred for duration of inpatient admission).

Summary of parent outcomes

Best supported

SSTP&ACT demonstrates efficacy at improving a variety of parent psychosocial adjustments post BI, with predominantly medium effect sizes in a range of outcomes: improving parenting confidence, adjustment, parent conflict, thoughts and feelings for parents of a young to middle childhood age group. Though no changes to parent relationships and depression identified, the authors note possible floor effects.

Mixed support

OFPST studies demonstrated varied results in relation to parenting outcomes. There is good support overall for OFPST to target parental depression based on effect sizes reported in the papers reviewed (medium to large effects; Wade et al. 2008 and 2014 a respectively): including for lower SES families (Wade et al, 2012- TOPS, large ES) and two-parent families (Narad et al. 2019- TOPS-F, small ES). Problem solving also improved (in relation to lower SES families, Wade et al., 2012), and anxiety was effectively reduced in one study (against IRC, Wade 2006c). Effectiveness in relation to global distress was unsupported, with positive outcomes in demonstrated in a third of papers assessing this. Despite promising outcomes in the initial efficacy study, stress has not been assessed further.

Minimally or not supported

The I-InTERACT studies detail inconsistent findings for depression and distress outcomes. Both domains were found to be impacted positively in one study but not in another (Raj et al., 2015; Raj et al., 2018); while stress and efficacy measures were not improved by either I-InTERACT or the abbreviated Express version. There is minimal support for its use in relation to parenting outcomes.

The Family Forward intervention does not demonstrate efficacy in its current format for parental psychosocial adjustment.

Face to face FPS (Wade et al., 2006a) demonstrated no differences found between groups. Though possible ceiling effects were noted, it is not currently supported.

Dyad/family outcomes

Eleven studies demonstrated dyadic and/or family outcomes (Table 9). Most papers were moderate to high quality (five of each), indicating the literature is generally of reasonable quality.

FPS

Wade et al.'s RCT (2006a, High QR) assessing FPS against TAU found no differences observed on parent child interaction.

OFPST

Five papers relate to OFPST. Three included assessments from both young people and parents to get a dyadic generating of outcome assessments, with one study also utilising coder rating. Wade et al.'s (2005a, Low QR) study demonstrated significant improvement in family burden of injury scores pre to post intervention. Wade et al.'s 2008 study (Moderate QR) found reductions in parent-adolescent conflict at follow up in a pre-post assessment of TOPS; as well as in parent adolescent problem issues and severity (effect sizes ranged from medium, (*d* of 0.74 for dyadic conflict) to high (*d* = 0.92 for issues, *d* = 1.45 for severity). A later TOPS study (Wade et al 2011; Moderate QR), found that parents of adolescents in the TOPS group reported significantly lower levels of parent-teen conflict at follow-up than IRC (large ES). However, this was not echoed by adolescents, who reported no significant differences between the groups. Most recently, in Narad et al.'s 2019 three-arm RCT (Moderate QR); differential effects were found for one and two-parent households. Among two-parent families, TOPS-F reported less depression than IRC (medium effect, *d* = 0.56) and less depression and greater cohesion than TOPS-TO (small effects, *d* = 0.44 and *d* = 0.43 respectively). However, among single parents, TOPS-TO reported better family functioning than TOPS-F (small effect, *d* = 0.41) and greater cohesion (small effect, *d* = 0.47) and less conflict than IRC (small effect, *d* = .40). Lastly, a 2015 CAPS study conducted by Narad et al. (2015, High QR) demonstrated benefits for only a subset of teens and were not consistently evident for both parent and teen outcomes.

I-InTERACT

All 3 studies carried the strength of having coder rated outcome assessment. Wade et al.'s (2009, Low QR) efficacy study demonstrated large, significant improvements on a pre-post study in positive parenting behaviour (large effect sizes, *d* = 1.01 – 1.72) and reductions in negative parenting behaviours (Questions *d* = 2.34; Total score *d* = 3.03). Antonioni et al.'s 2014 (Moderate QR) RCT found significant improvements were demonstrated in positive parenting skills for the I-InTERACT group when comparing both higher and lower income intervention groups against their counterpart IRC group. Most recently, in Wade et al.'s (2017, High QR) 3 arm trial., the I-InTERACT and Express groups displayed significantly higher levels of positive parenting at follow up in comparison to IRC. Only the I-InTERACT group demonstrated lower levels of negative parenting at follow up.

Family Forward

In (Hickey et al.'s (2018*b*, Moderate QR) study, no significant changes were identified on the FAD-GF family adaptation outcome. However, in comparison to TAU, the treatment arm demonstrated improvements in managing their YPs care at home and more satisfaction with focusing on their child's care.

Telephone Counselling

No differences were found on the parent-rated Family Burden of Injury measure between the usual care and the intervention group at follow up (Mortenson et al., 2016; High QR)

SSTP & ACT

Brown et al. (2015, High QR) found significant medium improvements were demonstrated in family functioning (*d* = 0.76) and in disagreement between parents (*d* = 0.62) in comparison to CAU (who demonstrated no significant changes). Improvements were maintained at 6 months follow up for family function, though significant decreases in parental agreement (small ES, *d* = 0.45) by follow up. No differences were found regarding relationship satisfaction for parents.

Summary of dyad/family outcomes

Best supported

The I-InTERACT uniformly demonstrated efficacy in improving parent child interaction (coder assessed) in three studies, twice against active controls in randomised conditions. SSTP & ACT was found to demonstrate improvements of medium effect size in both family function and disagreement in parents in comparison to CAU in a highly rated paper, indicating it may be a useful intervention. These two interventions are thus the most supported by the research included in the current review.

Mixed support

Family Forward intervention shows promising results in relation to parental satisfaction in focusing on their child's care and superior outcomes in managing care. More robust research is warranted.

OFPST demonstrated mixed results. In all three randomised studies on TOPS-F (Wade et al. 2008, Wade et al. 2011, Narad et al. 2019), it was demonstrated to be efficacious in improving dyadic/family outcomes relating to conflict and /or cohesiveness, either at a group or subgroup level; with two-parent families (Narad et al. 2019) reporting less depression and greater cohesion than a non-family version of the intervention. Thus, TOPS-F is well supported as an intervention targeted towards these outcomes, particularly in two parent homes. Important to note however that reductions in dyadic conflict were parent rated and not replicated in YP ratings (Wade et al. 2011). However, CAPS evidenced benefits for only a subsection of adolescents, with various different outcomes moderated by various differing variables, and with these findings not consistent across teen and parent rated measures. Thus, CAPS is not well supported for dyadic outcomes.

Minimally or not supported

The telephone counselling is not supported, nor face to face FPS, with both demonstrating no efficacy on respective outcomes.

Discussion

Key findings of the review

Ten of the fourteen studies demonstrated significant improvements on some psychosocial outcomes, either for whole group or when moderators were taken into account. (Lower SES, two-parent families, and an interaction between injury severity and age). Thus, the majority of findings indicated parent involved interventions can result in improved psychosocial outcomes (for the YP, parent and/or dyad). However, findings were inconsistent, and risk of bias issues mean that firm conclusions are difficult to draw and are tentative.

Despite this, while acknowledging the bias issues and tentativeness of the findings, some key outcomes emerge. The SSTP & ACT intervention (Brown et al. 2014, 2015) demonstrates the most promising psychosocial outcomes across the three outcome domains (child, parent and dyad/family) and seems the best supported intervention for improving psychosocial adjustment across the 3 domains of focus (young people, parents, and the dyad/family). However, findings have not yet been replicated for this intervention. For YP outcomes, the FPS intervention (Wade et al. 2006a) indicated efficacy. However, this was a precursor study to OFPST interventions which have not yielded consistent effectiveness in relation to the same outcomes as the face to face iteration of the intervention. For dyadic outcomes, I-InTERACT also shows promise as an intervention, though it is not as well supported for parent (minimally supported) or YP outcomes (mixed findings).

The SSTP & ACT intervention reviewed in this SR demonstrated efficacy across child, parent and dyadic/family outcomes; but could not elucidate upon the individual effect of the SSTP and the ACT elements in relation to changes. This warrants further exploration, in order to justify inclusion of different elements in the intervention. The same author group (Whittingham et al. 2016) examined this question in relation to another chronic illness group

- a cerebral palsy (CP) population. Here they examined the intervention elements (comparing both SSTP and SSTP & ACT against a control group) to ascertain the impact of ACT as an additional inclusion in the treatment package. Though SSTP by itself demonstrated efficacy in comparison to a control group, the ACT component delivered additive psychosocial benefits. STTP&ACT demonstrated greater improvements in child and parent outcomes than STTP alone (on child behaviour, parenting styles, parental psychological symptoms and improved quality of life). Psychological flexibility was identified as a process of change mediating effects on parental style and adjustment, highlighting a unique contribution of ACT to parenting outcomes (Whittingham et al. 2019). Thus, a useful next step would be to assess for a better understanding of processes of change with a paediatric BI population, though we may hypothesise based on these findings that the ACT provides a similar additive impact through its aim of improving psychological flexibility.

OFPST interventions were the most represented intervention type in the current review, but showed inconsistent findings that were challenging to synthesise. Change mechanisms were unclear, and interventions were multifaceted, with individualised extra sessions, which demonstrated efficacy across different groups for different outcomes dependent on varying participant characteristics. Some trends emerged however, around moderator effects of SES and number of parents.

Across the pool of studies, effect size was often unreported however, and methodological concerns including high risk of bias were present in all papers assessed. Inconsistencies between YP and parent reports were noted in some studies, while YPs perceptions were often not represented in self rating assessments. Thus, though the most promising evidence is highlighted based on a synthesis of the findings, firm conclusions cannot be drawn without support from further, more robust and less biased research.

Limitations within reviewed studies

Variation between studies

The wide scope of inclusion meant there was marked variation and heterogeneity across the total sample. The type of intervention varied in nature, intensity, duration and setting. The age range of young people varied widely (3-18 years), as did time since injury (3.5 - 40 months)- giving an unclear overall profile of who the interventions best fit. Though predominantly a moderate to severe sample, two papers included mild BI participants and two more did not adequately report.

Common methodological issues identified

Challenges in recruitment within this population context led often to relatively small or skewed samples of YPs. Participant pools often included individuals with a mean time since injury of fewer than six months, which is problematic in that the young person in this phase is still recovering and likely to show improvements. Some papers broadened inclusion criteria to ensure larger samples, but in doing so impacted homogeneity of the sample (e.g. severity) and potentially created floor effects through lower inclusion criteria that masked effectiveness of outcomes. Multiplicity of outcomes being assessed seems a key concern, with multiple papers generated by overarching studies, and often multiple outcomes reported within each article. This increases the risk of chance outcomes. Therapist or person-to-person attention was not considered in any of the papers as a comparator, and studies would benefit from controlling for the nonspecific effects of attention in order to elucidate the change mechanisms at play in interventions. Lastly, objective coder ratings were rarely used, and for behavioural outcomes. Objective measured outcomes could strengthen findings (Brown et al., 2012).

Quality and Bias

Issues with blinding participants and personnel resulted in ratings of high risk of bias across studies on the Cochrane tool - however this is arguably an issue about appropriateness of the specific item on the tool. Though the gold standard for assessing bias, blinding of people involved often becomes unfeasible or impossible in these types of interventions. However, aside from this domain, notable levels of incomplete data and of selective reporting remain- demonstrating that authors must improve their safeguarding against bias. Risks of attrition need to be considered at the earliest stages of design to minimise. Reporting needs to be focused and answer all questions asked. Further, this review of highlighted the abundance of papers which are generated by single overarching studies. This is an understandable result of the costs of getting a larger study to point of action, but hypotheses must be considered carefully and be based upon the theory and evidence base, to provide an acceptable level of focus. Otherwise, there is risk of chance findings and a misrepresentation of the impact of interventions, when so many outcomes are being taken from the same pools of individuals.

Dyadic considerations

A core issue which emerged while conducting the current review was the consideration of the dual members of the dyad. This emerged (1) in relation to the consideration and reporting of participant characteristics, and (2) in relation to the assessment of outcomes.

Though all approaches had parents as participants, there was a widespread weakness in reporting parent data, their amount of involvement, or considering parents in terms of design issues such as randomisation etc.

In contrast, when assessing outcomes, the voice and experience of the young person was often unconsidered, with outcomes predominantly parent assessed and their experience seeming often subjugated for the parent perception. The question therefore must be asked about whose needs are being addressed and whether YPs are being held enough in mind as their own people and not only individuals to be managed? Where outcomes are assessed and rated similarly by both members of the dyad, or are objectively rated, they can be more confidently interpreted as meaningful for both members of the dyad. In studies where parent and YP measures were available (e.g. CBCL, BASC and BERS-2 all have self-report options which were not utilised alongside parent measures in a range of included papers), but only the parent version was utilised, this risks losing valuable data on the YP experience. While parents may be appropriately placed to rate their child's behaviours, having a YP provide their own assessment on subjective domains such as emotional outcomes seems essential and needs to be facilitated whenever possible.

Review limitations

A limitation in the current study is that the articles for inclusion were co-reviewed for only a subsection of papers; while the quality appraisal of papers and risk of bias assessments were dually rated on only a sub-section of papers. Though the concordance of co-reviewers was high in both instances, there is the potential that having two reviewers both review all papers at full read level to determine inclusion and assessing all papers included may have yielded marginally different results.

What could also be considered a limitation is the inclusion of non RCTs and efficacy papers with small ns. Non RCTs do not meet the same gold standard that RCTs are accepted as meeting in terms of ability to accurately answer the question of effectiveness (Evans, 2003), and cannot be confidently interpreted owing to intrinsic weaknesses. However, systematic reviews can fail to determine findings owing to rejecting many non-randomised studies to maintain a high threshold (Ferriter & Husband, 2005); where a lowered threshold can introduce relevant evidence of improvements and can lead to the evidence base applying across a broader set of patients. The literature on parent involved interventions for psychosocial adjustment post YP BI and the potential systemic impacts of these is an emerging field which is still underdeveloped and where a high threshold results in too few studies to draw conclusions about the state of intervention literature more broadly. It is thus arguably of high value to introduce such research, cautioning around methodological concerns, which can be of complementary value for healthcare stakeholders (Arditi et al., 2016).

Findings in relation to gaps in the literature

The evidence base for chronic illness "demonstrates the bidirectional effects of child and parenting function in the context of chronic illness" (Law et al., 2019). Thus, we can consider parent and dyad/family intervention related positive adjustments as beneficial for the YP. In relation to parent outcomes, SSTP & ACT intervention demonstrates efficacy in improving a range of psychosocial outcomes, which is of key value for the YP given that the literature highlights how parent adjustment is associated with youth recovery outcomes (Rotondi, 2007). SSTP & ACT, and I-InTERACT findings demonstrate the potential for positive dyadic and family outcomes. These are relevant for the YP, given the literature identifies the importance of family context and the key role for families in relation to BI impact and rehabilitation (Ergh, Rapport, Coleman & Hanks 2002; Sander, Maestas, Clark & Havins, 2013). In relation to direct YP outcomes, these were generally parent rated and focused more on behavioural than subjective emotional outcomes. Distinct emotional outcomes were barely used in favour of behaviour focused assessments, and emotion outcomes were generally parent assessed, if assessed. This may create issues with interpreting findings and their representativeness, as despite being validated measures there is an absence of the child complementary assessments. However, though mostly parent rated and with many mixed and inconsistent findings, outcomes did overall indicate efficacy on a broad scale, with 10 of the 16 reporting some significant benefits of intervention in relation to psychosocial outcomes. This aligns with Ross et al.'s (2011) conclusion that families have a key role and that interventions are largely efficacious in relation to psychosocial outcomes.

Robust research in relation to child and parent outcome post YP BI is limited (Brown et al., 2012, Law et al., 2019). The three SR questions in tandem provide a systemic understanding of the efficacy of parent led interventions currently available for adolescent BI. It is acknowledged that what is provided is a nuanced picture of a body of research which sits at the lower end of a quality spectrum, in comparison to for example, Cochrane thresholds for SR inclusion. However, this lower criterion for inclusion allowed the review to meet its objective of providing a snapshot of the broader evidence base, and some promising findings are highlighted.

Conclusion

This review adds an up to date narrative synopsis of the parent-involved interventions for YP ABI and indicates the evidence base in relation to child, parent and dyadic/family psychosocial outcomes. The evidence base is found to be overall methodologically weak and with a high risk of bias as measured by Cochrane RoB tool, despite reporting quality being assessed as reasonably good overall. Promising findings in relation to certain interventions are demonstrated but evidence overall had to be interpreted with much caution given quality and risk of bias issues. Future research should consider greater attention to dyadic issues and the inclusion of child subjective or self-rated outcomes. Arguments remain for inclusion of parents / family in child ABI interventions, however, further high-quality RCT’s are required on which to base recommendations for approaches.

Implications for future research/clinical practice

Though findings indicate some efficacy (SSTP & ACT across domains, FPS for YP outcomes, I-InTERACT for dyadic/family outcomes), the literature demonstrates a high number of issues related to methodological quality and risk of bias which prevent firm conclusions being drawn. Further, the online research is dominated by one author group and independent studies would help verify findings. Robust and powered samples with no risk of attrition and reporting bias, assessing interventions demonstrating strongest evidence of efficacy against an active condition where there is some other type of personal interaction over the web as a comparator could be a next step in expanding the evidence base.

Limitations in this research review highlight a poor consideration of dyadic issues. It will be important for dyadic issues to be considered more carefully in future designs and, in particular, in relation to outcomes - to ensure representation of subjectively experienced outcomes for YP and to protect against their experiences being unattended to.

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Chapter 2: Bridging Chapter

Words: 507

Chapter Two: Bridging Chapter

This chapter serves to succinctly demonstrate the links between the systematic review and the empirical paper. It leads the reader comprehensively from the review into the empirical research and functions to enable the reader to understand how they complement and support each other.

The systematic review highlighted how parent involved interventions can demonstrate positive outcomes for the young person across a range of psychosocial domains. However, findings were mixed, and the picture remains somewhat unclear owing to issues pertaining to the bias of the evidence. What is made clear is that young people are embedded in a child-parent dyad and a family system, and this system has the potential to affect a range of psychosocial outcomes for them. Considerations emerge around whose perspective is prioritised, and the extent to which child and parent outcomes are reciprocally related. This raises a question about how well we understand the parent-injured child dyad following BI, and whether this gives any insights that might help guide the approaches we use to make decisions about interventions and outcome measurement.

A key question this raises then, is how might we understand identity adjustment for the young person, who is embedded in this family system? Identity vs. role confusion is the fifth of Erikson's proposed psychosocial stages of development (1959) and is proposed to occur in adolescence. Given the systematic review findings, can we expect to see an impact of parenting involvement on this process? If the systematic review points to the possibility of parental impact on psychosocial outcomes, what might a dyadic understanding of the psychosocial process of identity adjustment post brain injury in adolescence look like? We understand that the research base for brain injury demonstrates a well-established experience of identity adjustment post BI in an adult population, and there is an inductive process already put forward by Levack et al. (2014). However, there is no such equivalent grounded theory underpinning an understanding of adjustment in adolescence, and not within the systemic context of the dyad.

Thus, the systematic review establishes some interplay between parenting input and psychosocial outcomes for young people. The EP builds upon this, turning its attention specifically to the relational space between the parent child dyad. The key concern of the EP is to develop an understanding of the phenomena of the psychosocial challenge of identity adjustment for adolescents within a relativist but critical realist context, considering perspectives of adolescents and their parents. Given the issue with narrow / individualist conceptions of child and parent outcomes in child ABI, there is a potential use of a relativist approach in particular to orientate the analysis towards a contextually sensitive understanding of the underlying reality of the phenomena of adolescent identity adjustment. The empirical project is detailed in the next chapter.

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Chapter 3.

Empirical paper prepared for submission to Neuropsychological Rehabilitation

Author Guidelines available in Appendix A

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

An investigation of the process of identity change and adjustment in response to ABI from the perspectives of adolescents and their mothers –

- A Systemic Grounded Theory Approach

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Abstract

Aims: The aim of this study was to explore a relational understanding of the process of identity adjustment post adolescent bran injury, within the systemic context of the parent child dyad.

Methods: Six young people with an ABI (16.5 yrs., 15-18 yrs.; TBI: n=3) were individually interviewed, and six respective mothers (45 yrs., 37-50 yrs.). A qualitative approach was utilised, to develop an understanding of the process of post BI identity adjustment for young people and their parents. A novel grounded theory (GT) approach was used, with analyses of dyads linked in an attempt to capture understanding of the relational aspect of the dyad in relation to the underlying phenomenon.

Results: An individual process for the YP was described of experiencing discrepancies between the now self and other selves. Following this, mothers and adolescents both engaged in processes of responding to discrepancy, resolving discrepancy, and adjustment towards tentative equilibrium. Accounts highlighted a relational process where the mother turns towards the child in efforts to support them through an identity adjustment process to reduce experienced discrepancies, while the YP focuses predominantly on negotiating a socially determined sense of self.

Conclusions: Results provide a contextualised understanding of the process of identity adjustment post adolescent BI within the family context. Highlighted are the mothers' sense of responsibility and subjugation of self, and the adolescents constituting of identity through an interaction between self and social identities. This is a valuable addition to the literature, presenting a first GT on adolescent identity adjustment within a dyadic context.

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

Introduction

ABI is a leading cause of disability for young people and has the potential to affect the physical, emotional and psychological aspects of an individual's functioning (Kreutzer et al., 2016). It can lead to changes in an individual's very sense of self and the core qualities that define them (Ownsworth, 2014) and have devastating impacts for both the individual and their family. The experience post ABI of an altered identity has been recognized as a common experience among adult survivors and can contribute to negative psychological outcomes (Carroll & Coetzer, 2011).

Identity change and adjustment after acquired brain injury

Identity conceptualises our sense of who we are; generally a cohesive autobiographical narrative and experience of a unified self (Heller et al., 2006). Post adult BI, marked alterations have been recognized in how individuals view themselves, their identity and their roles (Ownsworth, 2014). Individuals can experience a loss of 'self' (Nochi, 1998) or sense of discontinuation of the individual's previous sense of self (Couchman et al, 2014); with major discrepancies identified between the 'present self' and both the pre-injury self and future self (Gracey et al., 2008). Discrepancies between selves can challenge development of a coherent sense of self (Ownsworth & Haslam, 2016), with poorer mental health outcomes linked with negative perceptions of discrepancy (Cantor et al., 2005). Therefore, it is argued that interventions need to be established which assimilate an understanding of identity change within them (Gracey, Evans & Malley, 2009).

A qualitative meta-synthesis by Levack et al. (2010) found that recurrent themes post adult BI related to loss and reconstruction of self-identity and personhood. Alongside the experience of loss, individuals can also experience gains and areas where no change is perceived (Whiffin, 2019). A key inductive exploration of the process of identity adjustment post adult TBI (Levack et al., 2014) identified themes related to one's place in the world, to others and to self.

Considering the family context around the brain injured individual

A gap in the BI literature is identified around a thorough understanding of adjustment within the family post brain injury (Verhaeghe et al., 2005) and Whiffin (2019) proposes exploring interactions as a means of better understanding the family context of identity adjustment. Though Levack et al.'s (2010) model supports an understanding of identity adjustment, no comparable grounded theory has been identified that looks specifically to adolescent identity and the process of adjustment post ABI in this population, within a family context.

Acquired brain injury and identity adjustment - Considering adolescents

Adolescence is a critical time for identity development, a successful negotiation through adolescence is considered to lay the groundwork for psychosocial development in adulthood (Erikson, 1959; Marcia, 1980). Belonging within a social group becomes pivotal in adolescence (Newman et al., 2007), with identity understood as something negotiated within a social context before becoming internalized within one's concept of self (Tajfel & Turner, 1986). Adolescents engage increasingly beyond the family, and wider social engagement becomes key to healthy development (Patton et al, 2016). The continuity of a social identity through the maintenance of group memberships is identified as predictive of wellbeing post BI (Haslam et al., 2008). With adolescence such a crucial phase for identity development, adolescents with ABI are particularly vulnerable to experience a sense of discrepancy between their current and pre-injury identities, and also between their current and imagined or hoped for identities. (Van Leer & Turkstra, 1999).

The role of systemic factors on identity adjustment after acquired brain injury

Families are the main structure within which adolescents' transition to adulthood (Elzakkers, 2014), and family are typically responsible for the provision of long-term care post BI (Degeneffe & Lee, 2015). The literature points towards a type of interacting pattern between the individual with BI and the family. Family context has been associated with emotional outcomes for the child with BI (Anderson et al., 2005) and the ways in which the parent perceives the child's identity post brain injury can impact markedly upon the self-identity of the child (Bohanek et al., 2006). Whiffin (2019) concludes that family members are active agents in the sense making of the 'self-concept' for the (adult) brain injured individual (alongside going through their own identity adjustment post injury). A successful resolution of self-identity for the brain injured individual has also been demonstrated as key to both individual and family functioning (Couchman et al., 2014) and better family function effects outcomes for young people with BI (Micklewright et al., 2012; Yeates et al., 2010).

Brain injury impacts upon identity and, in turn, upon outcomes in adults (Cantor et al., 2005). Identity can be understood as intrinsically linked to experiences in everyday life, giving rise to higher order sense of self and social identity (Muldoon et al., 2019, Ownsworth & Haslam 2016). Adolescence is a critical period in terms of personal and social identity development, during which skills for entering adulthood are developed. BI impacting on adolescence therefore risks significant disruption to these developmental processes at the level of the individual, but also importantly the relational processes between the individual and the family context. Therefore, there is a need to better understand issues relating to contextual or relational adaptation / adjustment in adolescents with BI. Current ways of understanding identity adjustment post ABI are based upon adult oriented models, and thus may not apply to a greater or lesser extent to an adolescent ABI population.

This current study thus aims to develop an understanding of the process of identity adjustment post adolescent BI, with sensitivity and attentiveness to the relational context of the parent-child dyad, so as to understand the process through the lens of both parent and adolescent perspectives. Family and social context have been recognized as the fundamental basis of all interventions post insult by Limond et al., (2014) and findings from the current study may thus lead to clinical benefits for this population.

Research Questions

The key questions that will be considered in relation to constructing an understanding of the process of identity adjustment post adolescent ABI will be:

- Following adolescent ABI, how can we understand the process of change, adjustment and re/construction of identity for the brain injured individual within a family system context?
- What can be learned about the relational experiences of the parent child dyad post adolescent ABI, and how might this help in understanding the underlying reality of the identity adjustment process?

Methods

Design

This study employs qualitative research methodology, using a contextually sensitive critical realist grounded theory (GT) approach to explore the shared and individual experiences and process of identity change in adolescents post-ABI and their parents. A critical realist approach will be taken, aiming to use the dual perspectives of the adolescent and parent to attempt to develop an understanding of the underlying process of identity adjustment post adolescent ABI. This study utilises a ‘grounded theory (GT)-lite’ (Pidgeon & Henwood, 1997). GT lite uses GT techniques to develop categories and concepts, and to develop an understanding of the relationships between these; but may not reach data saturation or generate a fully articulate grounded theory (Braun & Clarke, 2014).

Inclusion and Exclusion Criteria:

Key inclusion criteria were that the adolescent was a) between 10-19 years old, b) living at home, c) 6 months or more post insult, d) had ABI since turning 10 years old. For parents, inclusion criteria were a) must be primary caregiver. (Expanded criteria are presented in the extended methodology). Sufficient communication skills in English were also a requirement. Exclusion criteria for young people were severe language difficulties or impairments; and for both members of the dyad, severe mental health and/or substance misuse disorder.

Participants:

6 adolescents with ABI and a respective parent (Table 1) were recruited from a community-based NHS paediatric specialist neurorehabilitation service. All participants had ABI which had been evidenced through brain change recorded from scans and recorded in their patient notes. For a ‘GT Lite’, as few as 6 participants may be sufficient (Braun & Clarke, 2014, p. 50), thus guiding a sample size of 6 dyads.

Table 1 *Participant characteristics*

Dyad	Pseudonym	Gender	Age	Ethnic Group	Cause of ABI	Age at time of injury	Clinical details (including GCS if known)
1	Noah (adolescent)	Male	17	White British	Severe TBI caused by fall from height	15	Severe Traumatic Brain Injury – GCS4
	Kirsty (mother)		50				
2	Aiden (adolescent)	Male	17	White British	ABI - Stroke	14	Intracerebral haemorrhage from ruptured arterio-venous malformation- GCS3
	Kath (mother)		47				
3	Leah (adolescent)	Female	16	White British	ABI - Stroke	13	ABI- Left Middle Cerebral Artery infarct
	Jenny (mother)		47				
4	Matt (adolescent)	Male	18	White British	Moderate TBI caused by RTA- pedestrian hit by vehicle	11	Moderate TBI- Contusion between the skin and skull around the eye socket. Mild bilateral contusion of both apices.
	Natalie (mother)		37				
5	Jack (adolescent)	Male	15	White British	TBI caused by object falling on head	12	Two traumatic brain injuries (severity unknown) about 1 year apart
	Faye (mother)		41				
6	Jordan (adolescent)	Male	16	White British	ABI caused by infection	14	Empyema, cerebral venous thrombosis, and epilepsy requiring neurosurgery
	Amanda (mother)		49				

Procedure:

Ethical approval was sought and granted from the Health Research Authority and NHS Research Ethics Committee (Project ID: 213891). The local gatekeeper (clinical psychologist) within the service and the clinical team identified and recruited potential participants from their active caseloads to seek consent for the CI to contact; leading to recruitment into study. All agreed to participate when contacted to discuss further by the CI.

Measures

Semi-structured interviews (SSIs) were conducted and audio recorded in participants homes by the main author (CG, BA Hons., MSc). Parent and adolescents were interviewed separately to best enable each individual's narrative to be heard (Daly, 1992). SSIs utilised topic guides. These were fluid and amended as the process went on to increasingly elucidate the emergent theory (Appendix J, K). One mother interviewed twice, owing to time restraints in initial interview. One YP had his mother present owing to communication difficulties. Interviews averaged 68 minutes for YPs and 75 minutes for parents.

In line with guidance on a GT Lite approach (Charmaz, 2014), there was a simultaneous process of data collection and analysis. This entailed the use of constant comparative methods in order to examine new data in relation to existing data and emergent analysis; facilitating the development of conceptual categories; and the systematic use of GT analytic methods to navigate towards abstract analytic levels. Each dyad was analysed in tandem, and connections were sought within and then between dyads through an iterative constant comparison process of flip-flopping (Glaser and Strauss, 1968) between data and analysis; working towards an overarching account of the phenomenon of identity adjustment. Linked with the epistemology of the research, reflective processes were used throughout.

Results

The grounded theory analysis yielded themes illustrating individual and shared processes related to identity adjustment post adolescent BI (Figure 1, Appendix Y). Individual processes described for the YP post injury relate to experiencing discrepancies to self-identity. Following this, both members of the dyad described processes of making sense of discrepancies; leading to more or less acknowledged tensions around normality and abnormality for the YPs, and around perceptions of 'hereness' and 'goneness' for the mothers. Accounts detailed parallel processes of resolving discrepancies. The dyad indicated shared experiences of identity adjustment and a movement towards some kind of tentative equilibrium, as perceived discrepancies were reduced or became more accepted.

Core themes underpinning the overall theory are that of the tension between continuity and change experienced for the YP and those within their system, and then the response to this ranging from acknowledging to rejecting of experienced discrepancies.

Experience of the now self and other selves- tension between continuity and change

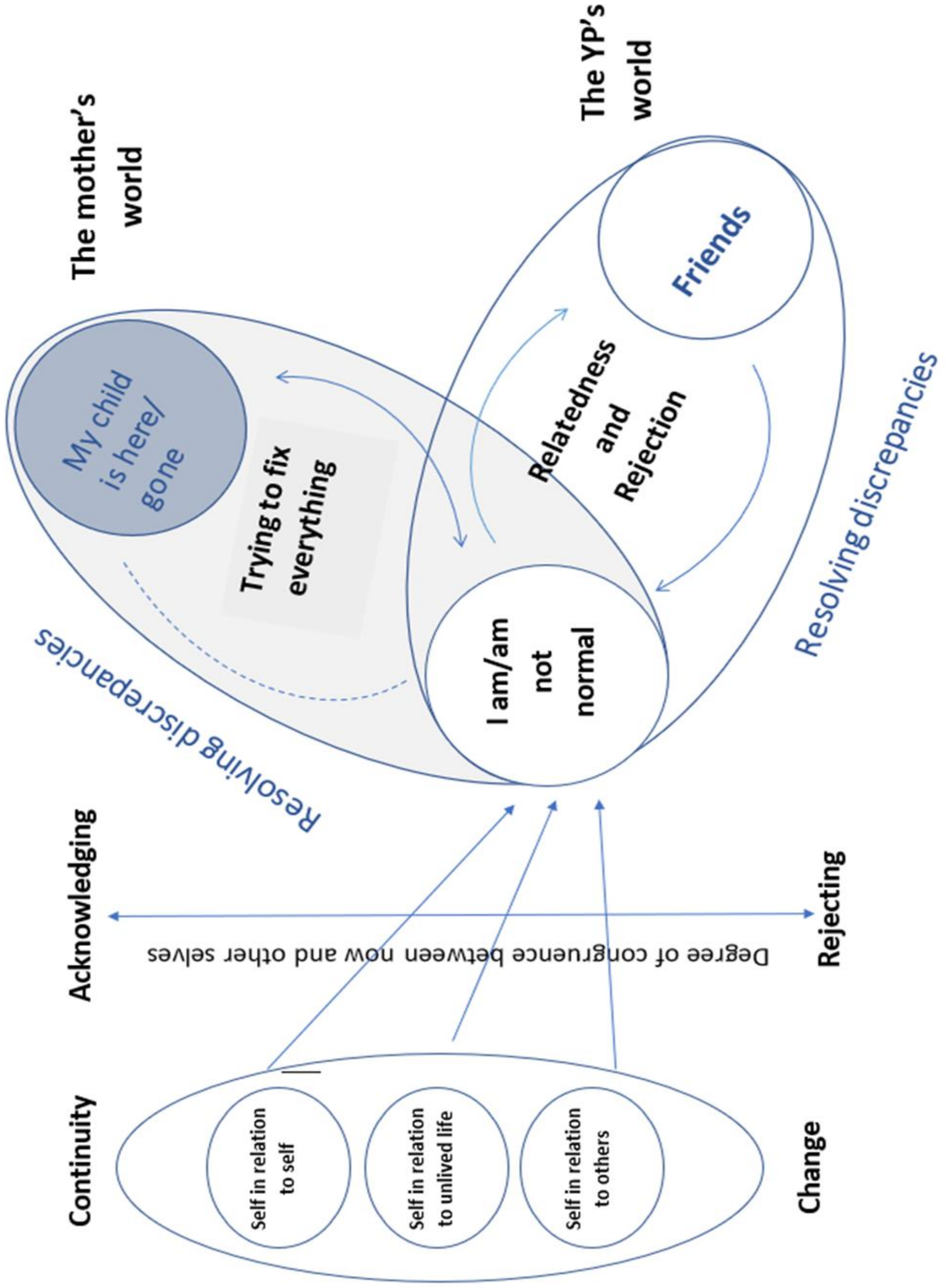
A series of dilemmas was described for the YP post BI and a rupture in life as was to a greater or lesser extent. Adolescents described how they experienced tensions between change and continuity across different aspects of ‘self’ after having had the injury.

Self in relation to self

Accounts all indicated some degree of a rupture to self along a spectrum from minimal perceived changes to experiences of being a different person. Young people could recognise differences in comparison to pre-injury selves in many domains-changes to skills, physicality, energy, sexual development. Changes in elements of self, when identified, provoked a range of responses- including frustration, upset and even suicidality--in the

Figure 1

Grounded theory of identity adjustment post adolescent BI



young people who expected themselves to be able to operate across life domains as they always had done. Leah spoke about physical development rupture: *"My stroke messed with my hormones, so my body is still basically like it was when I was 13 and it's kind of put my self-esteem real low"*.

Aiden detailed how *"Sports was my life"* prior to injury, and Matt spoke about being *"a different person when I came back."* For some, experienced discrepancies sat alongside experienced continuities of self.

Self in relation to the unlived life

Dyads recognised the unlived life of the child, the imagined future of the pre-injury child, had they not acquired a brain injury. Noah reflected how "*if I wouldn't have had the accident, I would've been in the big class with everyone else".* This unlived life was present and compared against, when developing perspectives on the child as is. Kath spoke about seeing her son Aiden's peers progress along the academic trajectory he would have gone down, and the life she had expected for him before the injury.

Self in relation to others

Salient and frequent accounts of relatedness and/or rejection from peers were shared in every dyad across both members.

For four adolescents, friendships were spoken of as fundamentally altered post injury, characterised by senses of being rejected or friendships withdrawing. For others, contesting accounts emerged, where mothers perceived peer rejection and the YP recognised friendships as continuous. In these cases, objective changes to friendships were recognised by YPs, but jarred against a fixed subjective state of friendships, possibly as to acknowledge change could evoke a threat to self-identity.

A sense emerged of the relational space of the young person being of a dynamic whereby sensitivity to rejection and being perceived as changed could lead to recoiling from that and withdrawing; impacting upon future opportunities for peer relatedness. Leah explained how: *"I don't like confronting people, so … I just kind of avoided it ...em so just ended up kind of accepting that, um, we just weren't friends anymore".*

Finally, intimate relationships were touched upon in interviews, and this element of the young person's life seemed ruptured and on the 'backburner' for some young people who alluded to it, while for others there was a replacement of challenging or rejecting experiences of friendships with the relative safety of 1:1 intimate relationships.

In all cases, YPs explanations of changed identity centred around stories about connectedness and/or rejection within social relationships more than parent relationships. Where friendships ceased, young people most often made meaning of this by attributing change to self, and internalising reasons for the rejection:

Response to experienced continuity/change

The ways in which participants made sense of or tried to resolve or acknowledge issues of change and continuity seemed to resonate across accounts of the YP and the mother

I am/am not normal

YP accounts indicated a questioning of their normalcy in response to experienced discrepancies, emphasising peer relationships and social identity. Across all dyads, there were descriptions of friendships shifting in their nature and within the broader relational systems for the YP: leaving YPs holding on to ideas of friendships objectively distanced or recognising changes and struggling with what this may mean about self. Leah shared her desire to see herself as normal –*"I just kind of want to be normal, I want to kind of see myself as a normal person*'- and a core fear she had after her acquired brain injury that others would reject her if they perceived her as not normal.

Normalcy was explicitly linked with pre-injury selves for all young people, with Jordan wanting to get *"back to my normal self*"'. 'Normalness' seemed incongruent with 'wrongness/brokenness' in YP accounts; often expressing concerns about others negatively perceiving them in some kind of 'wrong 'way because of the brain injury, or their own personally experienced sense of 'wrongness' as a result of not being 'normal' post injury.

Jack described a process where the fear of how others might perceive him was a projection of his own feelings towards himself, which then shaped his expectations of others; verbalising a self-identity to social identity interacting relationship-

"Just thought I was some weirdo.... I just thought that something was wrong with me...I just didn't know what. That's why I was thinking that they must be thinking the same thing".

He also highlighted the reciprocal nature of this by sharing experiences of inferring abnormality in himself as he recognised friendships distancing.

"As I was losing more and more people, I felt more and more different. Like ...I wouldn't be losing all these people if I was normal."

An intrinsic sense of not feeling as one used to feel was indicated, with Noah sharing a sense of surrealness since injury (*"it's been a bit sort of weird").* For some, internal discrepancy elicited catastrophic reaction, with Faye sharing how Jack had harmed his head in a bid to "fix" himself back to normal. Jack spoke of ruminating on his sense of "*how different I am to everyone else"*, which would trigger episodes of escaping from his house to go hide in the woods alone in the middle of the night. A deep distress attached to his experience of self, seeming to trigger efforts to escape his own skin. Mum described: *"(He) just couldn't explain what was going on, he never can...He just says, "I just don't get why," … seems like he's trying to get away from himself, but he can't."*

'Participants responded to discrepancy along a continuity to changed spectrum, with some seeing things in more binary terms and some recognising them self as experiencing both simultaneously. Jordan reflects this when he stated "I *do view myself in a little different way, but I still like to think I'm still the same person. It's just… something's wrong."*

Narratives of normalcy as an alternate to disability emerged, and mothers indicated tension around how to hold a disability identity alongside a normalcy one for their YPs, while some YPs indicated the importance of being seen as not disabled in order to retain a normalcy identity.

Throughout the dyads, normalcy seemed a concept often positioned as opposed to a person with a brain injury, and thus young people often struggled to accept their injury as this challenged their sense of normalcy and threatened to subsume their sense of personhood. Matt shared how "*I was talking about the injury like I wasn't there… I was talking about it, like I am just a side effect of it. Not it's a side effect of me."*

My child is here/gone

Mothers made meaning of rupture and discrepancies in their child's identity through perceiving their child from continuous/here to discontinued/gone. Sometimes accounts pointed to a phenomenon of simultaneous incongruent experiences of the grieved for and the remaining child (my child is here and gone)

Kirsty reported she did not recognise any elements of her child as different, indicating a belief that this would be incongruent with her role as mum. “*I don't (see him as different) because I'm his mum, so I'm not going to view him different*.”

Kath spoke at times about her son post injury in a way that inferred he was an iteration of her 'real' pre-injury son, who could be visible at moments post injury, describing oscillations between the now child and pre-injury child that she experiences.

This was echoed in Natalie’s description of ongoing interactions with a grieved for child, who she perceived was being refound in new roles such as the child’s volunteering role at a sports centre, where *“you suddenly see him again”;* while reflecting she sometimes struggled to recognise him: *“he can be cruel, and when he's like that I don't recognise him and it does feel like he's gone”*. She pointed towards a grieving process in terms of increasing distance from the pre-injured child and challenge of closure when “I*t’s not what you would call a clean grief….we are further away from the little boy we had and … there were a lot of key things about Matt that, some of them are core things, some of them are still very much there. But there's, there's a massive percentage of him that's been lost*.”

This ‘duality’ of the remaining and lost elements of the child seemed to present a unique challenge to grieving. The young person in this dyad echoed mums struggles to integrate the brain injury into a coherent narrative of her son, stating *'I do my best to ignore it (the fact I have had a brain injury) and pretend it's not there, which is not good or healthy.”*

Faye reflected that after his injury, her son “*just seemed lost*”, which echoed his experience of feeling a discontinuation of his previous self, who was replaced with a completely different person: Jack echoes this in a sense of being a completely different person: “*I just feel like that's something in my head, what's make me think differently, feel* *differently and just do stuff differently. Like I just feel like a completely different person because of it … than I was."*

Grief over incongruence of pre and post injury child was acknowledged also by Amanda. *'It is like a bereavement',' He is the same but different… Some of the boy has gone…. The bits that have gone are the bits that I'm hoping over time, we can support".* Here, mum seemed to indicate that this uncertainty over the possibility of resolving these discrepancies was related to the ongoing grief experience, and the idea of a 'core' ongoing personhood was indicated alongside this idea of elements of the boy as 'gone':

Resolving Discrepancies

YPs seeking social belonging respond to discrepancies in their experience of self-identity and peer perception of self by various means including: recognising continuity, seeking to renegotiate their way into relational belonging with peers or reordering relational systems to have family replace peer absence. Mothers spoke to attempts to rebalance, resolve, acknowledge or reject the various troubling, weird, abnormal frightening things experienced by their child and themselves. They attempt to 'fix everything' through a series of processes: sometimes incongruent with each other, as they try to protect the child but also promote autonomy.

Fitting in *- relatedness*

Where they experienced and perceived them, adolescents sought ways to manage discrepancies and tensions between their now self and other selves, in action or in reframing. YPs spoke about ways they attempted to negotiate or renegotiate their social domain in a response to experienced ruptures, tensions and discrepancies in their social relatedness pre and post injury. Responses to shifted friendships ranged from finding ways to frame objective distancing in relationships as unrelated to sense of friendship continuity); to seeking new avenues for relatedness; to shifting relational systems so that families and partners occupied greater amounts of time and/or engaging in socially isolative behaviours.

Several young people indicated that alongside a sense of friendships withdrawing, they also made active or reactive choices to pull away to seek others they could feel more relatedness with. YPs sought out new friendships, where friendship loss was identified; with Jordan noting a sense of relatedness with new friends based upon experiences of adversity, while feeling his own friends didn't understand him as '*hadn't been through stuff'.*

At times, objective changes to friendships were rationalised as owing to normal adolescent trajectories or to experiencing the other person as changed, to realign continuity of self narrative.

Leah responded to perceived rejection from old friends but refinding social acceptance with an online community, which was deeply meaningful and supportive for her, while also reflecting she and mum had grown less close (contested in mums account). After speaking about becoming more accepting of her injury, she explicitly referenced social relatedness as facilitating movement towards adjustment and integration of self.

"I think mostly … I think it was like the social side of things. Like both the online community and kind of starting to make new friends, em, so it was kind of just like em you know, 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. So yeah."

Aiden engaged in many disability sports activities with mum, which while he found boring, he and mum valued for the social engagement opportunities it provided for him, while Noah and Aiden valued reengaging with others at school and seeing friends again there.

My job is to fix everything- 'puts a fire in you that you never thought you had'

This process captures the ways in which the mothers attempted to work to reduce the discrepancies of the child as is and the 'other' selves and the challenges and distress associated; trying to balance competing needs they identified for their child. Narratives referred to the pressure and expectation of maternal omnipotence which mothers felt both expected of them and recognised as the fundamentality of being a mum. Kath explained how *'It's your job, to make him feel like everything's better”*). Two key and potentially discrepant processes were described: Preparing and Protecting.

Preparing referred to the process of looking towards the future, by getting all supports and structures in place that may reduce discrepancies experienced and support the child's needs on a pathway forward. Here, mothers looked to the ways they could might progress the child on an adjustment path, detailing efforts to set up and support their children with external and internal resources. Mothers identified themselves as fighting and advocating (Kath: *“puts a fire in you that you never thought you had”)* for appropriate services and supports. They supported their children to recognise and align with personally meaningful goals, and consciously or otherwise spoke to instilling resiliency outlooks towards the future.

Protecting refers to the mother's protective response to experienced discrepancies and associated difficult feelings and sense of abnormality for the YP: attempting to alleviate or prevent hurt or distress for the young person, through mediating and buffering their experiences with the world post injury. All mothers referenced elements of this in their treatment of the child. Mothers referred to processes to protect and buffer the child from distress elicited by their experiences inter and intrapersonally through processes of: padding (compensating, mediating relationships), being present, and holding the psychological load (subjugating and sacrificing, being the emotional punch bag, and worrying over vulnerability.

Efforts to protect included compensating in an attempt to help resolve/reduce or 'make up for' distress attached to the YPs experience post injury. Kath described efforts to make up for perceived friend rejection by attempting to fill the friend role: "*Because he hasn't got that best friend. You know. He doesn't see his friends as he would. So, I might be-…So I have to fit into all of these different roles and try and be a bit of everything for him, so he doesn't miss too much of it, you know."*

Mothers faced dilemmas over how to best support their children with discrepancies being experienced. Kirsty indicating a promoting of experiential avoidance in efforts to minimise distress for their son: *"I didn't want him feeling sorry for himself and getting in a deep depression and that. So yeah, we were out doing lots of stuff"*. While Faye spoke about how she dropped boundaries around her son for fear of triggering him into an episode of distress or mental health breakdown, but recognised with hindsight that this may have left her child feeling structurally uncontained: *"He was there doing whatever he wanted…. Not good. ... coming home two-two, three o'clock in the morning…., not feeling any structural routine"*.

These protecting and preparing processes sounded sometimes at odds with each other, and accounts described the tensions of negotiating the more protecting elements of mothering as well as preparing and promoting into independence and autonomy, as mothers strove to do everything they could to 'fix' everything.

Natalie reflected on how she *"didn't want (her son) feeling like he was wrapped in bubble wrap",* and so *"tried to sort of take a step back whenever I could".* She recognised the challenge of supporting autonomy while still perceiving her child as fragile and described an increasing need to hide scaffolding from him as he got older so he felt more like an adult, describing the tension between these desires to protecting and pad.: *"As he's getting older we're still having to do an awful lot of input, but having to hide him more and more and more because obviously as he's becoming an adult, is even more important that he's- he has the support, but he feels like he's got some independence".*

Alongside hiding efforts, she also spoke to carer burden, feeling unseen and wishing he would acknowledge efforts.

Amanda recognised challenges in stepping back and difficulties with stepping back and letting her child be more independent:

"*It's hard for me sometimes to not take over. I know I do that sometimes that if he's struggling to get something, I sometimes butt in.*" …. "*Because of what happened that stays in your head. It's my issues, not his issues of letting him go."*

This was reflected in her son Jordan's experience, who spoke about how he had felt infantilised post injury: "*she'd treat me like a child".*

Adjustment towards a tentative equilibrium

To various extents, all accounts pointed to processes of moving towards tentative balance. This stage involved finding new meaning in ways of being. Social reconnections had been reframed, reconstructed or new ones built. Improvements were recognised and mothers acknowledged reduced anxiety and dependence to greater or lesser extents. YPs indicated optimism while mothers acknowledged the path forward as unclear.

There were references to expansion of self and post traumatic growth. Aiden recognised his experience as valuable *("I think people can learn from me"*) and in the social connections the dyad had made ("*me and mum have met a lot of nice new people")* while

Leah shared a sense of transitioning from rumination towards an acceptance, and a sense of rebirth; acknowledging friendship loss but also the opportunities to start new ones.

Jack recognised that he is experiencing *“more good days than bad”, while* his mum looked tentatively forwards: *“I've accepted that the future is uncertain, and I've just got to take each day as it comes”.*

Matt reflected on reframing his injury “*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”.* His mother reflected on continuing dilemmas for the dyad - pointing towards a limbo position, where uncertainty around the lost and the retrievable elements of the YP seemed to impede adjustment for them both: *“He's either trying to, well I guess we all are in a way, either trying to let go of or reclaim, refind, or try and figure out what has to be let go of and what can be refound and what can be worked on you know. And, trying to accept ether way. It's still early days. And we are 7 years in.”*

No fixed end point was inferred, with ongoing struggles of sense making and new challenges discussed alongside a sense of optimism and acknowledgement that the young person was in a better place in terms of their experiences of self. Recovery narratives were redefined, with Natalie explaining “*it isn't as much something that you get past, it's more that you learn to live with it*.”

Discussion

Related, yet in ways seemingly disconnected, accounts across the dyad seem to indicate a relational experience of identity adjustment. Mothers detailed a turning towards the child and engaging in a myriad of efforts to ‘fix’ and reduce discrepancies for the child; while YPs content focused much more towards their peer groups and engaging in a process of maintaining or seeking new ways to constitute oneself socially in the context of tensions around continuity and change.

Salient accounts of experiencing fundamental changes to the sense of oneself were described (Ownsworth, 2014), with discrepancies of selves (Gracey et al., 2008), challenging development of a coherent sense of self (Ownsworth & Haslam, 2016). This seemed to elicit a response in both the YP and mum to attempt to resolve or minimise these discrepancies. Importantly, for both parts of the dyad, narratives around change often sat alongside narratives about continuity (Ellis Hill et al., 2019), and these sometimes were explicitly referenced as simultaneous, though incongruent, experiences.

Markedly, the elements of self and social identity seemed deeply intertwined for the adolescents or merged (De Battista et al., 2014); which contrasts with more individualist adult understandings of adjustment and aligns well with theories of adolescence (Tajfel & Turner, 1986). Personal disparities and tensions were often characterised within a social context, indicating an entrenchment of self within the social domain at this developmental stage, and accounts indicated reciprocal interaction between self and social identities to constitute one another. Perception of self in relation to peer group was described as highly meaningful for sense of self. The sense of a ‘lost’ self (Nochi, 1998) was strongly present in some accounts, with some YPs speaking about being in a different body, sensing ‘weirdness’ or disconnection or not being the person who they were before. Some responses seemed analogous to Goldstein's concept of catastrophic reaction (1959), which Ben-Yishay (2000, p.128) described as a ‘behavioural manifestation of threat to the person’s very existence’. For mothers, their YP was experienced along a spectrum from of hereness to goneness-and sometimes incongruent simultaneous experiences of both. Core and continuous elements of the child were acknowledged alongside at times loss and bereavement.

Mothers detailed negotiating internal tension between desires to protect and prepare, grappling to meet any needs (Roscigno and Swanson, 2011) and reduce discrepancies for the young person. The challenges faced in this negotiation of mothering a child post BI who is also an adolescent with autonomy needs sometimes pointed to mothers occupying more disempowering positions - which the person with BI may experience as contesting personhood (Yeates et al., 2007). There was a notable disconnect between explicit narratives, with mothers describing processes turning towards and attempting to envelop the child, while for the child their focus on renegotiating self was described within a social context. YP accounts indicated an unspoken but lived narrative around mothers input, implicating awareness issues (Yeates et al., 2007) but also possibly a reflection of the assumption of mum as ever present for them or response to the preparing and protecting dilemma mum faces which may be buffering them from recognising the various ways they are being supported.

Though mothers spoke to making efforts to mediate and scaffold friendships as well as compensate for friendship losses, this was the area where discrepancy seemed most located in the narrative of the YPs. This is aligned with adolescent literature on the increasing importance of social belonging (Roscigno et al., 2011), but may also be that this is the area where the YP most notices change because this is the one mum can least effect infiltrate to effect change in.

There are some key similarities with an adult inductive model on identity development (Levack et al., 2014), with both referencing themes around self-identity related to self and others. However, here the self-discrepancies recognised in relation to self and those that are socially mediated in relation to others seem intrinsically intertwined in a reciprocal relationship. Accounts spoke to perceiving self as different so worrying or assuming others would too; while others illustrated how they experienced an assignment of identity from others as different or not normal, precipitating fears and existential questions and crises about self-identity.

Themes of biographical disruption and continuity identified by Whiffin et al. (2019) when considering BI in the family context could relate to the experienced tensions of change and continuity for the mother in the current study. Mothers tried to come to a place of resolve in relation to the child as is, while seeing the unlived life alongside this, and drew upon discourses of continuity and change, presence and absence, normality and abnormality in their experiences of the child. Narratives of disability were shared across the dyad accounts and situated as aligned with non-normalcy. Mothers spoke of struggling with both accepting their child as in some way changed or disabled alongside recognising the continuous unchanged child; which sat in tension with YPs goal of finding ways to maintain or reclaim an identity of ‘normal’ upon which peer relationships often seemed dependent. In the adjustment towards equilibrium part of the process, there are references to elements which could sit alongside themes about expansion of identity and post traumatic growth (Muenchberger, Kendall, & Neal, 2008).

The current findings point to a process which has a dynamic momentum but is not linear and does not end in a ‘resolved/fixed’ endpoint, despite the mothers' intentions to fix all for the young people. Accounts testified the enduring psycho-emotional responses to BI, which can progress well beyond the period of physical recovery (Muenchberger, et al., 2008). Participants did not indicate reaching a static ‘resolved’ end point, pointing towards enduring, though more tolerable, discrepancies and dilemmas for both members of the dyad.

Strengths and limitations

A key strength of the current study is the dual interview process to gain multiple perspectives on the experience of identity adjustment post adolescent BI. This facilitated a deeply contextualised and linked analysis, providing some insight into the relational space and shared process in this aspect of family adaptation; with individual interviews supporting subjugated narratives to come to the fore (Daly, 1992). Another strength is the consideration throughout of quality and rigour issues, with Yardley's (2000) set of evaluative criteria for qualitative research considered throughout to ensure its validity.

Recruitment via the specialist care team may have limited the pool to those appearing already further 'adjusted' to alterations in their sense of self or able to speak to this. Further, findings (and in particular the more constructive and adaptive elements) may be impacted by the value of the input of such specialist services for the individual, mother or dyad.

Implications and recommendations

Key similarities and differences between proposed theories of adult identity adjustment (Levack et al., 2014) are observed – particularly a merging of personal and social identities in the current study. We also get an understanding of the maternal role, and the overwhelming and encompassing nature of it at this developmental stage, in a way not seen as explicitly within the dominant discourses in the field of adult BI.

Clinical implications include being aware of, valuing and adequately supporting mothers in the multifaceted roles that they perceive themselves as occupying, which could support them in negotiating preparing and padding tensions to support YP outcomes. For young people, the research points towards the social relational role in constitution of self, at this stage. This emphasises the importance of including social supports in practice. Findings indicate a need to be appreciative of the pushes and pulls between mum, the YP, friends, and other family members as all negotiate discrepancies and tensions- and to not impose therapeutic or service models that are overly linear or structured to prevent discovery and new meanings (i.e. being overly focused on reducing deficits or achieving goals).

Conclusions

This GT provides a novel and deeply contextualised approach to understanding identity adjustment post adolescent BI through exploring and analysing this adjustment within a dyadic framework of mother and child perspectives.

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Chapter 4

Extended Methodology of Empirical Paper

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Chapter 4: Extended Methodology of Empirical Paper

This chapter functions to extend further the methodology of the empirical paper. This will include making explicit the position of the researcher in keeping with qualitative methodology (Denzin & Lincoln, 2005). The GT approach alongside an example to make explicit the analytic process will be discussed, and consideration will then be given to issues of theoretical sensitivity, reflexivity and personal reflections on the work. Lastly, a quality evaluation of the work (Yardley, 2000) will be presented to close the chapter.

Philosophical positioning

Broadly, I embrace a philosophical position of critical realism (Maxwell, 2012). Critical realism (CR) acknowledges a distinction between ontology and epistemology, arguing that reality is static while knowledge is impermanent, dynamic and in constant flux (Leroyal, 2019). CR thus acknowledges an objective reality and a world which exists separate of its identification, but alongside this the understanding that the reality can only be understood through subjective perspective.

This positions the critical realist between constructionist and positivist positions. Where constructionists posit that various realities exist (Strauss & Corbin, 2008), the assumption with critical realism is that there is a singular reality which is open to interpretation (Kempster & Parry, 2011). However, there is an alignment with constructionism - and contrast with positivism - in that it is also believed that knowledge is a social construct which is both impermanent and transitive (Sayer, 1992, Kempster & Parry, 2011). Thus a critical realist, understanding the ‘reality’ of adolescent adjustment and adaptation to ABI, requires also consideration of the dynamic / impermanent processes that arise within the family and developmental context.

I am thus also explicitly occupying a relational perspective, with an assumption that an understanding of identity adjustment and development in post adolescent ABI needs to be (at least partly) understood as an experienced shared process between adolescents and others. A relational approach allows consideration of parent/mother perspective on the ‘reality’, the adolescent perspective, and the unique implied perspective that arises between the two which provides a further triangulation on the underpinning ‘reality’

Researcher perspective

I hold a longstanding personal and academic interest in exploring adolescence, and a particular interest in how adolescents navigate the route through adolescence and into adulthood. Through undergraduate research and postgraduate clinical experience, I recognise the potential role of systemic factors in the psychological development of adolescents and their adaptive negotiation from youth through to adulthood. This impacted upon my interest in the area of the current study and the development of my research questions. Another key element of my experience which I think warrants explicitly stating here is my status as a single parent to a young child. Though no experience of having a child with BI or any other health challenges, I strongly identify as a mother and the priority I place on this role and the challenges I have experienced from a sense of holding all responsibilities as a single parent ought to be stated here. The individual experiences and narrative of the researcher play an inevitable role how one navigates the research process (Horsburgh, 2003); and my experiences and personal narrative were present when I recognised and conceptualised the mothers’ experiences in this theory. To account for personal influences, I was attuned to and made explicit any influence of my experiences through the use of a reflective diary, which is acknowledged as good practice (Yardley, 2000), and supports the managing of my positioning and associated assumptions in order to give a voice to the participants not subsumed by my own (Ahern, 1999).

Inclusion and Exclusion criteria

Criteria for YPs

Inclusion criteria for adolescents (ABI sample) were: that they were aged 10-19 years old (adolescence as defined by WHO); were living at home or receive daily 1:1 parental care ; were 6 months or more post insult (Levack et al., 2014); had experienced ABI after turning 10 years old. YPs also were required to speak English and had capacity to consent (over 16s), assent (under 16s), as identified by CCPNR. YPs were required to have sufficient communication skills to allow participation in the study.

Exclusion criteria were : Current mental illness, mood disorder or substance misuse disorder of such severity as to prevent participation in study tasks or cause severe distress for the participant or their parent; and marked expressive or receptive language difficulties, or attention impairments associated with ABI that were of such severity that they would prevent the YP from being able to answer questions or tolerate an interview scenario (clinical judgement made by CCPNR gatekeeper, in conjunction with clinical team).

Criteria for parents (parents of individuals with ABI)

Inclusion criteria for parents were: that they identified as the primary caregiver for an adolescent who acquired ABI and who was participating in the study; with capacity to consent for themselves (and their adolescent child if under 16 years old) to participate. Parents had to have the intellectual capacity, be sufficiently fluent in English and have sufficient communication skills to participate.

Exclusion criteria for parents were: current severe mental health problems or substance misuse disorder of such severity as to prevent participation in study tasks or cause severe distress for the participant

Extended participant details

Of the six dyads, one young person (Jordan) had longstanding diagnoses of autism and ADHD, and two parents (Kath and Jenny) queried if their child was on the autism spectrum, though they did not hold formal diagnoses. All children had one sibling, apart from Noah who had several older siblings. Jack and Jordan were in single parent households living with their mothers, while the other young people were all living in two-parent/stepparent households.

Grounded Theory/GT lite Analysis

Grounded theory is not executed in a uniform fashion (Morse et al., 2009) and it is possible for each researcher to develop their own particular variant of this (Willig, 2008). In this study, analysis was conducted by the main author through a novel process of linked analysis across dyads. Following transcription, an initial read through of dyads transcripts was completed. Open coding was completed in a line by line fashion in each of the individual transcripts, with the other transcript being held 'in mind' simultaneously. In this way the unique contribution of each interview was attended to, but within its dyadic context. There was an attempted identification of shared themes emerging across dyads as codes were grouped together and abstracted outwards (moving from open line by line coding towards focused and then theoretical codes). Large quantities of codes were initially created for each transcript (ranging from 88 – 276 codes in initial open coding for transcripts) and coding was managed initially utilising NVivo and then Excel software, before moving to hard copy coding at later levels of focused analysis. Efforts were made to link the individual transcript analysis within the dyads through recognising shared, parallel, reactive and complementary processes that were emerging in a unique variant of GT. Where possible, counterpart quotes were aligned and there was an effort to recognise and link patterns across the two sets of codes in an effort to capture an understanding of the shared experience and the relational processes occurring within the dyads. Attempts were made to capture a picture of the parallel, discrepant and reactive experiences that developed from participants' testimonies, to elucidate the underlying phenomenon being explored. As themes and categories began to be developed, the topic guide was adapted to become more sharpened in its inquiry in order to get closer to elucidating the emergent theory. As is a core component of GT, data collection and analysis occurred concurrently. As data was gathered and analysed, dyad by dyad, efforts were made to recognise the processes occurring within each individual, within dyads, and then ultimately through an identification of processes occurring across the dyads (i.e. distinguishing processes between YPs and their parents which are shared or different across the participant pool) and the individual members of the dyad (processes within the YP and the mother experiences). Through this iterative process, analysis progressed towards identifying the processes which were appreciated as meaningful elements of the underlying phenomena. Following the coding of data, analytical memos were drafted, and themes and categories that were developed within the data were integrated to develop an overarching theory. Throughout, a reflective journal was utilised throughout (after interviews, during analysis, etc) to capture thoughts, reflections and decisions made and it was frequently referred to in order to support theory development. Supervision throughout the analytic process supported maintenance and development of reflexivity. Lastly, there was a diagram constructed to represent the analytic findings (Hallberg, 2006).

Some examples of coding ideas from during the analytic process are shared below, working from initial line by line outwards to focused and process codes.

Below is an example of coding from line by line to process in relation to Natalie, who was describing elements of the mother’s efforts to fix everything, and the dilemma of protecting and padding that emerged.

Table 1
Natalie coding

Quote	Line by line	Reflection	Focused	Process
I mean, that could be on us. Chances are Matt forgot. But it's difficult, because you don't want to step in at every point assuming he'll forget, you want to trust that he's going to try, and step back ....to let him do it himself.	trying to give him space to develop abilities to do things for himself	stepping back to promote child's personal development	Promoting independence and autonomy	Preparing and protecting tensions
I mean, as he's getting older we're still having to do an awful lot of input, but having to hide him more and more and more because obviously as he's becoming an adult, is even more important that he's- he has the support, but he feels like he's got some independence	hiding input from child and others as he gets older	attempting independence building by hiding input	Preparing and protecting tension	Preparing and protecting tension
I tried to sort of take a step back whenever I could, because I didn't want him feeling like he was sort of under control and under watchable guard all the time. I didn't want him feeling like he was wrapped in bubble wrap. But at the same time, it's weighing up his safety needs against his sort of almost against his emotional needs.	Didn't want him feeling wrapped in bubble wrap	tension and balancing between child's safety and emotional needs	competing needs within child with BI	Preparing and protecting tension

Here is an example of the coding process in relation to Jack. These excerpts demonstrate a reciprocal relational process between self-identity and social relatedness, and how his sense of normalcy was implicated in this process.

Table 2
Jack coding

Quote	Line by line		Reflection	Focused	Process
As I was losing more and more people, I felt more and more different. -Okay. -Like I wouldn't be losing all these people if I was normal.	Losing people and feeling more different	Increasing sensing being different with increasing friend losses	Relationship between difference and connectedness? Making meaning of friendship loss	I am not normal	Relational process self in relation to others impacting self in relation to self
Something changed between me and my mates. ---Yes. ---I think it was probably from the brain injury----Yeah. ---I think I've changed quite a bit-	Brain injury causing changes between self and mates	changes to me leading to changes in friendships	recognising distinct interpersonal change with friends- disruption of past self, recognising self as changed	changes in self - changes in friendships	Relational process self in relation to self impacting self in relation to others

Theoretical Sensitivity

Theoretical sensitivity posits that the researcher must carry as few predetermined ideas and hypotheses as possible; in order to allow for them to be as sensitive to the gathered data as possible; and historically it has been recommended to delay exploring the literature in this way. However, this delay has been debated and questions raised about when might be most appropriate to review literature during a grounded theory, with it argued by Giles, King & Lacey (2013), that the evidence base supports the use of earlier review to enhance theoretical sensitivity and rigor- arguably taking the approach of having an open mind as opposed to an empty head. With this approach, literature and theory can inform the development of categories, so long as these are deeply rooted in the data and continually subject to testing, amending and refuting as necessary. It is in this way that the CI approached the data, with some knowledge of previous literature but with a transparent and reflexive approach to make explicit all influences upon the theory work so as to never force the current data to fit in with previous published literature. Journaling, note keeping and memos supported the transparency of this process.

Reflections on the work

Reflexivity

Throughout the research project, I maintained a reflective journal, and used this alongside supervision opportunities to reflect on process both within and in analysing the interviews. Through this ongoing consideration and reflection upon the data I was gathering, a richer and more thoughtful analysis was facilitated (Sullivan, Gibson & Riley, 2012). This made explicit what I had derived from and was bringing to the theory separate of the direct interview content. After my initial session, where I felt I had not effectively drawn a lot of information from the subjects on the phenomenon I was exploring, a return to my reflective journal demonstrated what I had noticed within the process of the interview which gave me valuable process information from which I could understand better about the provision of space to acknowledge change, the importance for adolescents of being " normal", and the relationship between the two.

Reflective note after Noah and Kirsty interviews:

'So important the 'normal'. For them both? She disclosed getting very involved in supporting his recovery when the interview was at time and about to finish- is this like a therapeutic disclosure in a therapy session- she did not want to give it space and deliberately avoided until then?...She wonders if he doesn't want her to worry- does she also give him the message of no troubles- i.e. keep ''normal''? ... He acknowledges with her that he has no friends but seemed defensive of this with me, offering alternate versions of his friendship experience within the one interview.

Through discussion in supervision I was able to discuss my experiences in interviews, with the support of my reflective journal, and this extended my thoughts on the interviews with Noah and Kirsty to issues of ‘threat to self’ activation (Gracey, Psaila & Ford, 2015) and reflection on when it is safe to be vulnerable within interviews - sparking considerations for me about what iteration of a person's experience I am privy to at point of interview (considered further below in this extended methodology). In this way, keeping track of thoughts and reflections, and returning to them at different points in the process, allowed me to use this information to facilitate ongoing development of further reflections, and bolstered the emergent theory as it was being developed through the coding process.

Following the data when it seems to pull away from the original question, in order to maintain integrity of work.

Based upon what I knew from the literature on brain injury within families, and theories of adolescent identity development, I had a vision of an explicit bidirectional systemic process and the challenge became recognising what was in front of me when it did not fit into my expectations, and indeed seemed to pull away from assumptions inherent in my questions about understanding the dyadic interplay- when recognition of change or issues was different across the dyad, or there was lack of awareness or attentiveness from YP to mothers input. This challenged me as I saw my two accounts as separate, because they did not meet my expectations of explicit interplay, but instead forced me in fitting my theory to the data, to recognise the disconnectedness across systems and experiences and thus within the process of identity adjustment

Who is not heard here? The voice of the father and daughter

Though not a limitation, one issue to note is the absence of representation of fathers and minimal representation of daughters in the study, leading to an unplanned focus given to the mother son dyad. With only one female adolescent within the sample and no fathers, this potentially led to certain discourses being drawn upon relating to the roles and genders represented here. This may have led for example to certain discourse being drawn upon in interviews specific to experiences of the mothering role- discourses relating to social expectations about mothers, and what a ‘good mother’ is. Through requesting primary caregivers, fathers have inadvertently been excluded from the current study, though it is reasonable to expect that they may be impacted by their child's BI and to contribute to their child's identity adjustment, from accounts given herein and broader research. Do parents occupy different roles in the identity adjustment process, and what might the father's role look like and contribute to the phenomenon being explored? And how might a broader sample of female adolescents represent their experience of identity adjustment in comparison to this predominantly male sample? Had it been possible within the resources of the study, these cases would be sought out to purposively sample across fathers and daughter in order that the final theory could provide a broader account of contextualised identity change.

Future research could capture these unheard voices and share these underrepresented experiences.

To what iteration of accounts do I have access?

In engaging with young people and their parents through this process, I came to wonder about what iteration of the persons experience was being shared with me. Though all participants had consented in and were willing to share their experiences with me, and though I had made previous contact and we had developed a preliminary relationship, the question must be considered about what level of information can be shared in a first meeting with an interviewer such as those I undertook. Establishing rapport and empathy is an essential component of qualitative interviewing, and this ideally ought to be completed over some time (Partington, 2001). Within the remit of the project, this was not possible other than via a phone call and a conversation prior to the interview proper, which gave some opportunity for establishing a trusting relationship conveying empathy and rapport- but realistically this opportunity was limited and potentially impacted upon the information disclosed in session. Given the topic being explored could potentially feel threatening as it was an exploration of one's very sense and perception of self, there must be recognition that this may have felt too threatening a topic to explore safely with me, as a stranger, on a first face to face meeting. It is plausible that, for example, someone within a specialist service who has worked alongside a YP for some time in a supportive role and spent time building a rapport and developing a trusting relationships would receive a very different iteration of accounts where perhaps more risks could be taken in terms of allowing oneself to be vulnerable or recognise threats to self within the interview process. Thus, the limitation of one-off interviews with an unknown person is acknowledged here.

Indeed, the interviewer experience could potentially be understood within the framework of the theory itself. If one element of what has been identified in this GT is a recognition of discrepancies (tensions between continuity and changes in self) that the young person makes meaning of by questioning their normalcy- then does the act of interviewing someone about their experiences post brain injury in and of itself potentially emit the message of abnormality? Might it be potentially perceived by the young person as ‘I am interviewing you because you are not normal’? And if this is the case, what threat response might that evoke from the young person? Indeed, it may be that the co-constructed analysis presented here perhaps illustrates the processes that are particularly pertinent when the YP feels ‘under threat’ or in a less interpersonally safe relational context.

Personal reflections on analytic process

Though often energised and excited by the analytic process, I also often felt overwhelmed. I realised that the continuous traversing from feeling clearer to more lost, to clearer and back again echoed the nature of the iterative approach to the work: where every new semblance of sense making was interrogated by swimming again in the data to challenge and assess its validity and whether it were truly grounded therein. In this way I moved through the competency framework (Broadwell, 1969), from initial unconscious incompetence, to a very conscious incompetence. At these points I sought out ways to address the identified gaps in my learning and brought concerns to supervision. At times I felt consciously competent before again feeling out of my depth and abilities! At times I utilised supervision to support me in unpicking what elements of my sense of incompetence were related to skills and what elements reflected the elements of discomfort, confusion and ‘lostness’ that were conveyed by some of the study participants as part of their experience. This allowed me to better evaluate where I was sitting within the competency framework as I moved through the process. Through building experience in the analytic process and receiving good, supportive supervision, I was able to more often embody an unconsciously competent position as I moved through the process.

Expanding on strengths and limitations

The dual interview process:

This data triangulation allowed for an examination of the phenomena of identity adjustment post adolescent BI through the relational experiences of both members of the dyad- as opposed to only seeking to understand the process via interviewing the YP with BI. This enabled the opportunity to develop a nuanced relational understanding of adjustment experiences for the dyad members; giving a means to explore the underlying phenomenon of identity adjustment through multiple, rich, contextual and varied perspectives on this.

Further, all but one interview was carried out individually to provide the best opportunity for all voices to be heard. Concerns about young people and their parents potentially feeling unable to share elements of their experiences in front of each other motivated the choice to promote unsupervised interviewing whenever participants were agreeable to this. (In one interview, owing to the YPs communication difficulties, his mother attended but all agreed the mother would act only as an interpreter when necessary. This provided as much opportunity possible for the son's narrative to be shared unimpeded, though it is recognised that this could have been impacted by mum’s presence). Though individual interviewing created some challenge in terms of linking content across the dyads – the opportunity to gain individual perspectives without other family members in the room potentially allowed for an account to be shared by the participants more aligned with their experiences than might otherwise have been shared.

Attending to Quality:

Yardley (2000) puts forward key criteria by which to uphold quality standard in qualitative research.

Sensitivity to context

Sensitivity to context was attended in this process: through meeting the dyads and then interviewing participants in their own homes which allowed an opportunity to gain greater insight into relational dynamics and the individual context of the participants, through the consideration of ethical issues around participation of the YPs, through an understanding of the relevant literature to allow an ‘open mind’ but not an ‘empty head’ approach to the analysis, and through a commitment to providing opportunities for both members of the dyad to have their voices heard which was facilitated through individual interviews. The dyadic coding approach to analysis is a key strength in this domain, seeking a final analysis that is thoroughly contextualised by attempting a relational coding approach.

Commitment and rigour

Commitment and rigour were ensured throughout the process: through purposive sampling, through enacting the methodology described, and through engaging at an in depth level with the phenomena through ongoing iterative analysis alongside ongoing discussions within the research team as the emergent theory was being constructed to substantiate quality. Here a limitation was that more purposive sampling could not have been conducted within the remit of the project, as this could have sought out more female adolescent, varying ages, and the unheard fathers' perspective.

Transparency and coherence

Transparency is addressed through a transparent, reflexive process involving record keeping of thoughts, reflections and decisions throughout theory development, with the analytic process elucidated in this main paper and the extended methodology. Discussion within the research team and supervisory feedback on the write-up supported ensuring coherence.

Impact and Importance

This piece of work enriches understanding of the process of identity adjustment post adolescent BI within a systemic, dyadic context, providing a novel attempt at an inductive approach towards understanding of the mother adolescent processes which can occur and the narratives which can be enacted in relation to identity adjustment post BI. Practical implications for parents and YPs are considered.

Participant Sample

The participants in the current study were identified by the specialist care team; and in discussion with the team it was acknowledged by the team that they faced a dilemma of approaching certain participants out of concern about their readiness, willingness and ability to engage in such services. As such, though criteria were upheld, the identification of participants via staff may have limited the pool to those appearing already further ‘adjusted’ to alterations in their sense of self or able to speak to this as staff managed their duty of care to patients and their sense of protectiveness for their welfare. There is the possibility that there may have been adolescent voices neglected from within the service- YPs who would have wished or felt able to share their experiences, had they been approached. As noted in the main paper, results may also be impacted by virtue of the fact YPs were receiving support from a specialist service providing rehabilitative support to a paediatric BI population, and in particular the more adaptive elements of the findings may reflect this.

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Chapter 5

Discussion and Critical Evaluation

Word Count 7025

Chapter 5: Discussion and Critical Evaluation

This chapter sets out to collate and consider the findings of this thesis portfolio, placing them in the context of the broader evidence base, and consider the ways in which they have addressed my key concerns around developing an understanding of the interplay between the parent child dyad and how this may effect psychosocial adjustment; and in particular developing a relational contextualised understanding of the adolescent mother dyadic context of identity adjustment.

Summary of research base and key findings

BI in childhood is linked with enduring adverse effects on psychosocial development in adolescence (Mc Kinley et al., 2010).and the psychosocial effects from BI can be enduring and worsen over time (Fay et al., 2009). Family context is recognised as important in relation to the impact of and rehabilitation after brain injury for the YP (Sander et al., 2013), and a reciprocal relationship is identified between YPs and their families in terms of outcomes (Law et al., 2019; Rotondi et al., 2007). Thus, questions arise over what the relational space and processes may be like between parents and their children, as YPs with BI adjust post injury, and what ways might parents' effect psychosocial outcomes for young people.

In terms of interventions for BI, parent involved interventions are recognised as a key intervention for YP BI (Wade et al., 2006). However, gaps are identified in terms of exploration and synthesis of information on efficacy of parent led intervention on child with BI, parent and family outcomes post adolescent BI (Wade et al., 2018; Laatsch et al., 2019). Most literature which does address this area fell short of Cochrane thresholds in a recent chronic illness review, impairing their ability to determine findings (Law et al., 2019). High criteria thresholds might lead to the exclusion of useful data that can add value for stakeholders (Arditi et al., 2016). Thus, the SR sought to address identified gaps with a scoping review to assess efficacy across the broader evidence base in relation to 3 key domains: psychosocial outcomes for YPs with BI, their parents, and the dyad/family. Findings were mixed and demonstrated some evidence of efficacy, but conclusions were challenging to draw within the context of an evidence base with some inherent flaws in methodology and bias considerations. Efficacious results, though not uniformly demonstrated, indicated the potential effect of parents and family context on the experience and psychosocial adjustment of the YP.

The thesis turns towards a more in-depth exploration of relational space at this point, to try to build on this and develop a contextualised understanding of adjustment within the dyadic context, around identity adjustment in adolescence specifically. The thesis takes a CR orientation to a richer understanding of the mechanism of adolescent ‘adjustment’- recognising this to be embedded in and influenced by individual and relational / social / developmental / family processes. As such it brings together analysis of individual interviews and relational coding to get at these possible mechanisms.

A key element of psychosocial adjustment is identity adjustment, which is posited to be a core task of the transition through adolescence (Erikson, 1959; Marcia, 1980). Adult literature indicates experiences of changes and adjustment (Nochi, 1998; Gracey et al., 2009) which can be experienced as loss, but also as growth and gains (Ellis-Hill, 2008). An adult GT has been developed to conceptualise identity (Levack et al., 2014), but no such identity adjustment theories have yet been proposed in relation to adolescence, and within a family context. Given the importance of this phase in relation to identity development, adolescents with ABI are particularly vulnerable to experience discrepancies between their current self-identity and past or hoped for selves (Van Leer & Turkstra, 1999). Therefore, the EP sought to address an identified gap in understanding identity adjustment in an adolescent post BI population utilising a novel inductive approach to generate a critical realist and contextually sensitive grounded theory of identity adjustment. Core themes emerged around tension and incongruence between perceived continuity and change, and the acknowledging to rejecting of these. Findings pointed to a relational process whereby, following the experience of discrepancies with self, both the YP and mother engaged in processes of recognising and trying to resolve discrepancies in their own distinct ways. Both mothers and children recognised themes of readjusting towards a tentative equilibrium; though the process of identity adjustment was acknowledged as in flux, not linear, and without a sense of a final fixed end point but rather an ongoing liminality.

Key considerations emerging from the completion of this portfolio relate to:

a) A relational type of disconnect which emerged from the EP narratives, with mothers expressing being turned towards and trying to fully support and hold the YP, while the YPs narratives described being turned towards their peer relationships and efforts to constitute their sense of self socially

b) The subjugation of the narrative of the person with BI. A question about the YP with BIs voice and if/how this is being heard was highlighted across both papers

c) A consideration of the potential impact of the developmental stage of the YP upon the dyadic relationship and upon intervention outcomes

d) The mother’s role and responsibilities in terms of supporting adjustment for young people is highlighted, and a curiosity about the fathers positioning in psychosocial adjustment and their unheard narrative

Systematic Review

The systematic review provided useful findings on the state of the current research base; demonstrating mixed efficacy across intervention types. Though certain results seemed promising (SSTP & ACT for individual, parent and dyadic outcomes; FPS for child outcomes; I-InTERACT for dyadic outcomes); this was within the context of a broadly problematic evidence base in terms of study quality. Some outcomes were implicated as potentially effected by specific parental interventions, but there were key concerns around replicability, and uniformly high levels of risk of bias impacted upon interpretation. The discrepant overall quality of reporting quality and bias risk highlights how papers can adhere to CONSORT guidance and score well on reported methodology, while the studies detailed may still carry high risks of bias according to the Cochrane Risk of Bias tool. However, Cochrane RoB tool was found in an evaluation of user practice (Jorgensen et al 2016) to determine only 6% of papers as having low risk of bias across all core domains, indicating potential lack of usefulness on specific domains when assessing less than gold standard research, which may be problematic in emergent literature bases like paediatric BI. Though the breadth of papers included was poor quality in relation to bias, the same breadth allowed for a nuanced picture to be captured of the literature currently available and wide limitations and gaps in the research base were identified. Though certain parent involved interventions demonstrated mixed or positive findings in relation to parent, YP and dyadic/family psychosocial outcomes; more robust research with better consideration of dyadic issues and against appropriate active controls are needed to provide more robust findings and explore mechanisms of change.

Considerations emerging from the SR

A key question which emerged from the review was around the voice of the YP with BI, and the possibility of this being underrepresented in the research. Though there are arguments about who is best placed to rate on behavioural outcomes (with parents arguably more aware of behavioural changes, and objective raters providing useful objective data), there were concerns that the YPs subjective experience was not being attended to. Questions about whether outcomes tapped for this as well as they could have been were raised, and concerns about the risk for the YPs narrative to be subjugated were noted. This potentially reflects a discourse around the person with BI needing ‘management’ (reflected in the focus on parent rated behavioural outcomes), with less attention given to subjective experience. This perhaps reflects an assumption of disability impacting upon ability to complete measures in a way considered objectively useful, potentially marginalising individuals and losing valuable information that may support intervention development.

Leading on from this question about the experience of the person with BI being subjugated, consideration is also given to the developmental stage of participants; which may impact upon the dyadic process. While family involved interventions are a key rehabilitation approach post YP BI; the peer focus shift of adolescence to increasingly constitute elements of self-identity (Tajfel and Turner, 1986) within a social context, may have developmental implications for dyadic parent child relationships. This may affect level of engagement and outcomes for YPs in parent and family involved interventions. The completion of outcome measures was observed in this review to seem unconsidered for YPs. It is suggested that it may be of value to seek to understand the experience of the YP, but it is also noted that developmental stage ought to be appreciated alongside this. While a young child may struggle to reflect and answer questions on their subjective self-states in an outcome assessment approach, an older child or adolescent who is able to engage in a multifaceted intervention on problem solving may well be able to complete self-reports.

Lastly, mothers were noted to comprise the vast majority of participants in all interventions reviewed. When fathers were mentioned, this was sometimes as a second and supplemental parent, as opposed to parent completing in lieu of the mother. These observations lead to a curiosity about why the roles and responsibilities seem to have fallen heavily upon the mothers of the YP participants in the SR.

Limitations of the SR

Limitation of the review papers were noted, including the tentativeness of findings in the context of a poorer quality pool of research with high risk of bias throughout. Limitations of the review process were noted, including efforts at co-rating to substantiate quality: co-raters assessed only sub sections of papers considered for inclusion and completing quality and bias ratings on only sub sections of papers reviewed. Though co-rater reliability was high, this leaves a possibility of some difference in outcomes that a full co-rating process across all papers could have protected against.

Strengths of the SR

Strengths of the review were that it added a nuanced and systemic picture of a wide range of findings related to parent-involved interventions for YPs with BI, answering questions on the efficacy of such interventions for parents and children in relation to the broadest range of studies owing to lower criteria for inclusion of studies. Wide gaps in the evidence base are recognised, including high risks of bias, underreporting of effect sizes, and risks related to the multiplicity of outcomes assessed and published in relation to overarching parent studies. Challenges in interpreting findings and a lack of clarity about mechanisms of change are acknowledged. Dyadic issues are considered and implications for future research are suggested.

Empirical Paper

The EP provided a local understanding of a contextualised experience of identity adjustment post adolescent BI within a dyadic mother child context. Accounts highlighted parallel and interacting procedures as YPs and mothers both responded to experienced discrepancies for the YP with attempts to understand this, through the acknowledging and/or rejecting of experienced discrepancies; followed by efforts to reduce and resolve these tensions and discrepancies in the YPs identity. YPs spoke about a socially mediated process to determine their sense of continuity/changedness and normalcy/abnormalcy, and accounts detailed a sense of self and social identities being intrinsically linked for the YPs. Mothers shared accounts of continuity and change in their experience of their child's identity and their own, and sought to resolve discrepancy through attempting to fix things for their YPs. Tensions were described, with mothers engaging in potentially discrepant acts of preparing and protecting, as they sought to address any needs they could identify for the YP. Accounts detailed efforts to balancing different and sometimes discrepant interpersonal needs for the YP, in efforts to 'fix' everything for the YP. Adjustment processes were referred to within the dyads, with mothers supporting young people to reduce and resolve discrepancies between the now self and other selves. This occurred alongside efforts to resolve tensions in their own sense of their identity as mum being both changed and unchanged. Finally, a type of tentative equilibrium was described, though notably this was not in any dyad described as a fixed endpoint, and there was a sense that all dyads recognised (either individuals or the whole) a sense of ongoing challenges or remaining discrepancies which dyads were either still attempting to resolve or come to terms with in some way.

Considerations emerging from the EP

One key issue for consideration which emerged was one around the perceived disconnect between YP and parental accounts of identity adjustment within the dyadic context. The expectation of more explicitly spoken narratives around relational interplaying processes is acknowledged. Such expectation was not met during the analytic processes. Mothers explicitly enacted narratives around being mum and working to ‘fix everything’ for the YP, the counterpart accounts of YPs pointed more often towards lived but unspoken narratives in terms of relational processes with mum. Though some elements of the ways that mum supported identity and broader psychosocial adjustment were recognised, oftentimes mum occupied a less recognised role in the relationship from the YP perspective. YPs accounts detailed instead a negotiation of self-identity mediated through friend relationships: from senses of relatedness and belonging, to rejection and withdrawal. The lack of explicit links and apparent disconnect between narratives was experienced as a challenge to analysis initially. However, through the ongoing analytic process, this came to be understood as important information relevant to the emergent theory, as the misalignment of narratives for the person with BI and other family members was observed (Ellis Hill, 2019). This disconnection between the dyad contributed to a sense of the analytic process feeling challenging at times as connections and reactions between parent and YP processes were sought, but ultimately encouraged the CI into engaging at a more abstract level, moving beyond the literality of the transcripts into a more constructivist space- while continually interrogating developing ideas and theorising to ensure this remained rooted in the data.

The second key consideration which emerged from the EP was the question of the YPs accounts, and whether in some way related to their injury, the YPs experience and narrative had not been adequately captured. Much less codes were identified across the YP interviews than the parent interviews, covering less range of domains owing to the heavy focus on friendship connection and belonging. Interviews with YPs were shorter on average than parent interviews, and upon reflection, it was noted that YPs did not seem to bring the same level of enthusiasm to share their experiences as the mothers and sometimes appeared restless or uncomfortable during the process. In contrast, interview endings often felt difficult owing to the volume of content the mother sought to share. Though both parties received age appropriate information and were free to consent, not consent, or withdraw at any point through the interview; in hindsight a question arises around who might have been more motivated to participate in the research. Perhaps the lower levels of content (comparatively) for YPs represents the mother's narrative being the dominant discourse following their injury within the dyad. The nature of mother's accounts was about ways she was 'doing' in order to hold her child up in many senses, and an attempt carry them forward on the path of adjustment through her efforts. This 'doing' was echoed in the ways mothers engaged in 'doing' the interview, where accounts were experienced by the CI often as full and overwhelming in their nature. The nature of the YPs accounts were in many ways about confusion, uncertainty and loss in the experiencing of discrepancies in self. Interesting too then, that these interviews yielded much less volume and range of data. Perhaps this reflects the existential nature of the YP experience, and the 'lostness' of self-described in accounts.

From a brain injury sequelae perspective, concrete changes to the brain may have impacted upon how YPs could comprehend and engage with the interview content introduced by the CI, and the data could reflect interviewer inexperience at conducting qualitative research with this population or fielding questions at an appropriate level to facilitate comprehension. Issues potentially related to the 'fabric' of the interviews seeming so different may be issues around self-awareness (Yeates et al., 2007), and the threat to self-identity (Gracey et al., 2009). Both felt salient at certain points in certain interviews. Given contesting accounts and misaligned narratives which sometimes were described within dyads (Yeates et al., 2007; Whiffin et al., 2019), it may be that different or impaired self-awareness led to a different quality to the data. Alternately, or perhaps alongside this, it may be that (as reflected in the EM) the very nature of being interviewed by a doctoral student the interviewees did not know, about identity adjustment as a topic, may have heightened a sense of threat to self (Gracey et al., 2009) and impacted upon their ability to feel interrelation ally safe in the interviews and disclose more vulnerable elements of their experiences of self-identity. Indeed, in the first dyad, where the YP shared a strong narrative of 'I am unchanged in all ways and I am normal', threat activation seemed to be enacted in the interview. From the CIs perspective, there was a noticeable discomfort and restlessness from about 15 minutes in, before later him taking an extended break. Later the YP acknowledged that the questions made him feel uncomfortable, for reasons he struggled to elucidate, and he and the CI agreed to end the session early when this was suggested by her as an option. This might be understood as an example of threat to self-activation in vivo. In conclusion, for a great many reasons, the interview yielded by parents and YPs spoke not just to different aspects of identity adjustment in its content, but the data of the brain injured adolescent was different by its very fabric, with many potential reasons.

Adolescence development: Further possible explanations for difference context from mothers and young people could relate to challenges in interviewing adolescents in comparison to adults and in exploring reflections on identity with a population still going through a key developmental stage in relation to the negotiation of this as adolescents (Erikson, 1959; Marcia, 1980). Bassett et al (2008) explored the methodological challenges specific to interviewing adolescents in SSIs and reported that encouraging a conversation with an adolescent in this format was fraught with challenges, and that exploration of abstract concepts impacted upon conversational abilities, and challenges were observed both with recruitment and with the silencing effect of recording. The CI experienced all of these to greater or lesser degrees of salience through the process, and as with adjustment more generally, it was challenging in interviews to understand what was developmentally impacting upon the interview process owing to adolescence (as opposed to brain injury). Indeed, the challenge of understanding each other is in the interview process was within the context of these developmental issues alongside BI - and its cognitive and emotional sequalae that may impact a discussion encouraging self-reflection on a potentially emotive topic. This has implications for how YPs might engage within the parent child dyad, with increasing focus towards and time spent with peer relationships in a typical trajectory. For mother child dyads, the EP highlights how the fundamental value placed upon friendships to constitute self has an inevitable impact upon the relational space of the dyad, and identity adjustment is detailed as occurring within a social context, while physically occurs within a familial one. This is a key point to consider and may highlight a need to focus more on understanding identity within a social context in research and rehab approaches. If the child is seeking to reduce discrepancies by realigning or reframing so that he feels more in line with a ‘normal’ person on a ‘normal’ trajectory, then how might it feel to have it suggested to you that you are to be supported through family only interventions, at a time when peer relatedness feels core to a sense of self? While adolescence is long established as a period of identity transition mediated through social belonging, narratives in this EP speak to a deep need to feel aligned, accepted and assigned identity in the context of friendships- and some accounts detailed deep distress when perceiving friendships as withdrawn or rejecting.

Lastly, mums reflected processes of supporting their child’s identity adjustment through an occupying of all roles that needed filling and efforts to do everything, at all costs, to fix and resolve discrepancies for the YP. This brought up dilemmas, balancing discrepant needs for the child, and struggling with sometimes incongruent desires to simultaneously protect and prepare then. Mothers shared narratives aligned to social discourses expectations about mothering and what a good mother is, and described efforts to almost envelop and carry the child forwards on their identity adjustment path by whatever means they possibly could recognise to support a reduction of discrepancies and associated distress for the child and them self.

Limitations of the EP

One limitation of the current project may be the limited qualitative experience of the CI, as it has been proposed that the integrity and perspective of the researcher is integral for the conducting of the achieving of good quality qualitative analysis, and that it is often experience which facilitates these qualities in the researcher (Pope et al., 2000). Another is the participant recruitment, which it is acknowledged may have been impacted by the identifying care team's process of identifying potential recruits for the study, which may have inadvertently excluded voices which wished to and were able to be expressed. Purposive sampling had some limitations, and a more resourced GT could have looked at recruiting a braider age range and seeking individuals not represented yet in the data (giving opportunities to more daughters to share their narratives, and to give opportunity for the absent fathers accounts to be shared). This could have led to a broader understanding of the processes that might play out interrelationally in relation to identity adjustment post adolescent BI.

Strengths of the EP

The study provides a novel approach to exploring the phenomenon, providing a deeply contextualised account of identity adjustment within a systemic context that is grounded in the data. Efforts are made to hear the narrative of the individual with BI, and the study adds a valuable contribution in relation to an identified gap in the youth BI literature on identity adjustment. Clinical implications are considered in relation to YPs and mothers.

What this adds to the evidence base

Results from the SR were complicated, and mixed. The field of research was identified as problematic in many domains. However, some promising findings and reasonable effects were demonstrated in relation to parent involved interventions at the YP, parent and dyadic levels. This provides an up to date answer (following Brown et al., 2012), but was unable to provide a definitive one, on the question of demonstrated efficacy in relation to individual, parent and dyadic outcomes in relation to parent involved interventions post YP BI. The utilisation of a lower threshold approach to criteria for inclusion and a narrative synthesis of the data could be argued to complement higher threshold assessments like Law et al (2019); allowing for a consideration of the lower quality tiers of the research base alongside more stringently conducted RCTs with large numbers of participants.

The EP demonstrated a complex picture, where the dyad went through parallel process of identity adjustment, but with some disconnect within dyads in the context of these interacting processes. This adds valuable insight into the relational process post BI for YPs and their mothers, attending to an identified gap in the research and utilising a novel approach to provide a deeply contextualised account of identity adjustment within the family system.

Considering the key findings in tandem:

Disconnect within the dyad and the subjugated subjective narrative

Misalignment of narrative, disconnected accounts and absent accounts

One of the key findings from this portfolio is the question of the subjective experience of the person with BI. Oftentimes YPs and mums shared what seemed like disconnected narratives, with the mother's narrative seeming prioritised in her discourse as the aware version. Indeed, I struggled with hearing a YP tell me his friendships were all intact 5 minutes after telling me they were not, as I moved out of my epistemological stance and momentarily prioritised my own ability to ascertain objective truth higher than his. The subjugation of the YP narrative also seems a relevant consideration in relation to the SR, where there was not space given in more of the studies to seek child rated outcomes despite assessing children's emotional wellbeing. The thesis thus highlights the risk of subjugation of the narrative of the person with BI, inferring an awareness hierarchy and risking the devaluing of personhood in not attending to and appreciating subjective experiences. Including YPs with BI in assessing interventions they participate in, and in providing space for their narratives to be heard as in the EP; will enhance the understanding we can develop around psychosocial adjustment and identity.

Considering Adolescents

Child and adolescent developmental issues are highlighted in the findings- The developmental age and stage of the YP is considered, in relation to the SR and questions raised about when this might prevent engaging more with feeding back on their own experience, and when it may not. Appreciation of the developmental age and stage of the YP could allow for an individualised approach to assessment collection, as opposed to a blanket choice against this in relation to age. When emotional outcomes are being targeted, and outcomes available to assess this from a child's perspective, it is proposed that an absence to do so risks a disconnect between research findings and the lived experience for YPs. It may be that young people with BI are doubly disadvantaged in terms of having their experiences prioritised, seen as individuals who need a lot of management on both counts and seen as less able to attest to their own experience. This has implications for the interpretation of findings when parent rated; give the EP evidences dyads may have contesting perceptions and accounts on experiences.

Developmental considerations are considered in relation to adolescents specifically in the EP, and the relational context described between mother and child indicates an inevitable impact of adolescence on the dyads relational space. The GT demonstrates the enormous value placed on friend groups and social relatedness. Adolescents described experiences of feeling abnormal when perceiving self as socially not accepted, and peer relationships seemed intrinsically interwoven with self-identity for adolescent. The shift towards friendships for constitution of self is highlighted in the reciprocal nature of self and social identities; which is a process the YP is engaging with relationally even though physically is within the family context. This has implications for therapeutic approaches, and importance of appreciating this fundamental process of relatedness to peers, given these are likely to be in a family context.

The all-encompassing mother role (and a curiosity over the father child relational space)

The SR highlighted the responsibilities related to parent involved interventions were being held overwhelmingly by mothers. These observations lead to a curiosity about why the roles and responsibilities seem to have fallen heavily upon the mothers of the YP participants in the SR; and (leading from this) a curiosity about potential impacts of father child interactions and if there might be variance in outcomes for YPs, parents or the dyads with a different gender balance to the interventions assessed. The EP echoed this in a sense, with no fathers among the sample of primary caregivers and mothers strongly identifying with fighting for the child, advocating for them and doing everything they think will help for an indefinite amount of time at all costs. Fathers have not been heard in the EP, and as with the SR would no doubt add useful insight and further understanding about the relational space between the parent and child post BI.

Taken together, the two papers herein have sought to better understand the relational space between YPs with BI and their parents, and the way the dyadic interplay and co-constructed experience may potentially affect psychosocial outcomes (generally) and identity adjustment (specifically) for the dyad members individually and in tandem.

Strengths and limitations of the overall portfolio

What the SR offers is meaningful in demonstrating a current profile of the literature but is limited in some key ways. Though the low threshold for inclusion allowed a breadth of outcomes to be included, it also changes the profile of include papers by reducing quality of papers and increasing risk of bias. The EP brings a valuable and novel co-constructed dyadic understanding of identity adjustment post adolescent BI, which is a gap in the current research on adolescent BI. However, as with all qualitative constructivist research, the understanding developed here is specific to the dyads included and cannot be generalised the same way a more positivist approach to the grounded theory may have allowed for.

Limitations to the portfolio

The narrative approach to the overall portfolio could be considered a limitation in so far as there is not a quantitative focus to this portfolio in either analysis. Owing to the nature of this portfolio being conducted as part of a doctorate in clinical psychology, there was as a result a limitation of resource available – most notably time for completion. Ideally, as discussed amongst the research team, having the opportunity to return to the participants to reflect emergent theory and themes for feedback could have added a further level of integrity to the data.

It is acknowledged that this is an initial attempt to understand the adolescent individual adjustment in the context of the complex dynamics of the changing relationship with parents as they develop, and the role of parent as carer following BI. Further research is needed to explore and develop the tentative GT process outlined in this small study.

Strengths to the portfolio

There are key strengths to the work. There was a consideration throughout the portfolio of integrity of the work. Quality was attended to through utilising co-reviewers to support paper selection and review in the SR and recommended practices for maintaining quality (Yardley, 2000) were adhered to in relation to the EP. Throughout both papers, I strongly held in mind the YP whose experience I was trying to ensure was heard, and which I increasingly came to feel was not fully afforded an opportunity to be attended to. Through being explicit about my own self-identified alignment with a ‘mum holding all responsibilities’ type narrative -and thus my awareness that with this I might not attend as well to an understanding the YP- an explicit recognition of my risk to shape the theory in line with my own narrative allowed me to be sensitised to the YP position alongside my own. This came to heighten my attentiveness to key findings around subjugation of narrative for the YP.

Complexity of the picture

Findings in this portfolio demonstrate a complex relational picture of dyadic interaction and adjustment post youth BI. Though many outcomes were implicated in the SR as potentially affected by parent involved interventions, results were often not replicated or mixed. Moderators come into play, some interventions impact later, others are initially efficacious and then return to baseline. This creates a complex picture of the ways in which parents may be able to effect positive change for their children, themselves and the dyad. Not dissimilarly, in the EP, the results demonstrate a complex set of findings where there are ongoing tensions within and across the dyads. YPs are understood by themselves and their mothers and others as existing on a spectrum from continuous to changed in self-identity- and sometimes both simultaneously. Efforts are made to resolve inherent tensions between the now and other selves that are arguably inherently irresolvable in some sense by their nature. Liminality was indicated, and a dilemma seemed to be described of trying to find ways to resolve and feel ok with what feels inherently not ok? While some re-establishing of equilibrium is achieved, this is within a narrative of ongoing challenges, tensions and discrepancies.

Clinical Implications and directions for future research

Clinical implications are considered when looking to support individuals with YP BI and their families. Findings highlight the importance of recognising and supporting mothers in the all-encompassing role they speak to occupying post YP BI. Fathers are not as represented in the data from either the SR or EP, and adding this voice to the literature would be valuable in terms of developing insight on the nature of dyadic interaction and the relational space between, and how fathers may be understood within the context of psychosocial adjustment. Further understanding of the father position in relation to YP adjustments and the possible barriers or ways they might be supported to engage more in interventions for YPs, and the resultant efficacy of this, would be valuable in terms of an understanding of adjustment within a family context.

For the YP, the importance is highlighted of appreciating the developmental context of their age and stage. For adolescence, a complex set of within-family and outside family / peer dynamics seem to arise – the importance of appreciating the very major role of peers to adolescents with BI and need for this to be taken into account by those taking a systemic perspective to research or practice which might end up being more family / parent focused

Personal Reflection

In trying to develop an understanding of the phenomenon being explored in the EP, I found myself often seeking the ‘right’ answers and feeling anxious in the uncertainty of the unknown. In retrospect, I realised that the emergent findings were so multifaceted and what was developing was a complex dyadic interplay that felt challenging to capture. This led to me feeling the work was too overwhelming and complex for me (and thus eliciting a personal sense of worry and incompetence) as opposed to that the findings were actually pointing towards a deeply overwhelming and complex process for the dyads. In trying to manage this response, I at times moved into such a rigid anxious position that I would attempt to ensure that I stayed truly grounded in the data by occupying a more positivist position than I intended to. At these times I noted that my creativity would stall, and I would almost withdraw my self-assigned remit to develop a theory (transparently). On these occasions, reflective supervision and engaging with my reflective journal were very useful to support recognition of where I was personally in relation to the analytic process. The iterative nature of analysis and constant return to data alongside developing the theory was very useful in facilitating progress when I felt stalled in this way, as ongoing interrogation of data inevitably brought new ways of looking at things and was such an in flux process that it stimulated movement in myself in response to its fluid nature.

Overall Conclusion

This portfolio adds valuable insight on the relational space between the young person with BI and their parent post injury. The ways in which parents may affect adjustment for the YP, themselves and the dyad are explored in the SR; and the phenomenon of identity adjustment within the dyadic context is presented in the EP. The SR provides a nuanced synthesis of the current scope of parent involved interventions for BI and the EP provides a deeply contextualised understanding of the relational dyadic processes of identity adjustment post adolescent BI. In tandem, the findings explore the relational space between YPs with BI and their parents, and the ways in which parents and their children engage in relational processes of adjustment.

Four key considerations emerged from the findings: Issues around disconnection between experiences and narratives of the YP with BI and the parent; observation about the ways that mothers seem to occupy the position of the person in the family who holds a key responsibility in relation to supporting YP adjustment (and related to this, the absent data on and voice of fathers throughout); Issues around how the dyad is considered in research effectively so that the experience of the young person with BI is not unheard or subjugated to the dominant discourse of the mother; and considerations over child and adolescent development. This was considered both in terms of developmental ability to engage with and respond to self-reflective questions to convey own experiences, and in relation to the impact of adolescence development and the shift towards peer focus in relation to the parent child relationship and how they experience this.

As a whole, this portfolio supports understanding of the dyadic reciprocal relational space and the ways that the parent may support adjustment of the young person with BI in relation to psychosocial outcomes (SR) including identity adjustment (EP); with clinical implications and ideas for future direction suggested.

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Appendices

Appendix	Description
A	**Author Guidelines for submission to Neuropsychological Rehabilitation**
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M	**Consent to Contact Form- Adolescent**
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Y	**Appendix Y – Process elements elicited in the GT**

Appendix A- Author Guidelines

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Observational studies: submitted papers should follow the STROBE guidelines (https://www.strobe-statement.org/index.php?id=strobe-home) and also include a completed checklist of compliance, together with the corresponding page number of the manuscript where the information is located.

Qualitative studies: should follow the COREQ guidelines (http://www.equator-network.org/reporting-guidelines/coreq/) and be accompanied by a completed COREQ checklist of compliance, together with the corresponding page number of the manuscript where the information is located.

The EQUATOR Network (Enhancing the Quality and Transparency of Health Research) website provides further information on available guidelines.

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

Word Limits

Please include a word count for your paper. There are no word limits for papers in this journal.

Format-Free Submission

Authors may submit their paper in any scholarly format or layout. Manuscripts may be supplied as single or multiple files. These can be Word, rich text format (rtf), open document format (odt), or PDF files. Figures and tables can be placed within the text or submitted as separate documents. Figures should be of sufficient resolution to enable refereeing.

- There are no strict formatting requirements, but all manuscripts must contain the essential elements needed to evaluate a manuscript: abstract, author affiliation, figures, tables, funder information, and references. Further details may be requested upon acceptance.
- References can be in any style or format, so long as a consistent scholarly citation format is applied. Author name(s), journal or book title, article or chapter title, year of publication, volume and issue (where appropriate) and page numbers are essential. All bibliographic entries must contain a corresponding in-text citation. The addition of DOI (Digital Object Identifier) numbers is recommended but not essential.
- The journal reference style will be applied to the paper post-acceptance by Taylor & Francis.
- Spelling can be US or UK English so long as usage is consistent.

Note that, regardless of the file format of the original submission, an editable version of the article must be supplied at the revision stage.

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Checklist: What to Include

1. **Author details.** Please ensure everyone meeting the International Committee of Medical Journal Editors (ICMJE) requirements for authorship is included as an author of your paper. All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.
2. Should contain an unstructured abstract of 200 words.

3. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.
4. Between 5 and 5 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.
5. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:
   For single agency grants
   This work was supported by the [Funding Agency] under Grant [number xxxx].
   For multiple agency grants
   This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].
6. **Disclosure statement.** This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. Further guidance on what is a conflict of interest and how to disclose it.
7. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). Templates are also available to support authors.
8. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.
9. **Geolocation information.** Submitting a geolocation information section, as a separate paragraph before your acknowledgements, means we can index your paper's study area accurately in JournalMap's geographic literature database and make your article more discoverable to others. More information.
10. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.
11. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, TIFF, or Microsoft Word (DOC or DOCX) files are acceptable for figures that have been drawn in Word. For information relating to other file types, please consult our Submission of electronic artwork document.
12. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
13. **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.
14. **Units.** Please use SI units (non-italicized).

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Disclosure Statement

Please include a disclosure statement, using the subheading "Disclosure of interest." If you have no interests to declare, please state this (suggested wording: *The authors report no conflict of interest*). For all NIH/Wellcome-funded papers, the grant number(s) must be included in the declaration of interest statement. Read more on declaring conflicts of interest.

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In order to be published in a Taylor & Francis journal, all clinical trials must have been registered in a public repository at the beginning of the research process (prior to patient enrolment). Trial registration numbers should be included in the abstract, with full details in the methods section. The registry should be publicly accessible (at no charge), open to all prospective registrants, and managed by a not-for-profit organization. For a list of registries that meet these requirements, please visit the WHO International Clinical Trials Registry Platform (ICTRP). The registration of all clinical trials facilitates the sharing of information among clinicians, researchers, and patients, enhances public confidence in research, and is in accordance with the ICMJE guidelines.

Complying With Ethics of Experimentation

Please ensure that all research reported in submitted papers has been conducted in an ethical and responsible manner, and is in full compliance with all relevant codes of experimentation and legislation. All papers which report in vivo experiments or clinical trials on humans or animals must include a written statement in the Methods section. This should explain that all work was conducted with the formal approval of the local human subject or animal care committees (institutional and national), and that clinical trials have been registered as legislation requires. Authors who do not have formal ethics review committees should include a statement that their study follows the principles of the Declaration of Helsinki.

Consent

All authors are required to follow the ICMJE requirements on privacy and informed consent from patients and study participants. Please confirm that any patient, service user, or participant (or that person's parent or legal guardian) in any research, experiment, or clinical trial described in your paper has given written consent to the inclusion of material pertaining to themselves, that they acknowledge that they cannot be identified via the paper; and that you have fully anonymized them. Where someone is deceased, please ensure you have written consent from the family or estate. Authors may use this Patient Consent Form, which should be completed, saved, and sent to the journal if requested.

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Please include all relevant safety precautions; and cite any accepted standard or code of practice. Authors working in animal science may find it useful to consult the International Association of Veterinary Editors' Consensus Author Guidelines on Animal Ethics and Welfare and Guidelines for the Treatment of Animals in Behavioural Research and Teaching. When a product has not yet been approved by an appropriate regulatory body for the use described in your paper, please specify this, or that the product is still investigational.

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Authors are further encouraged to cite any data sets referenced in the article and provide a Data Availability Statement.

At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.

Where one or multiple data sets are associated with a manuscript, these are not formally peer reviewed as a part of the journal submission process. It is the author's responsibility to ensure the soundness of data. Any errors in the data rest solely with the producers of the data set(s).

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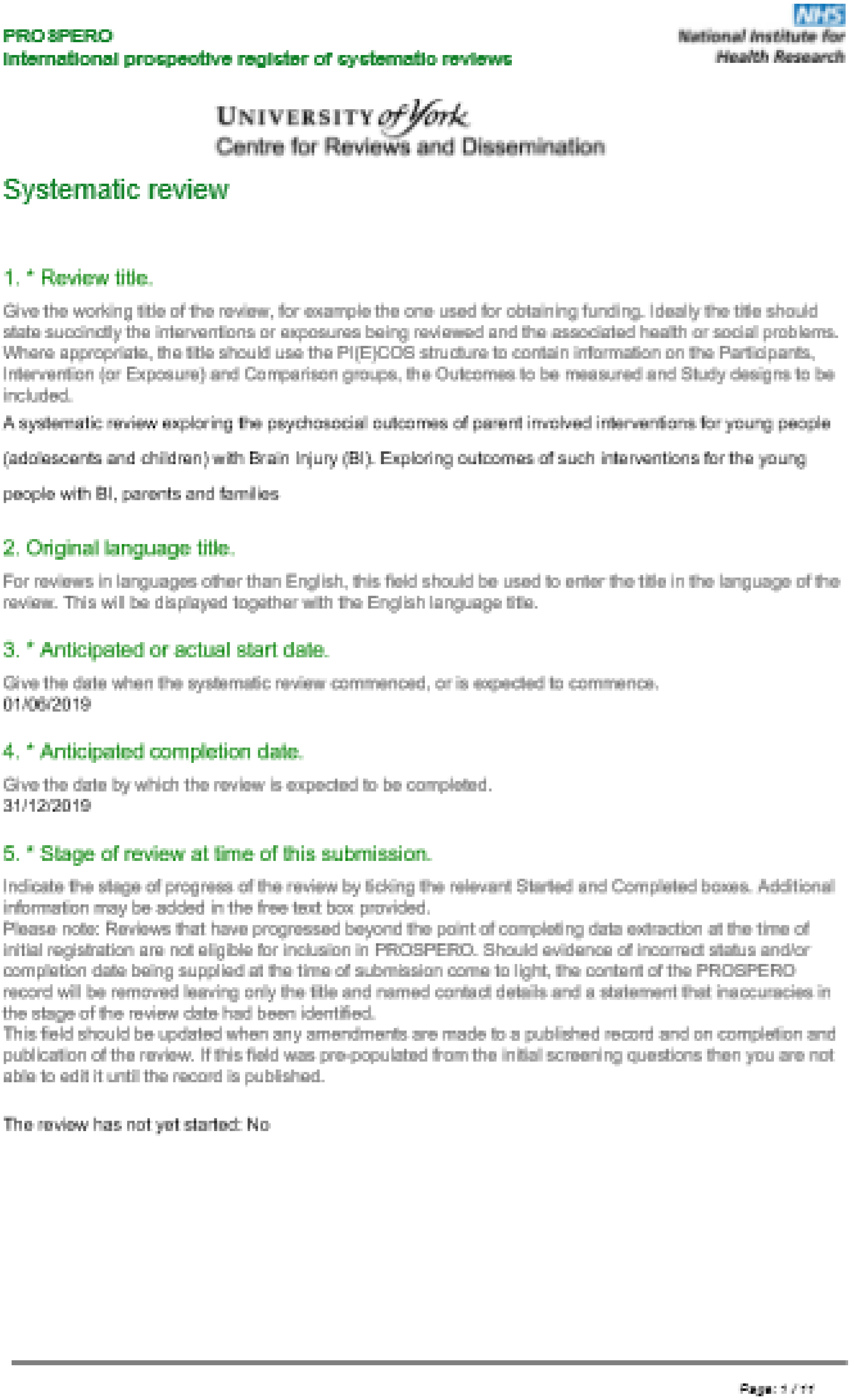
Updated 26-07-2019

Appendix B - Prospero Registration for Systematic Review



PROSPERO
International prospective register of systematic reviews

NHS
National Institute for
Health Research

UNIVERSITY of York
Centre for Reviews and Dissemination

Systematic review

1. * Review title.

Give the working title of the review, for example the one used for obtaining funding. Ideally the title should state succinctly the interventions or exposures being reviewed and the associated health or social problems. Where appropriate, the title should use the PI(E)COS structure to contain information on the Participants, Intervention (or Exposure) and Comparison groups, the Outcomes to be measured and Study designs to be included.

A systematic review exploring the psychosocial outcomes of parent involved interventions for young people (adolescents and children) with Brain Injury (BI). Exploring outcomes of such interventions for the young people with BI, parents and families

2. Original language title.

For reviews in languages other than English, this field should be used to enter the title in the language of the review. This will be displayed together with the English language title.

3. * Anticipated or actual start date.

Give the date when the systematic review commenced, or is expected to commence.
01/06/2019

4. * Anticipated completion date.

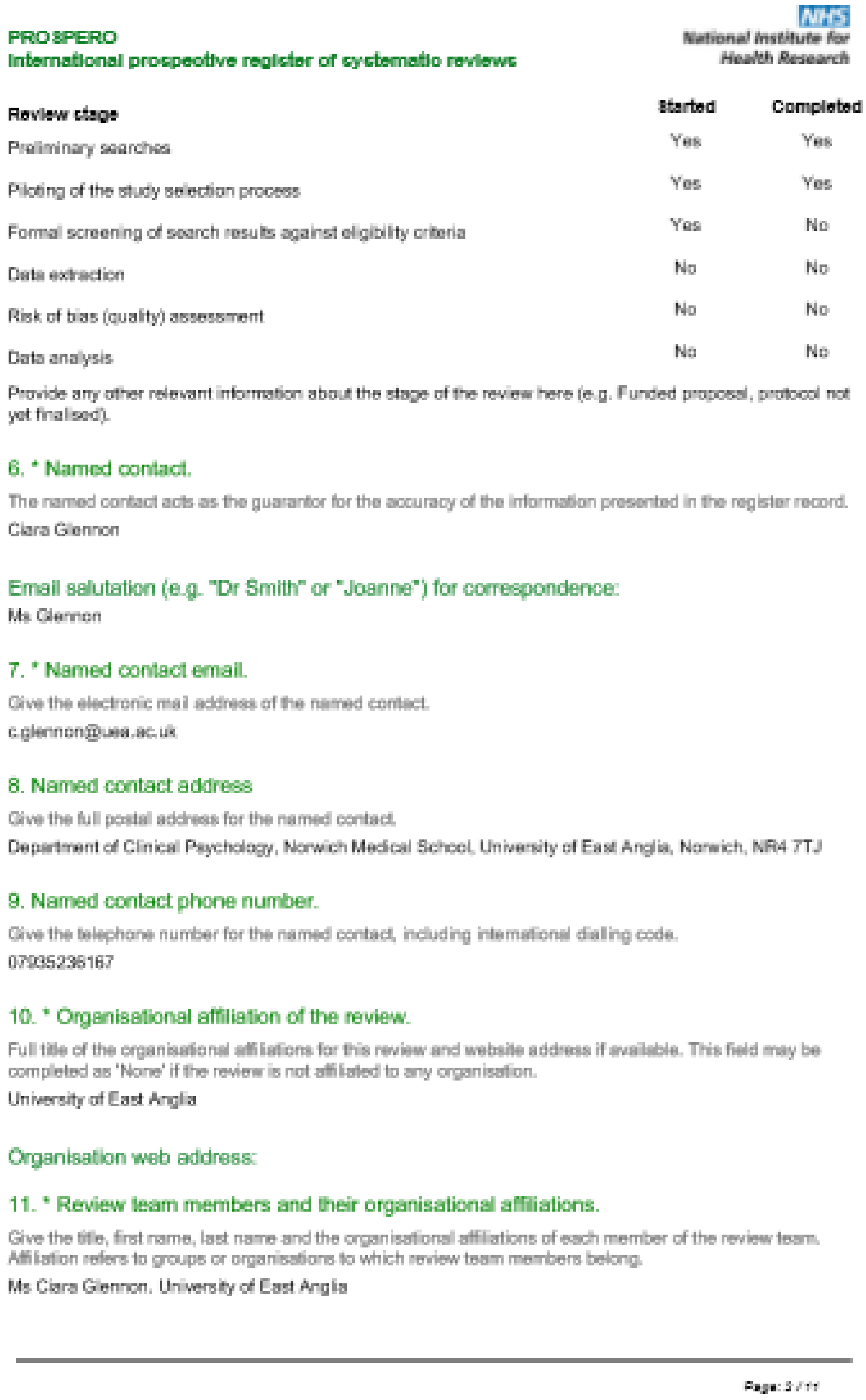
Give the date by which the review is expected to be completed.
31/12/2019

5. * Stage of review at time of this submission.

Indicate the stage of progress of the review by ticking the relevant Started and Completed boxes. Additional information may be added in the free text box provided.
Please note: Reviews that have progressed beyond the point of completing data extraction at the time of initial registration are not eligible for inclusion in PROSPERO. Should evidence of incorrect status and/or completion date being supplied at the time of submission come to light, the content of the PROSPERO record will be removed leaving only the title and named contact details and a statement that inaccuracies in the stage of the review date had been identified.
This field should be updated when any amendments are made to a published record and on completion and publication of the review. If this field was pre-populated from the initial screening questions then you are not able to edit it until the record is published.

The review has not yet started: No

Page: 1 / 11



PROSPERO
International prospective register of systematic reviews

National Institute for Health Research

Review stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Provide any other relevant information about the stage of the review here (e.g. Funded proposal, protocol not yet finalised).

6. * Named contact.

The named contact acts as the guarantor for the accuracy of the information presented in the register record.

Ciara Glennon

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

Ms Glennon

7. * Named contact email.

Give the electronic mail address of the named contact.

c.glennon@uea.ac.uk

8. Named contact address

Give the full postal address for the named contact.

Department of Clinical Psychology, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ

9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

07935236167

10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

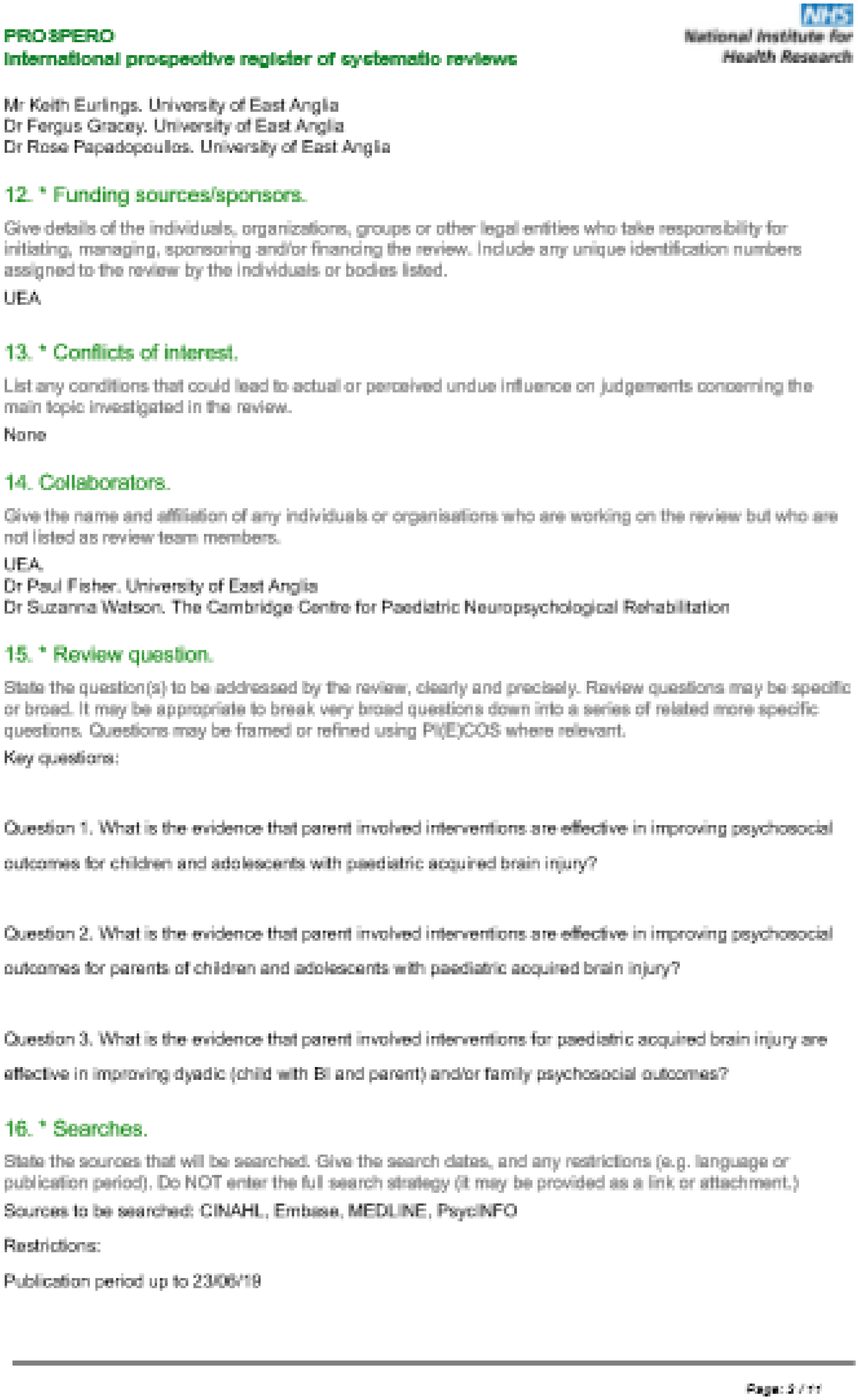
University of East Anglia

Organisation web address:

11. * Review team members and their organisational affiliations.

Give the title, first name, last name and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong.

Ms Ciara Glennon. University of East Anglia



Mr Keith Eurlings. University of East Anglia
Dr Fergus Gracey. University of East Anglia
Dr Rose Papadopoulos. University of East Anglia

12. * Funding sources/sponsors.

Give details of the individuals, organizations, groups or other legal entities who take responsibility for initiating, managing, sponsoring and/or financing the review. Include any unique identification numbers assigned to the review by the individuals or bodies listed.

UEA

13. * Conflicts of interest.

List any conditions that could lead to actual or perceived undue influence on judgements concerning the main topic investigated in the review.

None

14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members.

UEA
Dr Paul Fisher. University of East Anglia
Dr Suzanna Watson. The Cambridge Centre for Paediatric Neuropsychological Rehabilitation

15. * Review question.

State the question(s) to be addressed by the review, clearly and precisely. Review questions may be specific or broad. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS where relevant.

Key questions:

Question 1. What is the evidence that parent involved interventions are effective in improving psychosocial outcomes for children and adolescents with paediatric acquired brain injury?

Question 2. What is the evidence that parent involved interventions are effective in improving psychosocial outcomes for parents of children and adolescents with paediatric acquired brain injury?

Question 3. What is the evidence that parent involved interventions for paediatric acquired brain injury are effective in improving dyadic (child with BI and parent) and/or family psychosocial outcomes?

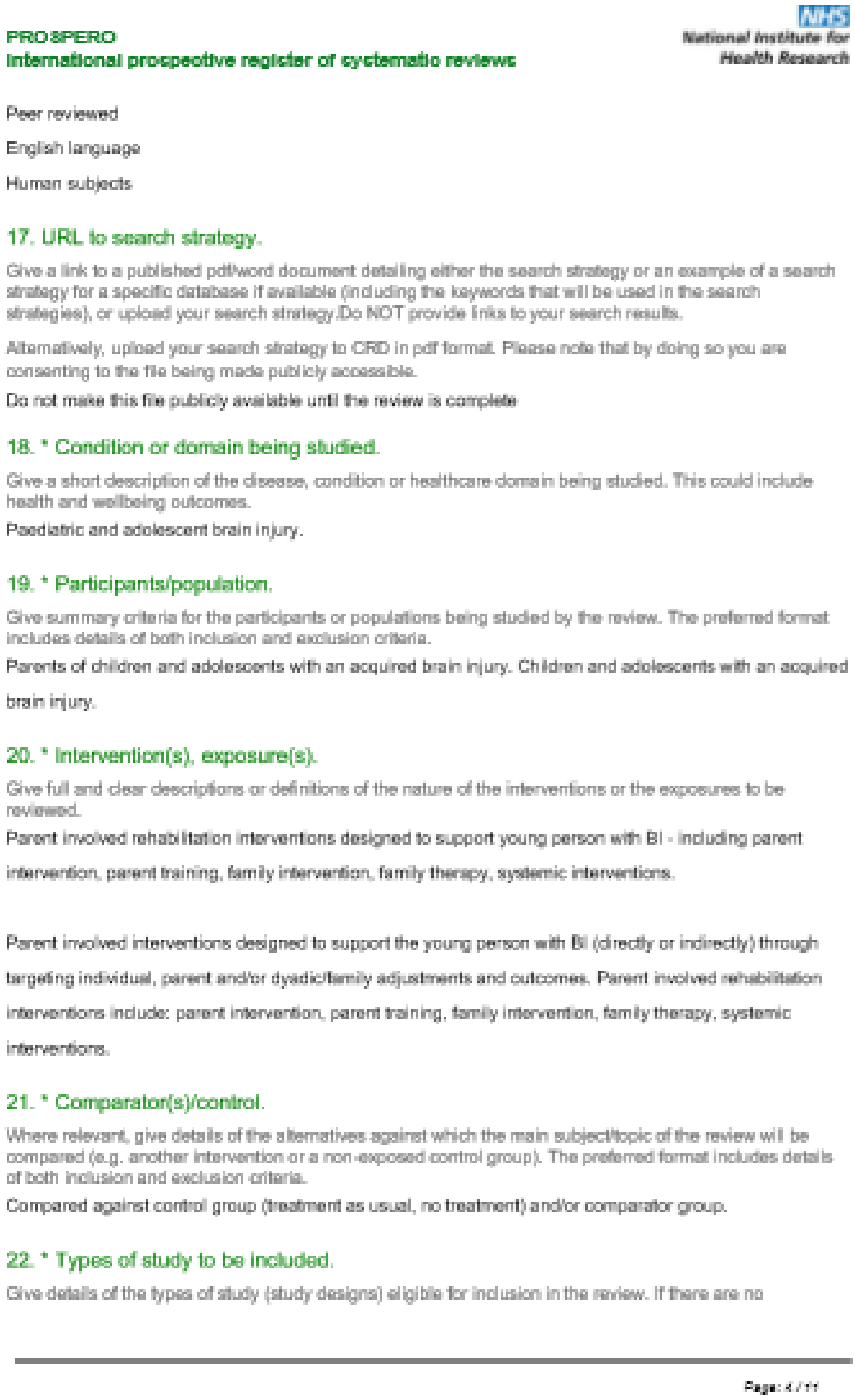
16. * Searches.

State the sources that will be searched. Give the search dates, and any restrictions (e.g. language or publication period). Do NOT enter the full search strategy (it may be provided as a link or attachment.)

Sources to be searched: CINAHL, Embase, MEDLINE, PsycINFO

Restrictions:

Publication period up to 23/06/19



Peer reviewed

English language

Human subjects

17. URL to search strategy.

Give a link to a published pdf/word document detailing either the search strategy or an example of a search strategy for a specific database if available (including the keywords that will be used in the search strategies), or upload your search strategy.Do NOT provide links to your search results.

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Do not make this file publicly available until the review is complete

18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied. This could include health and wellbeing outcomes.

Paediatric and adolescent brain injury.

19. * Participants/population.

Give summary criteria for the participants or populations being studied by the review. The preferred format includes details of both inclusion and exclusion criteria.

Parents of children and adolescents with an acquired brain injury. Children and adolescents with an acquired brain injury.

20. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the nature of the interventions or the exposures to be reviewed.

Parent involved rehabilitation interventions designed to support young person with BI - including parent intervention, parent training, family intervention, family therapy, systemic interventions.

Parent involved interventions designed to support the young person with BI (directly or indirectly) through targeting individual, parent and/or dyadic/family adjustments and outcomes. Parent involved rehabilitation interventions include: parent intervention, parent training, family intervention, family therapy, systemic interventions.

21. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the main subject/topic of the review will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

Compared against control group (treatment as usual, no treatment) and/or comparator group.

22. * Types of study to be included.

Give details of the types of study (study designs) eligible for inclusion in the review. If there are no restrictions on the types of study design eligible for inclusion, or certain study types are excluded, this should be stated. The preferred format includes details of both inclusion and exclusion criteria.

RCTs, controlled trials, pre to post designs.

Inclusion criteria: Injury must have occurred in paediatric / adolescent age range (0-19 years). Intervention must have occurred while young person was still within this age range. Psychosocial outcomes must be detailed for young person with BI and/or parent of young person with BI and/or dyad/family.

Exclusion criteria: Non psychosocial outcomes- eg. distinctly cognitive outcomes. Non paediatric / adolescent BI (injury acquired at 19 years+). Interventions which were designed to target only parents psychological outcomes without intervention being designed with the intention to support the young person with BI (directly or indirectly); interventions which were limited to only provision of TBI education materials; or interventions where clinicians worked only with the child/adolescent.

23. Context.

Give summary details of the setting and other relevant characteristics which help define the inclusion or exclusion criteria.

24. * Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

Psychosocial outcomes for children and adolescents with BI. Psychosocial outcomes for parents of children and adolescents with BI.

Timing and effect measures

All relevant formal psychosocial outcome measures.

25. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

Dyadic (child with BI and parent) and/or family psychosocial outcomes

Timing and effect measures

Not applicable.

26. * Data extraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how this will be done and recorded.

Searches of electronic databases (PsycINFO, CINAHL, Embase and MEDLINE) will be conducted in June 2019.

-Search terms will be categorised into 3 topic areas:

1) acquired brain injury (searched for in abstract)

2) parent involved interventions (searched for in abstract)

3) Child or Adolescent (searched for in abstract)

-Medical Subject Headings (MeSH terms) will be used for each topic area to ensure a wide-reaching search. Searches will be filtered for peer reviewed journals in English.

-Inclusion and exclusion criteria will be applied

-Papers will be excluded where they do not meet criteria upon reading of the title/abstract/full text (as necessary to ascertain this).

-Where papers have been considered at the title and abstract level and it is still unclear if they are acceptable for inclusion in the systematic review, the full text will be read.

-A second reviewer (another trainee clinical psychologist at UEA) will also independently review a sub sample of papers for which the full text needs to be read, and then the two reviewers will compare their selection results against each other in relation to this subset of papers to determine any differences between reviewers decisions and clarify any discrepancies through discussion and shared agreement. Discrepancies between reviewers will be referenced in the final review, if present.

-The main data to be extracted from each study will be: publication authors, year and country; participant N and characteristics (parents as well as young people); control and intervention group characteristics; study design; intervention and control treatment description; outcome measures and results. Any queries will be clarified with collaborator who will review extracted data.

-A data extraction form will be developed to hold all details extracted (as above).

27. * Risk of bias (quality) assessment.

Describe the method of assessing risk of bias or quality assessment. State which characteristics of the studies will be assessed and any formal risk of bias tools that will be used.

Risk of bias will be assessed using The Cochrane Collaboration Risk of Bias Tool (Altman & Stern, 2011). An adapted version (Lukens & Silverman, 2014) of same will be used for non randomised studies which do not include comparators.

The Consolidated Standards of Reporting Trials (CONSORT) guidance will be used upon which to develop criteria for the evaluation of articles in the current review. Items specific to ABI will be added, replicating amendments by Ross et al. (2011) in a previous relevant review.

A second reviewer will review a subsection of final selected papers included to independently evaluate bias, and any discrepancies will then be discussed between reviewers to agree a final decision.

28. * Strategy for data synthesis.

Provide details of the planned synthesis including a rationale for the methods selected. This **must not be generic text** but should be **specific to your review** and describe how the proposed analysis will be applied to your data.

The planned general approach to synthesis is to use aggregate participant data; with a narrative (descriptive) synthesis planned. From initial scoping review of the literature, there is an expected paucity of RCTs and a heterogeneity between the studies. Further, the very recent determination only months previously (March 2019) by a Cochrane Review (covering a far broader questions regarding interventions for chronic illness and associations with parental outcomes) that there was not strong data for analyses within the literature field (re TBI specifically), no meta-analysis is planned to be conducted in the current review.

Thus, to enable a meaningful review, given the limit and heterogeneity of studies, a narrative synthesis approach (Popay et al., 2006) is planned to be taken to the data. Though less robust than a quantitative approach such as meta-analysis, this approach is expected at this point to be the best fit for the data and will give the opportunity to present a meaningful synthesis of data which may be clinically useful. Characteristics of studies included will be presented in table format, psychosocial outcomes will be discussed, risk of bias will be assessed and presented, and there will be a summary of quality assessment. This data synthesis will then inform a discussion.

29. * Analysis of subgroups or subsets.

State any planned investigation of 'subgroups'. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach.

[illegible]ents with BI

3) parents of children and adolescents with BI and children and adolescents with BI

30. * Type and method of review.

Select the type of review and the review method from the lists below. Select the health area(s) of interest for your review.

Type of review

Cost effectiveness
No

Diagnostic
No

Epidemiologic
No

Individual patient data (IPD) meta-analysis
No

Intervention

Yes

Meta-analysis
No

Methodology
No

Narrative synthesis
Yes

Network meta-analysis
No

Pre-clinical
No

Prevention
No

Prognostic
No

Prospective meta-analysis (PMA)
No

Review of reviews
No

Service delivery
No

Synthesis of qualitative studies
No

Systematic review
Yes

Other
No

Health area of the review

Alcohol/substance misuse/abuse
No

Blood and immune system
No

Cancer
No

Cardiovascular
No

Care of the elderly
No

Child health
Yes

Complementary therapies
No

Crime and justice
No

Dental
No

Digestive system
No

Ear, nose and throat

No

Education
No

Endocrine and metabolic disorders
No

Eye disorders
No

General interest
No

Genetics
No

Health inequalities/health equity
No

Infections and infestations
No

International development
No

Mental health and behavioural conditions
Yes

Musculoskeletal
No

Neurological
No

Nursing
No

Obstetrics and gynaecology
No

Oral health
No

Palliative care
No

Perioperative care
No

Physiotherapy
No

Pregnancy and childbirth
No

Public health (including social determinants of health)
No

Rehabilitation
Yes

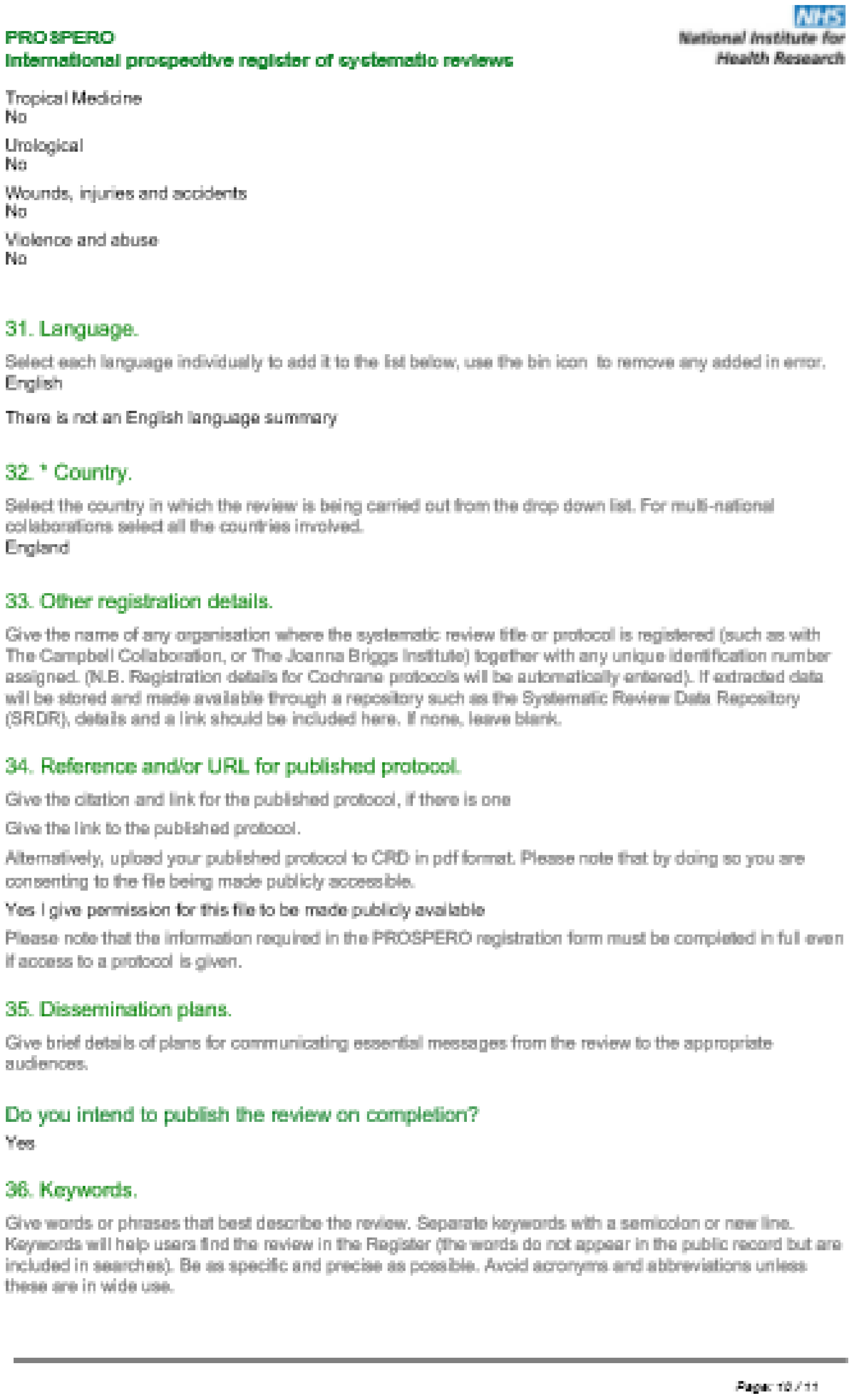
Respiratory disorders
No

Service delivery
No

Skin disorders
No

Social care
No

Surgery
No



Tropical Medicine
No

Urological
No

Wounds, injuries and accidents
No

Violence and abuse
No

31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.
English

There is not an English language summary

32. * Country.

Select the country in which the review is being carried out from the drop down list. For multi-national collaborations select all the countries involved.
England

33. Other registration details.

Give the name of any organisation where the systematic review title or protocol is registered (such as with The Campbell Collaboration, or The Joanna Briggs Institute) together with any unique identification number assigned. (N.B. Registration details for Cochrane protocols will be automatically entered). If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.

Give the citation and link for the published protocol, if there is one

Give the link to the published protocol.

Alternatively, upload your published protocol to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Yes I give permission for this file to be made publicly available

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

35. Dissemination plans.

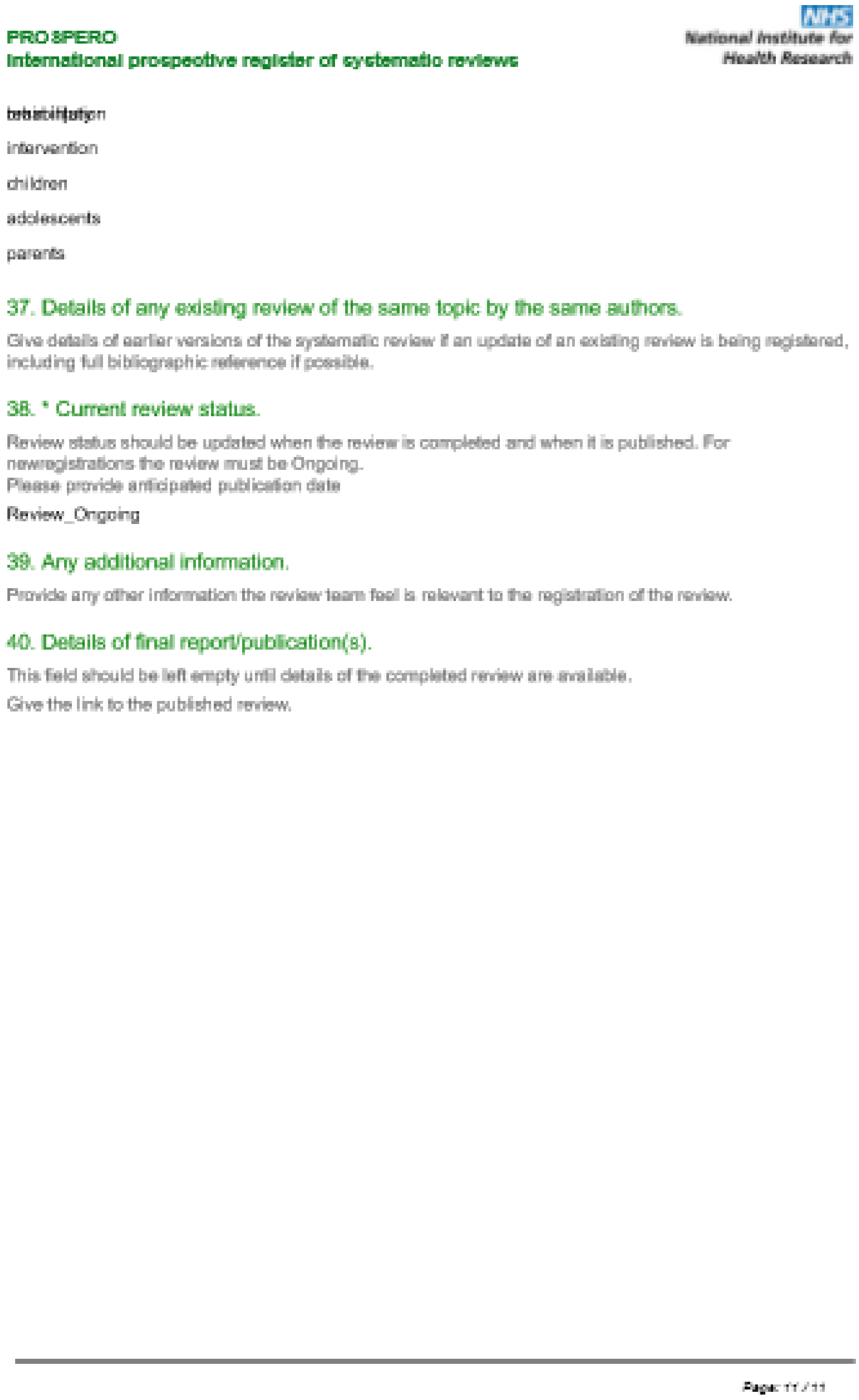
Give brief details of plans for communicating essential messages from the review to the appropriate audiences.

Do you intend to publish the review on completion?

Yes

36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords will help users find the review in the Register (the words do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.



rehabilitation

intervention

children

adolescents

parents

37. Details of any existing review of the same topic by the same authors.

Give details of earlier versions of the systematic review if an update of an existing review is being registered, including full bibliographic reference if possible.

38. * Current review status.

Review status should be updated when the review is completed and when it is published. For newregistrations the review must be Ongoing.
Please provide anticipated publication date

Review_Ongoing

39. Any additional information.

Provide any other information the review team feel is relevant to the registration of the review.

40. Details of final report/publication(s).

This field should be left empty until details of the completed review are available.

Give the link to the published review.

Appendix C- PRISMA Checklist for Systematic Review

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	7
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	8
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	10
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	12
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	13, Appendix B
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	13-14
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	14
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	14, Appendix D
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	14
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	15
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	15
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	15
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A

Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	16
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	15
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	17, 18
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	20, 26-28, 38-44
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	23-24 Appendix H
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	33-36, 45-47, 49-51
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	20-14
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	36-37 48-49, 51-54
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	55-58
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	58-60
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	60

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

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

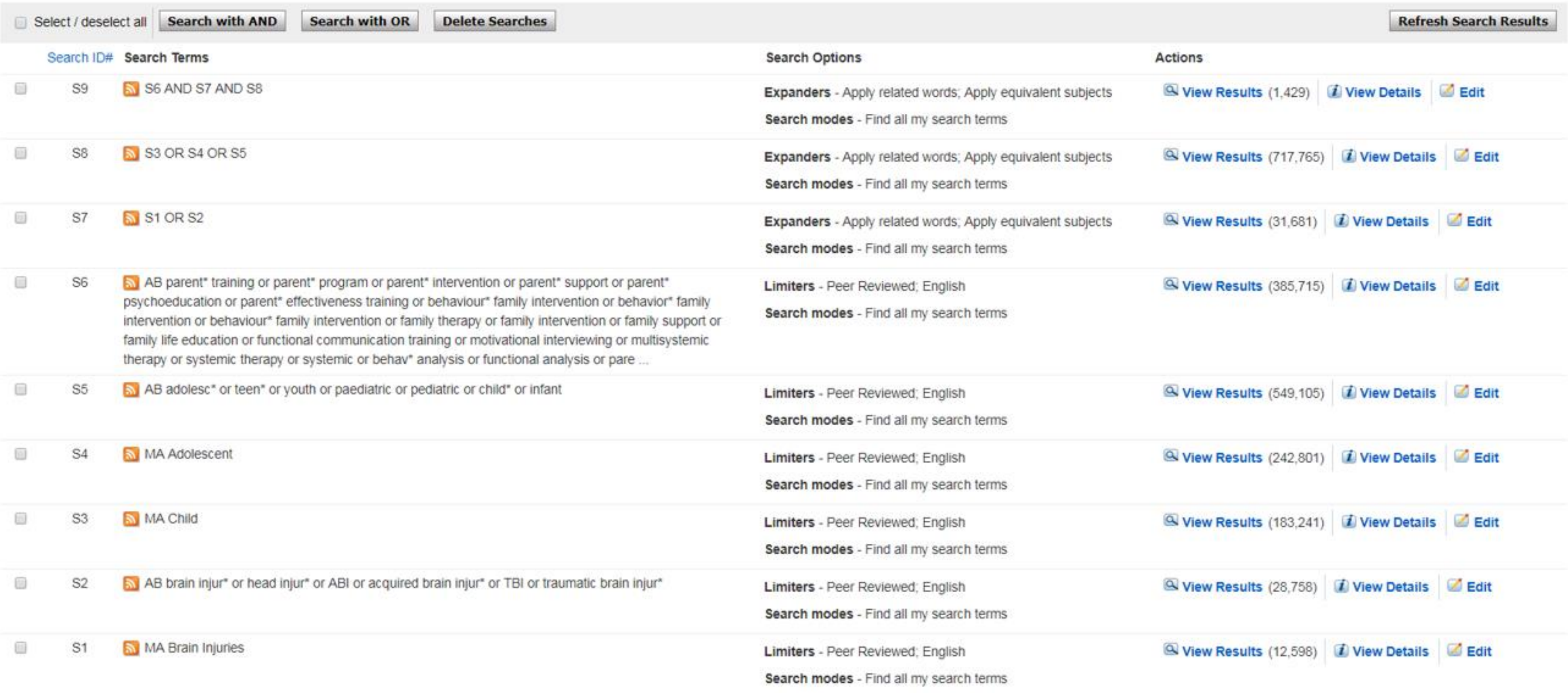
Appendix D- Full search terms for Systematic Review

1) brain injur* or head injur* or ABI or acquired brain injur* or TBI or traumatic brain injur*.

2) parent* training or parent* program or parent* intervention or parent* support or parent* psychoeducation or parent* effectiveness training or behaviour* family intervention or behavior* family intervention or behaviour* family intervention or family therapy or family intervention or family support or family life education or functional communication training or motivational interviewing or multisystemic therapy or systemic therapy or systemic or behav* analysis or functional analysis or parent* program* or family program* or behav* therapy or functional assessment or behav* support or behav* management or parent* education. (Terms here primarily based on Brown et al. (2012) search terms, with several terms added (guided by Law et al., 2019 systematic review) to further broaden the scope of the search)

3) adolesc* or teen* or youth or paediatric or pediatric or child* or infant.

Appendix E- Example of database search for Systematic Review



	Search ID#	Search Terms	Search Options	Actions
☐	S9	S6 AND S7 AND S8	**Expanders** - Apply related words; Apply equivalent subjects **Search modes** - Find all my search terms	**View Results** (1,429) | **View Details** | **Edit**
☐	S8	S3 OR S4 OR S5	**Expanders** - Apply related words; Apply equivalent subjects **Search modes** - Find all my search terms	**View Results** (717,765) | **View Details** | **Edit**
☐	S7	S1 OR S2	**Expanders** - Apply related words; Apply equivalent subjects **Search modes** - Find all my search terms	**View Results** (31,681) | **View Details** | **Edit**
☐	S6	AB parent* training or parent* program or parent* intervention or parent* support or parent* psychoeducation or parent* effectiveness training or behaviour* family intervention or behavior* family intervention or behaviour* family intervention or family therapy or family intervention or family support or family life education or functional communication training or motivational interviewing or multisystemic therapy or systemic therapy or systemic or behav* analysis or functional analysis or pare ...	**Limiters** - Peer Reviewed; English **Search modes** - Find all my search terms	**View Results** (385,715) | **View Details** | **Edit**
☐	S5	AB adolesc* or teen* or youth or paediatric or pediatric or child* or infant	**Limiters** - Peer Reviewed; English **Search modes** - Find all my search terms	**View Results** (549,105) | **View Details** | **Edit**
☐	S4	MA Adolescent	**Limiters** - Peer Reviewed; English **Search modes** - Find all my search terms	**View Results** (242,801) | **View Details** | **Edit**
☐	S3	MA Child	**Limiters** - Peer Reviewed; English **Search modes** - Find all my search terms	**View Results** (183,241) | **View Details** | **Edit**
☐	S2	AB brain injur* or head injur* or ABI or acquired brain injur* or TBI or traumatic brain injur*	**Limiters** - Peer Reviewed; English **Search modes** - Find all my search terms	**View Results** (28,758) | **View Details** | **Edit**
☐	S1	MA Brain Injuries	**Limiters** - Peer Reviewed; English **Search modes** - Find all my search terms	**View Results** (12,598) | **View Details** | **Edit**

Appendix F- Cochrane Risk of Bias tool

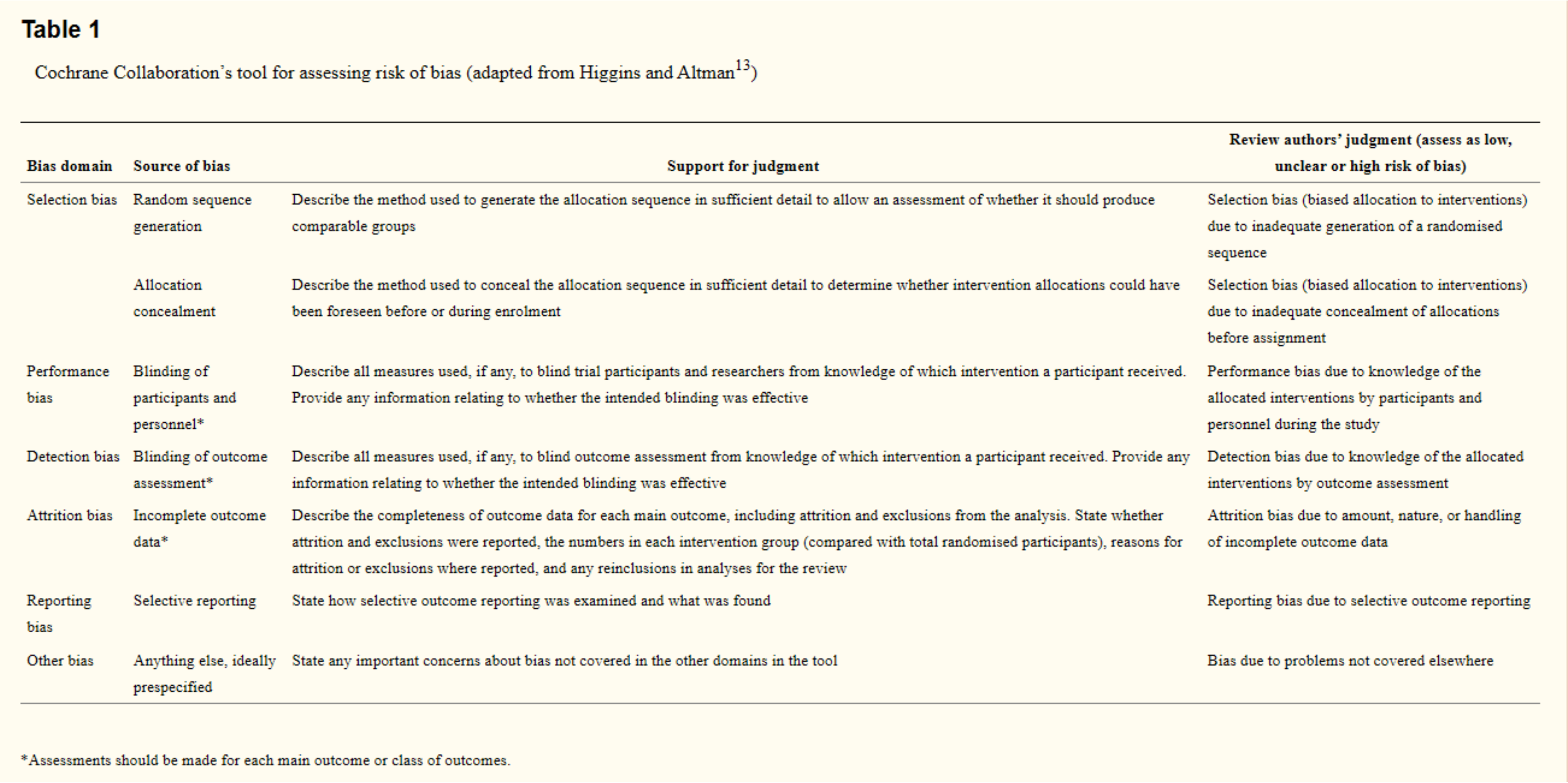


Table 1

Cochrane Collaboration's tool for assessing risk of bias (adapted from Higgins and Altman[13])

Bias domain	Source of bias	Support for judgment	Review authors' judgment (assess as low, unclear or high risk of bias)
Selection bias	Random sequence generation	Describe the method used to generate the allocation sequence in sufficient detail to allow an assessment of whether it should produce comparable groups	Selection bias (biased allocation to interventions) due to inadequate generation of a randomised sequence
	Allocation concealment	Describe the method used to conceal the allocation sequence in sufficient detail to determine whether intervention allocations could have been foreseen before or during enrolment	Selection bias (biased allocation to interventions) due to inadequate concealment of allocations before assignment
Performance bias	Blinding of participants and personnel*	Describe all measures used, if any, to blind trial participants and researchers from knowledge of which intervention a participant received. Provide any information relating to whether the intended blinding was effective	Performance bias due to knowledge of the allocated interventions by participants and personnel during the study
Detection bias	Blinding of outcome assessment*	Describe all measures used, if any, to blind outcome assessment from knowledge of which intervention a participant received. Provide any information relating to whether the intended blinding was effective	Detection bias due to knowledge of the allocated interventions by outcome assessment
Attrition bias	Incomplete outcome data*	Describe the completeness of outcome data for each main outcome, including attrition and exclusions from the analysis. State whether attrition and exclusions were reported, the numbers in each intervention group (compared with total randomised participants), reasons for attrition or exclusions where reported, and any reinclusions in analyses for the review	Attrition bias due to amount, nature, or handling of incomplete outcome data
Reporting bias	Selective reporting	State how selective outcome reporting was examined and what was found	Reporting bias due to selective outcome reporting
Other bias	Anything else, ideally prespecified	State any important concerns about bias not covered in the other domains in the tool	Bias due to problems not covered elsewhere

*Assessments should be made for each main outcome or class of outcomes.

Appendix G- Interventions covered in Systematic Review

Online Family Problem Solving (OFPST)

Most papers reported on variants of OFPST. Five reported on OFPST, another five on teen online problem solving (TOPS/F), and a final five on counsellor assisted problem solving (CAPS)

The first studies on OFPST utilised an approach of providing problem solving training in cognitive– behavioural skills relevant to coping with TBI via self-guided web materials followed up with therapist biweekly appointments. Parents, the adolescent with brain injury and siblings were all invited to participate. Within TOPS/F, content was covered in two separate parts: initially, participating family members completed a self-guided online module; and then, this was reviewed with a therapist during a synchronous videoconference. (This intervention is referred to as TOPS-Family in two later papers (Wade et al., 2018; Narad et al., 2019) in order to differentiate from the newly developed TOPS-Teen Only). CAPS was similarly a web based FPST with online psycho educational modules and synchronous counsellor videoconferencing for families. The teen with TBI and the primary caregiver were asked to participate in each of seven core sessions.

I-InTERACT

Used in 6 papers, I-InTERACT is an internet-based parenting skills program, incorporating other evidence-based programs and in particular, PCIT (Eyberg, 1988). The program teaches positive parenting skills, consistent discipline techniques and antecedent behaviour management strategies, information on cognitive and behavioural sequelae of TBI and training in stress and anger management. Intervention was through online content in tandem with a synchronous videoconference with a therapist. Here participants could role-play new skills with the therapist and receive simultaneous feedback through a wireless earpiece during in vivo play with the child.

BrainSTARS

BrainSTARS (Brain Injury: Strategies for Teams and Re-education for Students) was assessed in one paper included in this review. This is a personalised consultative intervention involving educators and parents, and is based on a neurodevelopment model of paediatric ABI. The intervention works to improve outcomes for the young person by educating parents and school personnel on the associations between observed behavioural deficits and underlying neurodevelopmental vulnerabilities: aiming to improve "goodness of fit" between the student's capabilities/weaknesses and the expectations/supports in his or her environment.

Stepping Stones Triple P & Acceptance & Commitment Therapy (SSTP & ACT)

Two papers in this review assessed efficacy of an SSTP plus ACT intervention. **'**The intervention was delivered in groups and consisted of the 2-session ACT program (Whittingham et al., 2010) and 9-session SSTP program (Sanders et al., 2009).

Telephone Counselling Intervention

One study utilised an early follow up intervention, comprised of structured follow-up and symptom counselling at both 1 week and 1-month post injury for parents of individuals with a concussion injury. Parents engaged in structured telephone calls about the impact of symptoms on everyday function and activities. For those with ongoing symptoms and effects, clinical guidelines for paediatric concussion recovery and return to activity current at the time the study began informed discussions and recommendations for symptom management and activity participation. Discussions were adapted to accommodate family and child values and circumstances.

Family Forward

The Family Forward intervention (used in two papers included in this review) is designed to improve family adaption following paediatric ABI. It consists of two counselling sessions and one multi-family group session (optional) per week throughout the child’s inpatient rehabilitation admission. Developed upon a Resiliency Model framework, family sessions are made available to all family members affected by the child’s injury.

Appendix H- Risk of Bias Decisions for Systematic Review

Wade et al 2005- *Putting the pieces together: preliminary efficacy of a web-based family intervention for children with traumatic brain injury*

WADE 2005 a **Source of bias** ***(bias domain)***	**Support for judgement-**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	No randomisation as pre-post: Because of the preliminary nature of the project, a convenience sample of six families was recruited to participate	High
Blinding of participants and personnel ***(performance bias)***	N/A given nature of design	N/A
Blinding of outcome assessment ***(detection bias)***	Outcomes not dependent on the judgments of the research staff - thus minimising risk of researcher bias on this domain. All measures were participant rated, not possible to blind from knowing they received intervention. Thus, no blinding of outcome assessment re participants, but the review authors judge that the outcome measurement is not likely to be influenced by lack of blinding.	Low
Incomplete outcome data ***(attrition bias)***	Complete set of outcome data, all families reported to have completed outcome data, parents (n=8) and YPs (n=6), all included in analysis	Low
Selective reporting ***(reporting bias)***	Incomplete reporting, with one predefined measure represented in analysis and tabled results but not discussed in results/discussion.	High

Wade et al 2005- *Can a Web-based family problem-solving intervention work for children with traumatic brain injury?*

WADE 2005 b **Source of bias** ***(bias domain)***	**Support for judgement-**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	Non randomisation as pre-post study	High
Blinding of participants and personnel ***(performance bias)***	N/A given nature of design	N/A
Blinding of outcome assessment ***(detection bias)***	Outcomes not dependent on the judgments of the research staff or at risk of researcher bias on this domain. All measures were participant rated and so by nature of intervention blinding of outcome from participants was not possible. Thus, no blinding of outcome assessment re participants, but the review authors judge that the outcome measurement is not likely to be influenced by lack of blinding.	Low
Incomplete outcome data ***(attrition bias)***	Complete set of outcome data, all families reported to have completed outcome data, parents (n=8) and YPs (n=6), all included in analysis	Low
Selective reporting ***(reporting bias)***	Incomplete reporting, with one predefined measure represented in analysis and tabled results but not discussed in results/discussion.	High

Wade et al 2006- Putting the pieces together: preliminary efficacy of a family problem-solving intervention for children with traumatic brain injury

WADE 2006 a **Source of bias** ***(bias domain)***	**Support for judgement-**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	After obtaining informed consent, families were randomly assigned to the FPS or UC group using a random numbers table	Low
Allocation concealment **(selection bias)**	No information provided pertaining to this	Unclear

Blinding of participants and personnel ***(performance bias)***	Given the nature of the study, neither the participants nor the research assistant was blind to group assignment.	High
Blinding of outcome assessment ***(detection bias)***	Given the nature of the study, neither the participants nor the research assistant was blind to group assignment. However, the primary outcome measures were based on participant report and therefore not dependent on the judgments of the research staff- minimising risk of researcher bias on this domain. Review authors judge that the outcome measurement is not likely to be influenced by lack of participant blinding.	Low
Incomplete outcome data ***(attrition bias)***	Incomplete data for main outcomes, attrition reported. 37 families consented to participate and completed the baseline interview (19 intervention, 18 comparator group). All but one family completed the follow-up assessment (97%). However, because of literacy issues and changing informants, pre-post data were invalid for 2 participants. In addition, 2 children assigned to the control group received intensive day/residential treatment during the interval between the initial and follow-up assessment, making their circumstances substantially different from those for other participants. As a result, pre-post data were reported for 32 children and their parents (86.4% of initial participants). No analysis reported on difference between completers and non-completers.	High
Selective reporting ***(reporting bias)***	All predefined hypotheses and measures were reported on in results.	Low

Wade et al 2006-The efficacy of an online cognitive-behavioural family intervention in improving child behaviour and social competence following paediatric brain injury

Wade 2006 b **Source of bias** ***(bias domain)***	**Support for judgement**	**Assessment of authors judgement (low, unclear or high risk of bias)**
Random sequence generation ***(selection bias)***	'families were randomly assigned to FPS or IRC via a computer program'	Low
Allocation concealment (selection bias)	No information in paper pertaining to this	Unclear
Blinding of participants and personnel ***(performance bias)***	'Given the nature of the study, neither the participants nor the research assistant was blind to group assignment.	High
Blinding of outcome assessment ***(detection bias)***	Outcomes not dependent on the judgments of the research staff - minimising risk of researcher bias on this domain. No blinding of outcome assessment re participants, but the review authors judge that the outcome measurement is not likely to be influenced by lack of blinding.	Low
Incomplete outcome data ***(attrition bias)***	41 sets of outcome data for main outcomes, 2 necessitated exclusion, leaving 39 of initial sample of 45 for inclusion in main analysis. Attrition and exclusion reported- follow up data reported as available for 93% of initial sample, 12% attrition in the intervention group vs. 0% in the control group. However, it was reported that this difference was not statistically significant, and dropouts did not differ significantly from remaining participants on any of the baseline measures, reasons for exclusion/ attrition were reported. These 5 families did not differ from remaining families in terms of SES, injury severity, time since injury, child's age or total behaviour problems. However, excluded children had significantly lower social competence at baseline than those included. Child data was also unavailable for one child who was minimally responsive. Data from 2 families who had not completed enough sessions was reintroduced for post hoc intent to treat analyses.	Unclear
Selective reporting ***(reporting bias)***	Protocol for intervention available, not all measures in method were reported on in study results	High

Wade et al 2006- An online family intervention to reduce parental distress following paediatric brain injury

Wade 2006 c **Source of bias *(bias domain)***	**Support for judgement**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation *(selection bias)*	Families were randomly assigned to FPS or IRC using a Web site that provides randomization schemes for studies of various sizes (www.randomizer.org).	Low
Allocation concealment (selection bias)	No information in paper pertaining to this	Unclear
Blinding of participants and personnel *(performance bias)*	‘Given the nature of the study, neither the participants nor the research assistants were blinded to group assignment.	High
Blinding of outcome assessment *(detection bias)*	Given the nature of the study, neither the participants nor the research assistants were blinded to group assignment. However, outcomes not dependent on the judgments of the research staff – minimising risk of researcher bias on this domain. No blinding of outcome assessment re participants, but the review authors judge that the outcome measurement is not likely to be influenced by lack of blinding.	Low
Incomplete outcome data *(attrition bias)*	Outcome data incomplete for main outcomes (at 93.3%), attrition and exclusion reported- 12% attrition in intervention vs. 0% in comparator group. The difference was not statistically significant, and dropouts did not differ significantly from remaining participants on any of the baseline measures.	Low
Selective reporting *(reporting bias)*	Protocol available, all predefined objectives were not reported on in the study results	High

Wade et al 2008- Preliminary efficacy of a Web-based family problem-solving treatment program for adolescents with traumatic brain injury

Wade 2008 **Source of bias *(bias domain)***	**Support for judgement**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation *(selection bias)*	Families were randomly assigned (using a computer program) to the TOPS intervention with or without audio. However, no stratification described and small n so groups at risk of still differing at baseline.	High
Allocation concealment (selection bias)	After obtaining informed consent from the participating parents and adolescents, families were randomly assigned (using a computer program), with researcher aware of group assignment. Comment: concealment not described and seems unlikely to have occurred.	High
Blinding of participants and personnel *(performance bias)*	Given the nature of the study, the research coordinator was aware of group assignment.	High
Blinding of outcome assessment *(detection bias)*	Not possible for participants to be unaware of intervention received, given nature of intervention, and coordinator was aware of group assignment. However, primary outcomes were based on parent and adolescent report and this not dependent on judgement of research staff. Though no blinding of outcome assessment re participants, but the review authors judge that the outcome measurement is not likely to be influenced by lack of blinding.	Low
Incomplete outcome data *(attrition bias)*	States that all 9 families completed the 10 core sessions, thus 100% completion and no attrition, with mean sessions completed provided.	Low
Selective reporting *(reporting bias)*	The two main hypotheses related to effects of TOPS intervention, but the group was split into two conditions, and yet the data was treated as one group from one intervention to answer these questions. Given the two groups into which participants were randomised, to effectively answer whether TOPS impacted on all outcomes named in the two key hypotheses, these should have been looked at within each individual group. However, only selected outcomes were looked at in post hoc analyses (those significant at overall TOPS group level)	High

Dise-Lewis 2009- BrainSTARS: pilot data on a team-based intervention program for students who have acquired brain injury

Dise-Lewis 2009 **Source of bias** ***(bias domain)***	**Support for judgement-**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	Not carried out as pre-post study	High
Blinding of participants and personnel ***(performance bias)***	N/A given nature of design	N/A
Blinding of outcome assessment ***(detection bias)***	Not possible given nature of intervention and self-rated measures. However, outcomes not dependent on the judgments of the research staff - thus minimising risk of researcher bias on this domain. Though no blinding of outcome assessment re participants, but the review authors judge that the outcome measurement is not likely to be influenced by lack of blinding.	Low
Incomplete outcome data ***(attrition bias)***	Incompleteness of data - Not all team participants completed both pre- and post consultation questionnaire. Original sample of 41 parents/guardians and 66 school personnel. Incomplete data related to analysis plans presented in results: of 41 parent/guardians only 21 completed intervention (51%) and 18 (44%) completed post intervention outcomes. Of 66 school personnel, only 38 completed interventions (58%) and 18 school personnel completed all outcomes (27%). Attrition not reported on- No details on reasons for attrition provided. No information on dropouts or differences between those who did not complete outcomes and those that did.	High
Selective reporting ***(reporting bias)***	Incomplete data provided pertaining to predefined hypotheses.	High

Wade 2009- Feasibility and preliminary efficacy of a Web-based parenting skills program for young children with traumatic brain injury

Wade 2009 **Source of bias** ***(bias domain)***	**Support for judgement-**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	Not carried out as pre-post study	High
Blinding of participants and personnel ***(performance bias)***	N/A given nature of design	N/A
Blinding of outcome assessment ***(detection bias)***	Parent rated measures were completed, but not possible to blind participants due to nature of the intervention, however risk of researcher bias minimised on this domain. Though no blinding of outcome assessment re participants, but the review authors judge that the outcome measurement is not likely to be influenced by lack of blinding. In-session, process ratings were completed by the therapist- concealment of the treatment status was not possible here.	High
Incomplete outcome data ***(attrition bias)***	Incomplete outcomes data, with 4 of 9 families dropping out (44%) after beginning intervention. Reasons for attrition reported, all participants not included in analyses. No reporrting of differences between completers and no completers.	High
Selective reporting ***(reporting bias)***	All predetermined objectives were explored via analysis and discussed in results section.	Low

Wade 2011- Effect on behaviour problems of teen online problem-solving for adolescent traumatic brain injury

Wade 2011 **Source of bias *(bias domain)***	**Support for judgement**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	families were randomly assigned to either the TOPS or IRC group by use of a randomization scheme that stratified participants on the basis of the adolescent's gender and race/ethnicity to ensure comparable diversity in each group	Low
Allocation concealment **(selection bias)**	Given the nature of the study, we were unable to conceal group assignment from the participants and research staff	High
Blinding of participants and personnel ***(performance bias)***	Given the nature of the study, we were unable to conceal group assignment from the participants and research staff	High
Blinding of outcome assessment ***(detection bias)***	Parents were not blind to groups and completed outcomes- however outcomes not dependent on the judgments of the research staff - thus minimising risk of researcher bias. Though no blinding of outcome assessment re participants, but the review authors judge that the outcome measurement is not likely to be influenced by lack of blinding.	Low
Incomplete outcome data ***(attrition bias)***	Incomplete data for main outcomes, with 35 (88%) of the 41 families who completed baseline assessment completing follow up post intervention and included in main analysis. One family were excluded post baseline assessment for cognitive capacity issues (caregiver unable to complete content). Attrition and exclusion were reported, 20% attrition in intervention group vs. 5% in control arm, leaving complete outcome data for 16 of 20 families (intervention group) compared to 19 families (in the control arm). Reasons for attrition were: x5 drop out. Comparison of completers and dropouts revealed no statistically significant differences in demographic or injury characteristics or baseline behaviour or family conflict.	Low
Selective reporting ***(reporting bias)***	Protocol available, all predefined hypotheses were reported on in the study results	Low

Wade 2012- A Randomized Trial of Teen Online Problem Solving: Efficacy in Improving Caregiver Outcomes After Brain Injury

Wade 2012 **Source of bias (*bias domain)***	**Support for judgement** Wade	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	Families were then randomly assigned to either TOPS or IRC using a randomization scheme that stratified participants based on sex and race/ethnicity. This was done to ensure that the groups were equivalent with respect to these characteristics.	Low
Allocation concealment **(selection bias)**	No information in paper pertaining to this	Unclear
Blinding of participants and personnel ***(performance bias)***	Both participants and research staff were aware of group assignment.	High
Blinding of outcome assessment ***(detection bias)***	Primary outcome measures were based on participant report, and participants were aware of group assignment. However, outcomes not dependent on the judgments of the research staff - thus minimising risk of researcher bias on this domain.	Low
Incomplete outcome data ***(attrition bias)***	Incomplete outcome data for main outcomes- 41 began intervention of which 35 cases (16 intervention, 19 comparator) (88% in total) provided complete pre to post outcome data. Differences between completers and non-completers- Though completers did not differ from non-completers with respect to many variables (sex, race, age at injury, injury severity, time since injury, or caregiver ratings of problem solving at baseline), they demonstrated significantly higher depression and caregiver distress levels. -Attrition and exclusion were reported- 41 randomised (21 intervention, 20 control) of which there was exclusion of 5 from analysis in intervention arm (x1 not of adequate cognitive capacity, x4 no longer interested in participating) and exclusion of x1 in the control arm (family no longer interested in participating).	High

	-Due to administration error, satisfaction surveys were only completed by participants in the IRC group at one of the two sites	
Selective reporting ***(reporting bias)***	All hypotheses are not explicitly addressed in results discussion, though data is accessible in tables.	Low

Antonioni et al 2014- A pilot randomized trial of an online parenting skills program for paediatric traumatic brain injury: improvements in parenting and child behaviour

Antonioni 2014 Source of bias (*bias domain)*	**Support for judgement**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	Thirty-seven families of children with TBI provided informed consent and were randomized to I-InTERACT (n = 20) or IRC (n = 17). The randomization scheme was generated using SAS by the medical centre's Division of Biostatistics and created using permuted block sizes for each of the randomizations.	Low
Allocation concealment (selection bias)	No allocation concealment procedure described after randomisation, though it is clarified that assignment was not concealed from personnel or participants	Unclear
Blinding of participants and personnel ***(performance bias)***	Group assignment was not concealed from the study coordinator, therapists, or participants.	High
Blinding of outcome assessment ***(detection bias)***	DPICS coders assessing videoed interactions of participating dyads remained unaware of treatment condition through study. However, parents were not blind and responsible for rating CBCL. However, as these outcomes were not dependent on the judgments of the research staff – this minimises risk of researcher bias on this domain. Thus, no blinding of outcome assessment re participants, but the review authors judge that the outcome measurement is not likely to be influenced by lack of blinding.	Low
Incomplete outcome data ***(attrition bias)***	Incomplete data for main outcomes, with attrition and exclusion reported. Initial group numbers were 20 per intervention and 20 per control (total sample of 40). 3 of initial randomised sample of 40 were excluded because they had brain lesions (all within control arm), leaving sample of 37. And a further four participants dropped out of the study or were lost to follow-up (three I-InTERACT, one IRC)). There were incomplete datasets as a result owing to attrition. A further 2 child play interaction videotapes were missing due to lost videos/sound recording problems (one I-InTERACT, one IRC). No differences between dropouts and those remaining in study- We found no significant differences in race, parent age, parent education, employment status, or computer ownership among dropouts, those completing ≤ 3 sessions, and those completing ≥ 9sessions	High
Selective reporting ***(reporting bias)***	Protocol available, all pre-described hypotheses and measures were reported and addressed in study	Low

Brown et al 2014- Improving child and parenting outcomes following paediatric acquired brain injury: a randomised controlled trial of Stepping Stones Triple P plus Acceptance and Commitment Therapy

Author, Brown 2014 **Source of bias (*bias domain)***	**Support for judgement**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation *** ***(selection bias)***	Families were randomised to ACT + SSTP or CAU. Randomisation was via computer-generated random number sequence.	Low
Allocation concealment (selection bias)	Allocations were placed in concealed envelopes by non-study personnel, which were opened in order by the study coordinator	Low

Blinding of participants and personnel ***(performance bias)***	Given nature of intervention, blinding not possible	High
Blinding of outcome assessment ***(detection bias)***	Blinding to groups not possible given nature of intervention, with parents participating and then completing outcome measures. However, outcomes not dependent on the judgments of the research staff - thus minimising risk of researcher bias. Though no blinding of outcome assessment re participants, but the review authors judge that the outcome measurement is not likely to be influenced by lack of blinding.	Low
Incomplete outcome data ***(attrition bias)***	27 of 29 allocated to CAU group completed post treatment assessments (93%), 25 of 30 allocated to treatment group completed post treatment assessments (83%) thus total completion of data at 88% immediately post treatment. By 6 months follow up however, 20% attrition in intervention group. Incomplete data on reason for dropouts. Differences noted in anxiety between completers and non completers.	High
Selective reporting ***(reporting bias)***	Protocol available, predefined hypotheses and measures reported and discussed in study findings	Low

Wade et al 2014- Counsellor-Assisted Problem Solving Improves Caregiver Efficacy Following Adolescent Brain Injury

Author, Wade 2014*a* **source of bias** ***(bias domain)***	**Support for judgement**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	Adolescents and their families were randomly assigned to one of two 6-month long Internet-based interventions: A SAS program was created using permuted block sizes for each of the randomizations.	Low
Allocation concealment (selection bias)	A SAS program was created using permuted block sizes for each of the randomizations. A sealed envelope containing group assignment was handed to the participants at the end of the baseline visit allowing interviewers to remain naïve to group assignment at the baseline assessment	Low
Blinding of participants and personnel ***(performance bias)***	A sealed envelope containing group assignment was handed to the participants at the end of the baseline visit allowing interviewers to remain naïve to group assignment at the baseline assessment. Thus, interviewers/research assistants were unaware of group assignment at both assessments, whereas parents were naïve to group assignment only at the baseline visit- not possible to blind participants owing to nature of intervention	High
Blinding of outcome assessment ***(detection bias)***	Outcomes not dependent on the judgments of the research staff - thus minimising risk of researcher bias.	Low
Incomplete outcome data ***(attrition bias)***	65 allocated to intervention arm, of which 4 did not begin or discontinued intervention after baseline assessment (leaving 61). Of 67 randomised to control arm, all completed intervention but x3 cases were lost to follow up (leaving 64). Attrition / exclusion data was provided, with 3 participants failing to provide complete measures at baseline and 11 failing to complete measures at follow up, with an attrition rate of 10.6%. Rate of attrition considered reasonable. No significant differences had been found between the groups, however. All participants with valid data were included in analyses using intent to treat framework.	Low
Selective reporting ***(reporting bias)***	Incomplete reporting of predetermined objectives	High

Wade et al 2014- Counsellor-assisted problem solving (CAPS) improves behavioural outcomes in older adolescents with complicated mild to severe TBI

Wade 2014*b* **Source of bias** ***(bias domain)***	**Support for judgement**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	Participating families were randomly assigned to one of two internet-based interventions. To ensure that both gender and race were balanced within each of the sites, randomization was carried out by stratifying on these two factors	Low
Allocation concealment (selection bias)	A SAS program was created using permuted block sizes for each randomization. Group assignment was contained in a sealed envelope that was handed to the participants at the end of the baseline visit.	Low

Blinding of participants and personnel ***(performance bias)***	Studies where personnel deliver specific interventions treatment are presumed to be at risk for performance bias as blinding is not possible’	High
Blinding of outcome assessment ***(detection bias)***	Group assignment was concealed from the research coordinators completing the baseline and follow-up assessments, but parent completing outcomes could not be blinded owing to nature of intervention. However, outcomes not dependent on the judgments of the research staff - thus minimising risk of researcher bias.	Low
Incomplete outcome data ***(attrition bias)***	Completeness of data- initial sample of 132 reduced via attrition to 89% post follow up. Those who failed to complete the 6-month follow-up did not differ significantly from those who completed follow-up on child age, race/ethnicity, gender, grade, time since injury, injury severity, or baseline levels of behaviour problems (all ps >. 10). There was a non-significant trend (p < .10) for parents who did not complete the follow-up assessment to be younger than those who did	Low
Selective reporting ***(reporting bias)***	Objective of study and Measures outlined in methods section were adequately discussed in results.	Low

Brown 2015- Does Stepping Stones Triple P plus Acceptance and Commitment Therapy improve parent, couple, and family adjustment following paediatric acquired brain injury? A randomised controlled trial

Brown 2015 **Source of bias** ***(bias domain)***	**Support for judgement**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	participating parents were randomly assigned to ACT þ SSTP or CAU.	Low
Allocation concealment (selection bias)	No data pertaining to this available	Unclear
Blinding of participants and personnel ***(performance bias)***	Given nature of intervention, blinding not possible	High
Blinding of outcome assessment ***(detection bias)***	Data was via self-reports collected at baseline, post-intervention, and 6-months post-intervention- outcome questionnaires were completed via online or paper questionnaires. But outcomes not dependent on the judgments of the research staff - thus minimising risk of researcher bias. Though no blinding of outcome assessment re participants, but the review authors judge that the outcome measurement is not likely to be influenced by lack of blinding	Low
Incomplete outcome data ***(attrition bias)***	Completeness of data at 88% post treatment, adequate retention rate, attrition and reasons for attrition reported.	Low
Selective reporting ***(reporting bias)***	Protocol available, all measures referred to in results, but not all predefined objectives explored (two parent families re conflict over parenting)	High

Narad 2015- Effects of a Web-Based Intervention on Family Functioning Following Paediatric Traumatic Brain Injury

Narad et al 2015 **Source of bias** ***(bias domain)***	**Support for judgement**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	Participating families were randomly assigned to either the CAPS (n=65) or IRC (n=67) internet-based interventions, with randomization stratified by sex and race within each site	Low
Allocation concealment (selection bias)	Examiners naïve to treatment assignment completed baseline assessments in the family homes where parents and teens completed questionnaires regarding child functioning, family functioning, and participated in parent-teen videotaped interactions- after which randomisation occurred	Low

Blinding of participants and personnel ***(performance bias)***	No possible to be blinded owing to nature of intervention	High
Blinding of outcome assessment ***(detection bias)***	Not possible for parents to be blinded owing to nature of intervention, and they rate outcomes measures. However, outcomes not dependent on the judgments of the research staff - thus minimising risk of researcher bias. Though no blinding of outcome assessment re participants, but the review authors judge that the outcome measurement is not likely to be influenced by lack of blinding	Low
Incomplete outcome data ***(attrition bias)***	Attrition and exclusion were reported- 2 cases dropped out of intervention group (of 65) prior to receiving intervention and no cases dropped out of control arm (of 67). A further 2 discontinued intervention from CAPS group, none in control arm. Outcome data was therefore high immediately post intervention, (4 dropouts on CAPS group, 0 in control arm), with 128 of 132 cases providing complete data on main outcomes. By 18 months follow up however, attrition was 28 cases (14 from each arm), totalling 24% attrition from original randomised sample by 18mos. All 132 cases originally randomised to groups were included in analysis. -Some differences found between completers and non-completers- participants comprised proportionally fewer non-whites compared to non-participants (19.7% vs. 24.4%) and had more severe TBI (GCS: M = 11.90 SE = 3.89 vs. M = 10.03 SE = 4.56). Participants from both groups who completed the intervention did not differ from those who did not complete it on TBI severity, age or sex; however, proportionally more completers were white	High
Selective reporting ***(reporting bias)***	Key hypotheses all addressed in analysis and discussed in results	Low

Raj et al 2015- Web-Based Parenting Skills Program for Paediatric Traumatic Brain Injury Reduces Psychological Distress Among Lower-Income Parents

Raj 2015- Web-Based Parenting Skills Program Source of bias *(bias domain)*	**Support for judgement**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	Parents were randomly assigned to either the parenting skills treatment group	Low
Allocation concealment (selection bias)	At the end of the visit, parents received a packet detailing their study assignment (i.e., I-InTERACT or IRC)- probably done	Low
Blinding of participants and personnel ***(performance bias)***	Therapist could not be blind to knowing what treatment they were delivering, presumed high risk	High
Blinding of outcome assessment ***(detection bias)***	Participants completed a follow-up visit (at the completion of treatment). Prior to each visit, parents were sent a questionnaire packet that included the measures examined in this study. The completed questionnaires were collected during the visit. Though no blinding of outcome assessment re participants, the review authors judge that the outcome measurement is not likely to be influenced by lack of blinding	Low
Incomplete outcome data ***(attrition bias)***	Incomplete data, 3 dropouts within intervention group (originally 20), with no dropouts in comparator group (n=17). Attrition reported but not reasons for this. No significant differences found between dropouts and completers	Low
Selective reporting ***(reporting bias)***	Incomplete data presented- Analyses of covariance were used to examine overall group differences (i.e., I-InTERACT and IRC) for the 4 outcomes of interest (i.e., parent depression, parent psychological distress, parenting stress, and caregiver self-efficacy), but not all were presented in results (details on group differences absent for parent distress, where interaction effects were discussed from further analyses)	High

Wade et al 2015- Online Problem-Solving Therapy After Traumatic Brain Injury: A Randomized Controlled Trial

Wade 2015 **Source of bias** ***(bias domain)***	**Support for judgement**	**Assessment of authors judgement**

		(low, unclear or high)
Random sequence generation ***(selection bias)***	Participants were randomly assigned to the following groups: (1) Counsellor-Assisted Problem Solving (CAPS), a 6-month Web-based, therapist-moderated intervention providing training in problem-solving, communication, and self-regulation, or (2) IRC, a control intervention providing self-guided, Web-based TBI information and resources. Randomization was stratified according to race and gender.	Low
Allocation concealment (selection bias)	A sealed envelope containing group assignment was handed to participants at the visit completion, allowing the coordinator to remain naive to assignment.	Low
Blinding of participants and personnel ***(performance bias)***	Not possible due to nature of the intervention for either psychologist or participants to be unaware of treatment group they were in	High
Blinding of outcome assessment ***(detection bias)***	Coordinator was blind to assignment but unclear who conducted interviews- assumed CAFAS coders blind to assignment groups but not explicit in paper- probably did happen given coordinator blind. Assessments were also scheduled without knowledge of whether the participant had completed treatment.	Low
Incomplete outcome data ***(attrition bias)***	Complete follow up data available for 75% of original sample of 132. Intervention group of 65 had a 31% dropout (n=20), comparator group had a 19% dropout (n=13). Attrition did not differ significantly across the groups. Mixed models analysis retained participants in the model who were missing data for $1 assessments and is thus less affected by attrition. - Analysis was conducted to examine intention to treat group differences on the CAFAS total across follow up. – Differences identified between completers and non-completers: Caregivers of non-completers had disproportionately lower income and were more often single than caregivers of completers.	High
Selective reporting ***(reporting bias)***	Presented analysis and discussion in line with predefined objectives	Low

Mortenson et al 2016- Impact of Early Follow-Up Intervention on Parent-Reported Post concussion Paediatric Symptoms: A Feasibility Study

Mortenson 2016 **Source of bias** ***(bias domain)***	**Support for judgement**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	A single, masked, block randomized controlled trial design was conducted. Eligible participants were randomized (generated by a random number generator, www.random.org) into 2 separate treatment arms, within 20 person blocks.	Low
Allocation concealment (selection bias)	Not referred to	Unclear
Blinding of participants and personnel ***(performance bias)***	Participants were masked to the study methods; however, first author conducted calls to intervention participants	High
Blinding of outcome assessment ***(detection bias)***	The Post-Concussion Symptom Inventory and the Family Burden of Injury Interview were administered with parents by a blinded therapist at 3 months post injury (parents also unaware which arm of intervention they were in)	Low
Incomplete outcome data ***(attrition bias)***	Initial sample of 76 composed of 38 in intervention and CAU groups. Attrition reported and reasons provided, with 6 attrition in intervention group (16%) and 4 in control group (11%). 66 of 76 included in analysis (87%). No discussion or analyses on differences between completers and non-completers.	High
Selective reporting ***(reporting bias)***	Though main objectives explored, incomplete outcome data (no means, ranges) presented/tabled in relation to key measures, though unlikely to impact understanding of overall outcome.	Low

Tlustos et al. 2016 - A randomized problem-solving trial for adolescent brain injury: Changes in social competence

Tlustos 2016 **Source of bias** ***(bias domain)***	**Support for judgement-** Tlustos[iv] 2016	**Assessment of authors judgement (low, unclear or high)**

Random sequence generation ***(selection bias)***	Teens with TBI were randomly assigned to one of two treatment conditions (CAPS and IRC groups) in a comparative effectiveness trial.	Low
Allocation concealment (selection bias)	Assignment was made immediately after the baseline assessment and individuals conducting the assessments remained naïve to group membership	Low
Blinding of participants and personnel ***(performance bias)***	Presumed high as blinding of psychologists delivering intervention not possible	High
Blinding of outcome assessment *(detection bias)*	individuals conducting the (baseline) assessments remained naïve to group membership- probably remained naive for final assessments	Low
Incomplete outcome data ***(attrition bias)***	Attrition reported, though reasons not explained: Of the 132 teens participating in the baseline assessment, 124 completed the 6-month follow-up (6% attrition rate). No sig difference reported between the groups.	Low
Selective reporting ***(reporting bias)***	Data not fully reported in relation to main objectives	High

Wade et al 2017 - Randomized Clinical Trial of Online Parent Training for Behaviour Problems After Early Brain Injury

Wade 2017 **Source of bias** ***(bias domain)***	**Support for judgement** Wade^{v} 2017	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	Randomization was stratified by race (white versus other) and sex to ensure comparable numbers of boys and girls and whites versus other races across groups. Families were randomized to 1 of 3 groups (I-InTERACT; Express, an abbreviated web-based parent skills training; or IRC) using a SAS-generated randomization scheme (SAS Institute, Cary, NC).	Low
Allocation concealment (selection bias)	Families were randomized to 1 of 3 groups (I-InTERACT; Express, an abbreviated web-based parent skills training; or IRC) using a SAS-generated randomization scheme (SAS Institute, Cary, NC. But further description of allocation following this is not included, though likely occurred.	Unclear
Blinding of participants and personnel ***(performance bias)***	Group assignment was concealed to coders of parenting skills videos, but not from coordinators, therapists, or participants.	High
Blinding of outcome assessment *(detection bias)*	Group assignment was concealed to coders of parenting skills (DPICS). ECBI measures post treatment would have been rated by parents who were aware of group assignment. However, as rated by parents this minimises researcher bias on this domain. Though no blinding of outcome assessment re participants, the review authors judge that the outcome measurement is not likely to be influenced by lack of blinding	Low
Incomplete outcome data ***(attrition bias)***	Incomplete data: 13 (11%) dropped out before the 3-month assessment, and an additional 20 participants (18%) failed to complete the 6-month assessment. Thus, eighty participants (71%) completed the 2 follow-up assessments. Differences identified between completers and non-completers: Non-completers were more likely to be unmarried and have lower incomes than completers.	High
Selective reporting ***(reporting bias)***	All pre-specified outcomes were reported on	Low

Hickey et al 2018 - Family appraisal of paediatric acquired brain injury: a social work clinical intervention trial

Hickey 2018 **Source of bias** ***(bias domain)***	**Support for judgement**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	Families were recruited prospectively and sequentially as their child was admitted to the inpatient rehabilitation based in a ward at the hospital.	High
Allocation concealment **(selection bias)**	N/A given sequential nature of design	N/A
Blinding of participants and personnel ***(performance bias)***	To reduce bias, blinding was used to prevent participants from knowing to which group they were assigned- not possible for social worker delivering intervention to be unaware of group owing to nature of intervention- presumed high risk	High
Blinding of outcome assessment *(detection bias)*	Parents were blind to groups in relation to own self reports	Low
Incomplete outcome data ***(attrition bias)***	The attrition rate of the 'Usual Care' group was higher with a reduced sample reporting on the outcomes. The 'Usual Care' group had lower response rates at post-intervention and follow-up than the 'Family Forward' group and this may have resulted in attrition bias, changing the characteristics and outcomes of this group.	High
Selective reporting ***(reporting bias)***	All predefined hypotheses and all measures outlined in plan for analyses were addressed in analysis and discussion.	Low

Hickey et al 2018 - Family Forward: a social work clinical trial promoting family adaptation following paediatric acquired brain injury

Hickey 2018[vi] **Source of bias** ***(bias domain)***	**Support for judgement**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	A prospective, sequential comparison group design was used, with Usual Care delivered to the first cohort of participants and Family Forward to the second cohort. Families were approached on their child's admission to inpatient rehabilitation and those agreeing to participate received the intervention during their child's admission.	High
Allocation concealment **(selection bias)**	N/A given sequential nature of design - Families were approached on their child's admission to inpatient rehabilitation and those agreeing to participate received the intervention during their child's admission.	N/A
Blinding of participants and personnel ***(performance bias)***	Not possible to blind social worker delivering intervention, given nature of intervention	High
Blinding of outcome	Parents were blind to groups in relation to own self reports	Low

assessment ***(detection bias)***		
Incomplete outcome data ***(attrition bias)***	Of 22 enrolled into usual care, data collected at t1=22, t2=15, t3=13. Completion rate of 59%. For intervention group, data collected at t1=25, t2=23, t3= 18. Total completion by t3 of 72% There was a higher rate of attrition in the Usual Care group post-intervention and at follow-up, leading to a low number of respondents at these two time-points and possible changes to the characteristics of this group.	High
Selective reporting ***(reporting bias)***	Analysis and discussion explicitly address predefined objectives of the research	Low

Raj et al 2018 - Effects of Web-Based Parent Training on Caregiver Functioning Following Paediatric Traumatic Brain Injury: A Randomized Control Trial

Raj 2018 **Source of bias** ***(bias domain)***	**Support for judgement**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	A random allocation sequence generator stratified for child race and gender was used to assign families to I-InTERACT (n=39), Express (n=36), or the active control condition	Low
Allocation concealment **(selection bias)**	No information pertaining to this in the data	Unclear
Blinding of participants and personnel ***(performance bias)***	Assumed high risk given nature of intervention	High
Blinding of outcome assessment ***(detection bias)***	Study personnel remained naive to group assignment. Though parents would not have been blind to group assignment and completed outcome measures- this is presumed to minimise risk of bias on this domain. Though no blinding of outcome assessment re participants, the review authors judge that the outcome measurement is not likely to be influenced by lack of blinding	Low
Incomplete outcome data ***(attrition bias)***	Losses to follow up were disclosed across all three arms of the intervention. There was no significant difference in the number of caregivers who did not complete follow-up measures across the 3 groups. However, differences found between completers and non-completers were found: Comparing caregivers who did not complete follow-up measures with those who did, there were no significant between group differences for baseline scores on study outcomes. There was, however, a significant difference in family income, with caregivers with an annual income of less than $50 000 being disproportionally more likely to drop out (χ2 = 0.5, P< .05).	High
Selective reporting ***(reporting bias)***	All measures reported on in results, post hoc analyses completed but reported as planned.	Low

Wade et al 2018 - Online problem solving for adolescent brain injury: A randomized trial of 2 approaches

Wade 2018 **Source of bias** ***(bias domain)***	**Support for judgement**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	Randomisation occurred- On completion of baseline measures, participants received an envelope with their randomization assignment. To ensure that sex and race were balanced across sites, randomization was stratified on these factors using an SAS program with permuted block sizes.	Low
Allocation concealment **(selection bias)**	On completion of baseline measures, participants received an envelope with their randomization assignment. Unclear re concealment from staff but likely done	Low
Blinding of participants and personnel ***(performance bias)***	Not possible given nature of intervention- presumed high	High

Blinding of outcome assessment ***(detection bias)***	Parents would not have been blind to group assignment and completed outcome measures. Though no blinding of outcome assessment re participants, but the review authors judge that the outcome measurement is not likely to be influenced by lack of blinding	Low
Incomplete outcome data ***(attrition bias)***	In the TOPS-Family and TOPS-TO groups completed equivalent numbers of treatment sessions. In addition, comparable proportions completed 1 or more supplemental sessions and completion of supplemental sessions was not related to injury severity or child demographic characteristics. Forty-one participants did not complete the follow-up assessment (27% of total randomised sample). Attrition did not vary significantly by group. Differences identified between completers and non-completers- Dropouts were more likely to have severe traumatic brain injury (TBI) (p 5 .01) and to be of a non-white race (p 5 .02). All participants with follow-up data, regardless of the number of sessions completed, were included in the analyses	High
Selective reporting ***(reporting bias)***	All pre-specified outcomes were reported	Low

Aguilar et al 2019 - A Comparison of 2 Online Parent Skills Training Interventions for Early Childhood Brain Injury: Improvements in Internalizing and Executive Function Behaviours

Aguilar 2019 Source of bias ***(bias domain)***	**Support for judgement**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	Families were randomized to (1) I-InTERACT (full version); (2) I-InTERACT Express; or (3) the IRC group. To ensure comparable numbers of males and females and whites versus other races across groups, the randomization process included stratification according to these 2 factors.	Low
Allocation concealment (selection bias)	Group assignments were placed in sealed envelopes by staff not involved with data collection, and envelopes were selected in order within each stratum.	Low
Blinding of participants and personnel ***(performance bias)***	Staff completing baseline assessments was unaware of group assignment until the envelope was opened at the end of the visit. At follow-up assessments, both research staff and participants were aware of group assignment	High
Blinding of outcome assessment ***(detection bias)***	However, as measures were participant rated, this minimises researcher bias in this domain. Though no blinding of outcome assessment re participants, the review authors judge that the outcome measurement is not likely to be influenced by lack of blinding	High
Incomplete outcome data ***(attrition bias)***	71% completed follow up assessments at 6mo, so 29% attrition of total sample. Missing data were ignored because there were no group differences in attrition at 6 months. Differences identified between completers and non completers.	High
Selective reporting ***(reporting bias)***	All measures in procedure reported on	Low

Narad et al 2019 - Randomized Controlled Trial of an Online Problem-Solving Intervention Following Adolescent Traumatic Brain Injury: Family Outcomes

Narad 2019 Source of bias ***(bias domain)***	**Support for judgement**	**Assessment of authors judgement (low, unclear or high)**
Random sequence generation ***(selection bias)***	Families were randomly assigned to 1 of the 3 conditions: TOPS-F (nZ49), TOPS-TO (nZ51), or IRC (nZ52). Group assignment was stratified by adolescent sex and race/ethnicity and were generated prior to study initiation using a computer program developed by biostatisticians at the primary site	Low
Allocation concealment (selection bias)	A program at primary site produced list but description of allocation not included	unclear
Blinding of participants and personnel	We were unable to conceal group assignment from the families or research staff, thus no blinding possible on this	High

(performance bias)		
Blinding of outcome assessment ***(detection bias)***	We were unable to conceal group assignment from the families, who then completed outcome measure post intervention. However, as participant measures served as the primary outcome measure, this minimised potential researcher bias. Though no blinding of outcome assessment re participants, the review authors judge that the outcome measurement is not likely to be influenced by lack of blinding.	Low
Incomplete outcome data ***(attrition bias)***	Rates of attrition were equivalent across groups. Difference found on race between completers and non-completers- White participants were more likely to complete follow-up (79%) than were non-white participants (57%).	High
Selective reporting ***(reporting bias)***	Limited verbal reporting of one of the stated outcomes (family cohesion) which is verbally reported but not supported by any statistical information (e.g. Effect sizes, significance tests) - however seems a problem with level of detail as opposed to omission of outcome finding as such.	Low

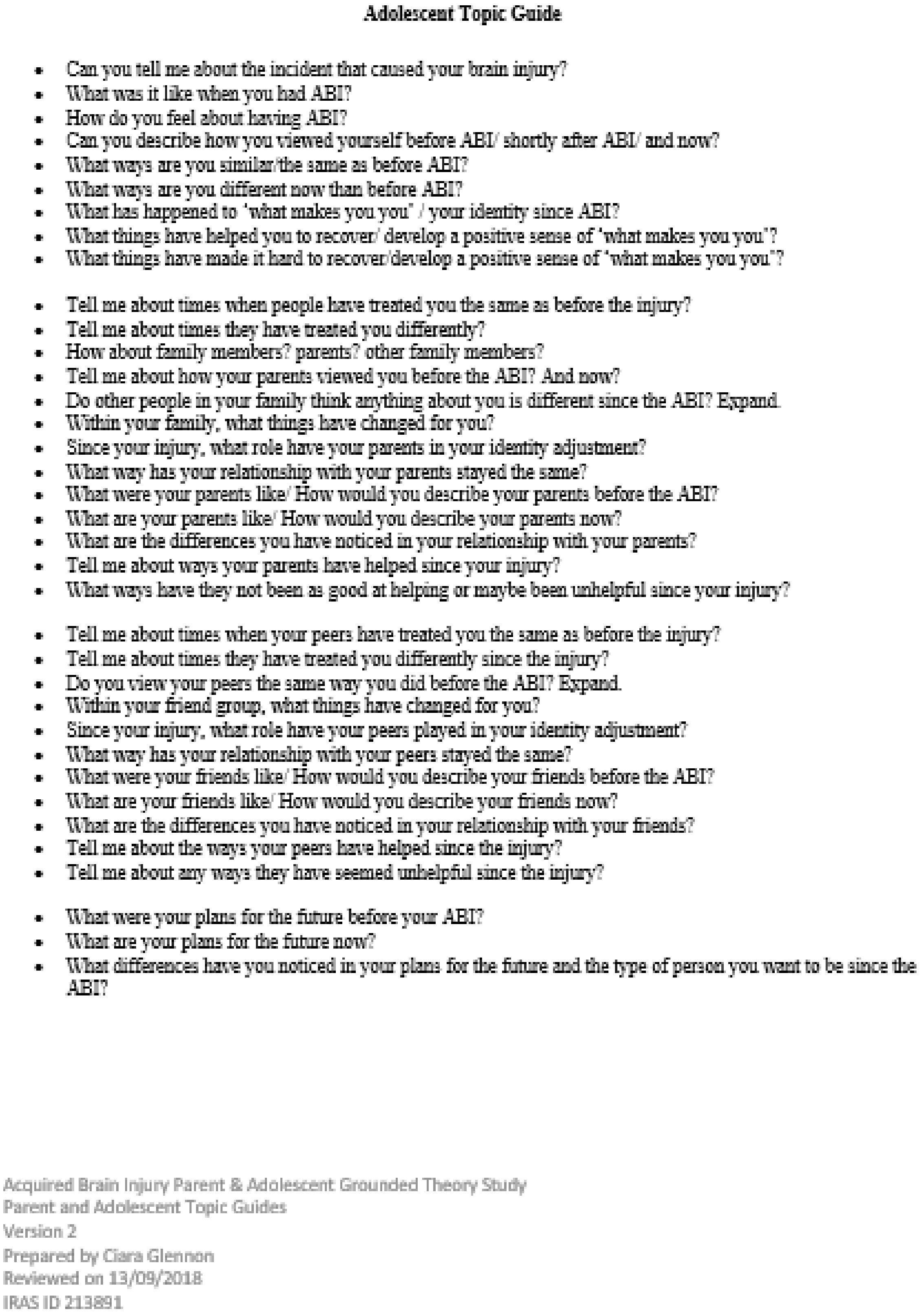
Appendix I- CONSORT Appraisal of Articles for Systematic Review

Methodological quality appraisals of papers *Score 1 if met, 0 if not met or unable to determined*	Wade 2005 *b*	Wade 2005 *a*	Wade 2006 *a*	Wade 2006 *b*	Wade 2006 *c*	Wade 2008	Dise Lewis 2009	Wade 2009	Wade 2011
Were specific hypotheses and/or objectives stated?	1	1	1	1	1	1	1	1	1
Were the settings and locations where data was collected stated?	0	0	0	0	0	0	0	1	0
Control or comparison group used?	0	0	1	1	1	1	0	0	1
Were participants randomly allocated to groups?	0	0	1	1	1	1	0	0	1
Is the method of randomization appropriate?	0	0	1	1	1	1	0	0	1
Was the total sample size >20 participants?	0	0	1	1	1	0	1	0	1
Was the total sample size >40 participants?	0	0	0	1	1	0	0	0	0
Were at least some of the measures standardized assessment tools?	1	1	1	1	1	1	1	1	1
Were the measures appropriate for age group?	1	1	1	1	1	1	1	1	1
Were inclusion/ exclusion criteria clearly stated *or referenced?*	1	1	1	1	1	1	1	1	1
Did the article specify the severity of the brain injury for participants with acquired brain injury and was the method of diagnosis appropriate (e.g. by a medical professional, Glasgow Coma Scale)?	1	1	1	1	1	1	1	0	1
Did the injury occur at least 6mo ago (*MEAN*) (to ensure the results were not a reflection of the recovery process)?	1	1	1	1	1	1	0	1	1
Were follow-up data collected after post-intervention data (i.e. to see if effects were maintained post intervention)?	0	0	1	1	1	1	0	0	0
Were all participants included in the analysis?	1	1	1	0	0	1	0	0	0
If not, was intent-to-treat analysis used? (Award 1 point if a point is granted on the above item)	1	1	1	1	1	1	0	0	1
Were those assessing the outcomes blind to the group?	0	0	0	0	0	0	0	0	0
Was a power calculation used or sample size justified?	0	0	1	0	0	0	1	0	0
Was the intervention described in detail (i.e. how it was administered, etc.) or was there reference to a manual?	1	1	1	1	1	1	1	1	1
Were the characteristics of participants clearly described (e.g. demographic information such as age, sex)?	0	0	0	0	0	0	0	0	0
Did the results relate to the initial hypotheses?	1	1	1	1	1	1	1	1	1
Was statistical analysis appropriate?	0	0	1	1	1	0	1	0	1
Were data adequately described (mean, range etc.)?	1	1	1	1	1	1	0	0	1
Were effect sizes calculated?	0	0	1	1	1	1	0	1	1
Were effect sizes moderate or better (for studies with small sample sizes n<10)?	0	0	1	1	1	1	0	1	1
Was there sufficient information to calculate effect size (i.e. mean and SD)?	1	1	1	1	1	1	0	1	1
Was age taken into account as a possible confounding factor?	0	0	1	1	1	0	0	0	1
Total quality rating /26	12	12	22	21	21	18	10	11	19
%	46	46	85	81	81	69	38	42	73

Methodological quality appraisals of papers *Score 1 if met, 0 if not met or unable to determined*	Wade 2012	Antonioni 2014	Brown 2014	Wade 2014 *a*	Wade 2014 *b*	Brown 2015	Narad 2015	Raj 2015	Wade 2015
Were specific hypotheses and/or objectives stated?	1	1	1	1	1	1	1	1	1
Were the settings and locations where data was collected stated?	0	1	0	0	1	0	1	1	1
Control or comparison group used?	1	1	1	1	1	1	1	1	1
Were participants randomly allocated to groups?	1	1	1	1	1	1	1	1	1
Is the method of randomization appropriate?	1	1	1	1	1	1	1	1	1
Was the total sample size >20 participants?	1	1	1	1	1	1	1	1	1
Was the total sample size >40 participants?	1	0	1	1	1	1	1	0	1
Were at least some of the measures standardized assessment tools?	1	1	1	1	1	1	1	1	1
Were the measures appropriate for age group?	1	1	1	1	1	1	1	1	1
Were inclusion⁄ exclusion criteria clearly stated *or referenced?*	1	1	1	1	1	1	1	1	1
Did the article specify the severity of the brain injury for participants with acquired brain injury and was the method of diagnosis appropriate (e.g. by a medical professional, Glasgow Coma Scale)?	1	1	1	1	1	1	1	0	1
Did the injury occur at least 6mo ago (*MEAN*) (to ensure the results were not a reflection of the recovery process)?	1	1	1	0	0	1	0	1	0
Were follow-up data collected after post-intervention data (i.e. to see if effects were maintained post intervention)?	1	0	1	0	1	1	1	1	1
Were all participants included in the analysis?	0	0	0	1	1	0	1	1	1
If not, was intent-to-treat analysis used? (Award 1 point if a point is granted on the above item)	1	0	1	1	1	0	1	1	1
Were those assessing the outcomes blind to the group?	0	1	0	1	1	0	1	0	1
Was a power calculation used or sample size justified?	0	1	0	0	0	1	0	0	0
Was the intervention described in detail (i.e. how it was administered, etc.) or was there reference to a manual?	1	1	1	1	1	1	1	1	1
Were the characteristics of participants clearly described (e.g. demographic information such as age, sex)?	0	0	1	1	1	1	0	1	0
Did the results relate to the initial hypotheses?	1	1	1	0	1	1	1	0	0
Was statistical analysis appropriate?	1	1	1	1	1	1	1	1	1
Were data adequately described (mean, range etc.)?	1	1	1	1	1	1	1	1	1
Were effect sizes calculated?	1	0	1	1	1	1	1	1	0
Were effect sizes moderate or better (for studies with small sample sizes n<10)?	0	0	1	1	0	1	0	1	0
Was there sufficient information to calculate effect size (i.e. mean and SD)?	1	1	1	1	1	1	1	1	1
Was age taken into account as a possible confounding factor?	1	0	0	0	1	1	1	0	1
Total quality rating ⁄26	20	18	21	20	23	22	22	20	20
%	77	69	81	77	88	85	85	77	77

Methodological quality appraisals of papers *Score 1 if met, 0 if not met or unable to determined*	Mortenson 2016	Tlustos 2016	Wade 2017	Raj 2018	Wade 2018	Hickey 2018 *a*	Hickey 2018 *b*	Aguilar 2019	Narad 2019
Were specific hypotheses and/or objectives stated?	1	1	1	1	1	1	1	1	1
Were the settings and locations where data was collected stated?	1	0	0	0	1	1	1	0	1
Control or comparison group used?	1	1	1	1	1	1	1	1	1
Were participants randomly allocated to groups?	1	1	1	1	1	0	0	1	1
Is the method of randomization appropriate?	1	1	1	1	1	0	0	1	1
Was the total sample size >20 participants?	1	1	1	1	1	1	1	1	1
Was the total sample size >40 participants?	1	1	1	1	1	1	1	1	1
Were at least some of the measures standardized assessment tools?	1	1	1	1	1	1	1	1	1
Were the measures appropriate for age group?	1	1	1	1	1	1	1	1	1
Were the inclusion⁄ exclusion criteria clearly stated *or referenced?*	1	1	1	1	1	1	1	1	1
Did the article specify the severity of the brain injury for participants with acquired brain injury and was the method of diagnosis appropriate (e.g. by a medical professional, Glasgow Coma Scale)?	1	1	1	1	1	0	0	1	1
Did the injury occur at least 6mo ago (*MEAN)* (to ensure the results were not a reflection of the recovery process)?	0	0	1	1	0	0	0	1	0
Were follow-up data collected after post-intervention data (i.e. to see if effects were maintained post intervention)?	1	1	1	1	1	1	1	1	1
Were all participants included in the analysis?	1	1	1	1	0	0	0	1	0
If not, was intent-to-treat analysis used? (Award 1 point if a point is granted on the above item)	1	1	1	1	1	0	0	1	1
Were those assessing the outcomes blind to the group?	1	1	1	1	0	0	0	1	0
Was a power calculation used or sample size justified?	0	0	1	1	1	0	0	1	0
Was the intervention described in detail (i.e. how it was administered, etc.) or was there reference to a manual?	1	1	1	1	1	1	1	1	1
Were the characteristics of participants clearly described (e.g. demographic information such as age, sex)?	0	0	0	0	0	0	0	0	0
Did the results relate to the initial hypotheses?	1	1	1	1	1	1	1	1	1
Was statistical analysis appropriate?	1	0	1	1	1	1	1	1	1
Were data adequately described (mean, range etc.)?	1	1	1	1	1	1	0	1	1
Were effect sizes calculated?	0	1	0	1	1	1	0	1	0
Were effect sizes moderate or better (for studies with small sample sizes n<10)?	0	0	0	1	1	0	0	0	0
Was there sufficient information to calculate effect size (i.e. mean and SD)?	0	1	1	1	1	1	0	1	1
Was age taken into account as a possible confounding factor?	1	1	1	1	1	1	1	1	1
Total quality rating ⁄26	20	20	22	24	22	16	13	23	19
%	77	77	85	92	85	62	50	88	73

Appendix J- Adolescent Topic Guide for Interviews - Empirical Paper



Adolescent Topic Guide

- Can you tell me about the incident that caused your brain injury?
- What was it like when you had ABI?
- How do you feel about having ABI?
- Can you describe how you viewed yourself before ABI/ shortly after ABI/ and now?
- What ways are you similar/the same as before ABI?
- What ways are you different now than before ABI?
- What has happened to 'what makes you you' / your identity since ABI?
- What things have helped you to recover/ develop a positive sense of 'what makes you you'?
- What things have made it hard to recover/develop a positive sense of 'what makes you you'?

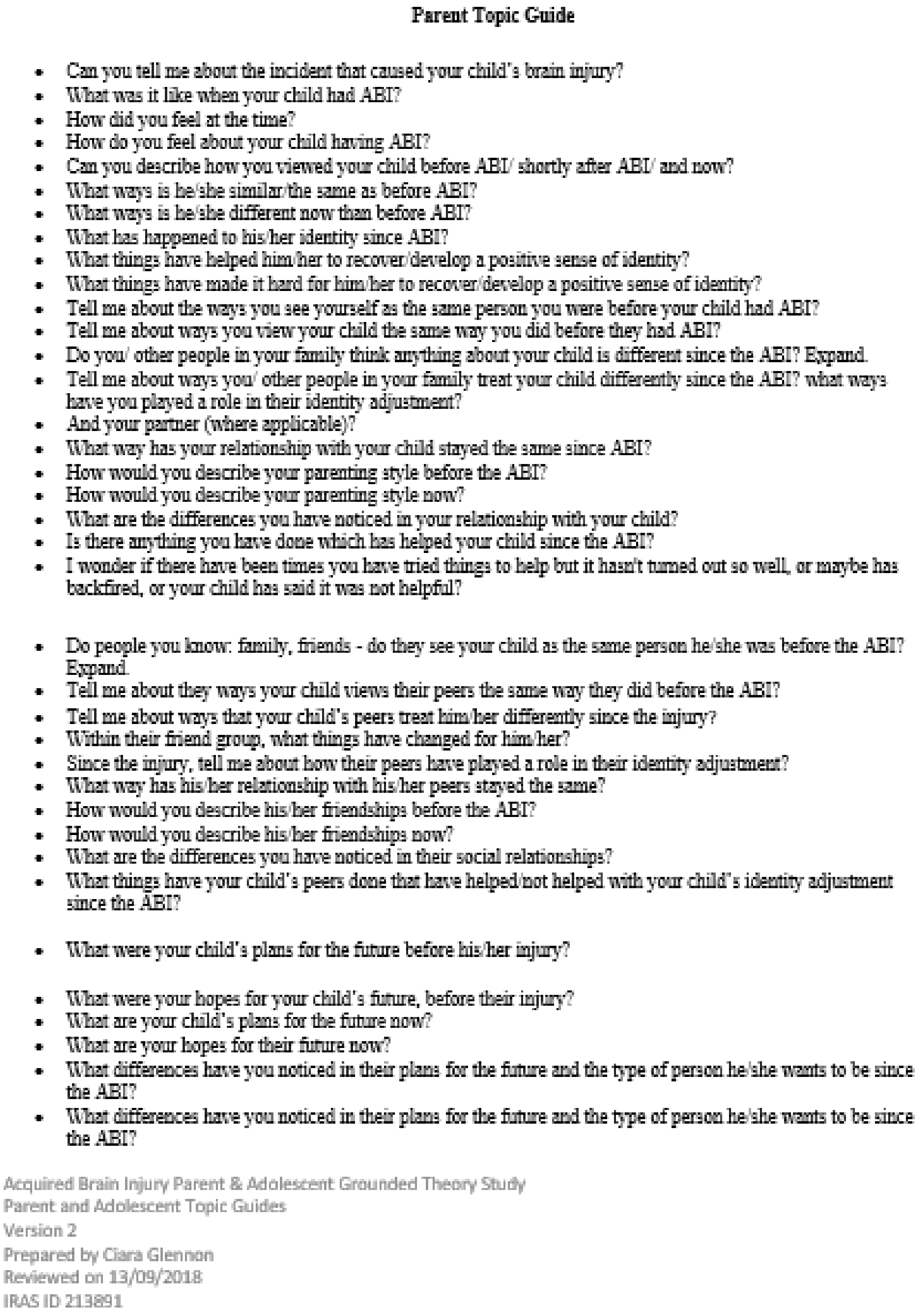
- Tell me about times when people have treated you the same as before the injury?
- Tell me about times they have treated you differently?
- How about family members? parents? other family members?
- Tell me about how your parents viewed you before the ABI? And now?
- Do other people in your family think anything about you is different since the ABI? Expand.
- Within your family, what things have changed for you?
- Since your injury, what role have your parents in your identity adjustment?
- What way has your relationship with your parents stayed the same?
- What were your parents like/ How would you describe your parents before the ABI?
- What are your parents like/ How would you describe your parents now?
- What are the differences you have noticed in your relationship with your parents?
- Tell me about ways your parents have helped since your injury?
- What ways have they not been as good at helping or maybe been unhelpful since your injury?

- Tell me about times when your peers have treated you the same as before the injury?
- Tell me about times they have treated you differently since the injury?
- Do you view your peers the same way you did before the ABI? Expand.
- Within your friend group, what things have changed for you?
- Since your injury, what role have your peers played in your identity adjustment?
- What way has your relationship with your peers stayed the same?
- What were your friends like/ How would you describe your friends before the ABI?
- What are your friends like/ How would you describe your friends now?
- What are the differences you have noticed in your relationship with your friends?
- Tell me about the ways your peers have helped since the injury?
- Tell me about any ways they have seemed unhelpful since the injury?

- What were your plans for the future before your ABI?
- What are your plans for the future now?
- What differences have you noticed in your plans for the future and the type of person you want to be since the ABI?

Acquired Brain Injury Parent & Adolescent Grounded Theory Study
Parent and Adolescent Topic Guides
Version 2
Prepared by Ciara Glennon
Reviewed on 13/09/2018
IRAS ID 213891

Appendix K- Parent Topic Guide for Interviews - Empirical Paper



Parent Topic Guide

- Can you tell me about the incident that caused your child's brain injury?
- What was it like when your child had ABI?
- How did you feel at the time?
- How do you feel about your child having ABI?
- Can you describe how you viewed your child before ABI/ shortly after ABI/ and now?
- What ways is he/she similar/the same as before ABI?
- What ways is he/she different now than before ABI?
- What has happened to his/her identity since ABI?
- What things have helped him/her to recover/develop a positive sense of identity?
- What things have made it hard for him/her to recover/develop a positive sense of identity?
- Tell me about the ways you see yourself as the same person you were before your child had ABI?
- Tell me about ways you view your child the same way you did before they had ABI?
- Do you/ other people in your family think anything about your child is different since the ABI? Expand.
- Tell me about ways you/ other people in your family treat your child differently since the ABI? what ways have you played a role in their identity adjustment?
- And your partner (where applicable)?
- What way has your relationship with your child stayed the same since ABI?
- How would you describe your parenting style before the ABI?
- How would you describe your parenting style now?
- What are the differences you have noticed in your relationship with your child?
- Is there anything you have done which has helped your child since the ABI?
- I wonder if there have been times you have tried things to help but it hasn't turned out so well, or maybe has backfired, or your child has said it was not helpful?

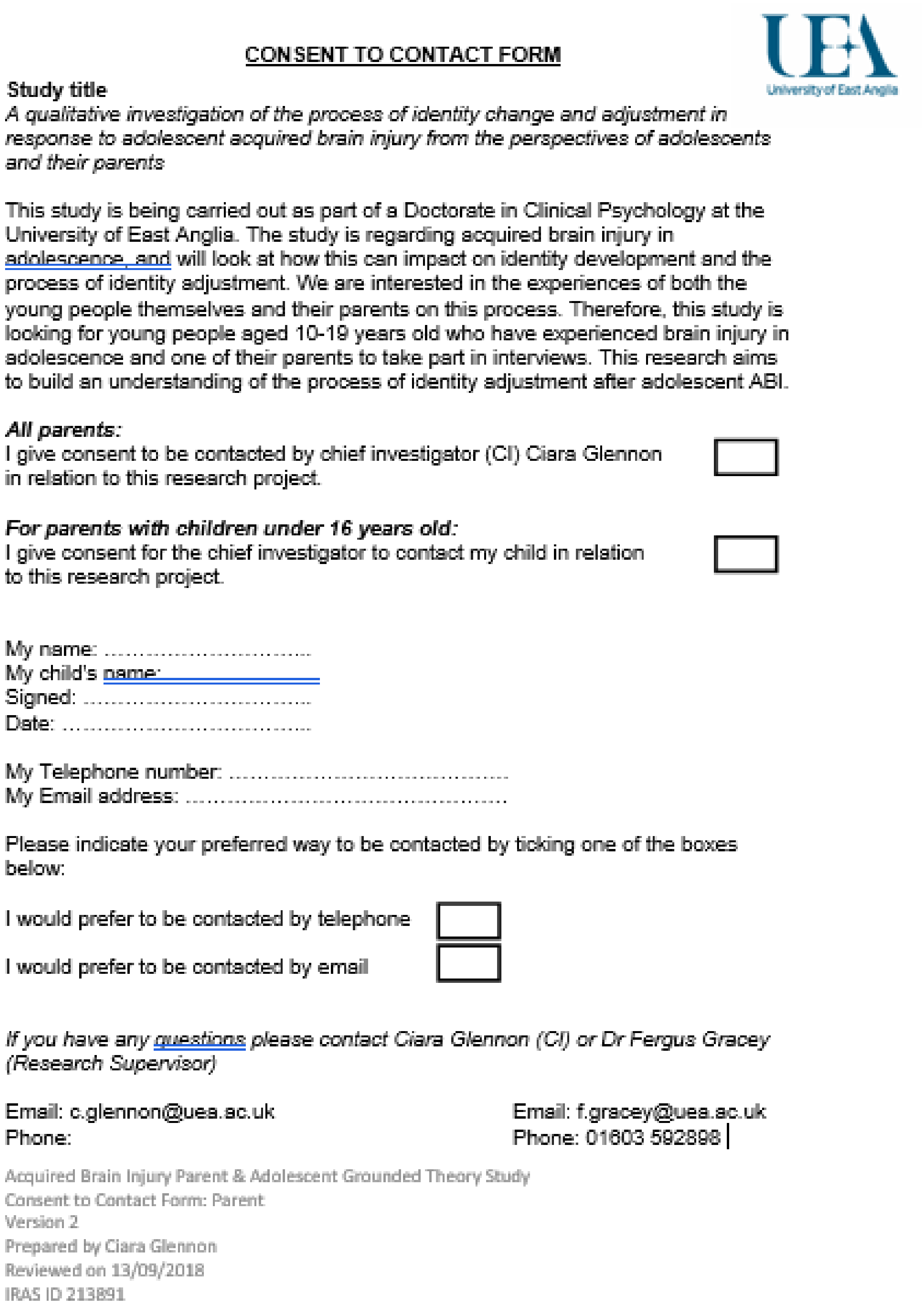
- Do people you know: family, friends - do they see your child as the same person he/she was before the ABI? Expand.
- Tell me about they ways your child views their peers the same way they did before the ABI?
- Tell me about ways that your child's peers treat him/her differently since the injury?
- Within their friend group, what things have changed for him/her?
- Since the injury, tell me about how their peers have played a role in their identity adjustment?
- What way has his/her relationship with his/her peers stayed the same?
- How would you describe his/her friendships before the ABI?
- How would you describe his/her friendships now?
- What are the differences you have noticed in their social relationships?
- What things have your child's peers done that have helped/not helped with your child's identity adjustment since the ABI?

- What were your child's plans for the future before his/her injury?

- What were your hopes for your child's future, before their injury?
- What are your child's plans for the future now?
- What are your hopes for their future now?
- What differences have you noticed in their plans for the future and the type of person he/she wants to be since the ABI?
- What differences have you noticed in their plans for the future and the type of person he/she wants to be since the ABI?

Acquired Brain Injury Parent & Adolescent Grounded Theory Study
Parent and Adolescent Topic Guides
Version 2
Prepared by Ciara Glennon
Reviewed on 13/09/2018
IRAS ID 213891

Appendix L - Consent to Contact Form- Parents- Empirical Paper



CONSENT TO CONTACT FORM

Study title
A qualitative investigation of the process of identity change and adjustment in response to adolescent acquired brain injury from the perspectives of adolescents and their parents

This study is being carried out as part of a Doctorate in Clinical Psychology at the University of East Anglia. The study is regarding acquired brain injury in adolescence, and will look at how this can impact on identity development and the process of identity adjustment. We are interested in the experiences of both the young people themselves and their parents on this process. Therefore, this study is looking for young people aged 10-19 years old who have experienced brain injury in adolescence and one of their parents to take part in interviews. This research aims to build an understanding of the process of identity adjustment after adolescent ABI.

All parents:
I give consent to be contacted by chief investigator (CI) Ciara Glennon in relation to this research project. ☐

For parents with children under 16 years old:
I give consent for the chief investigator to contact my child in relation to this research project. ☐

My name: ……………………………..
My child's name: __________________
Signed: ………………………………..
Date: …………………………………..

My Telephone number: ……………………………………….
My Email address: ……………………………………………..

Please indicate your preferred way to be contacted by ticking one of the boxes below:

I would prefer to be contacted by telephone ☐

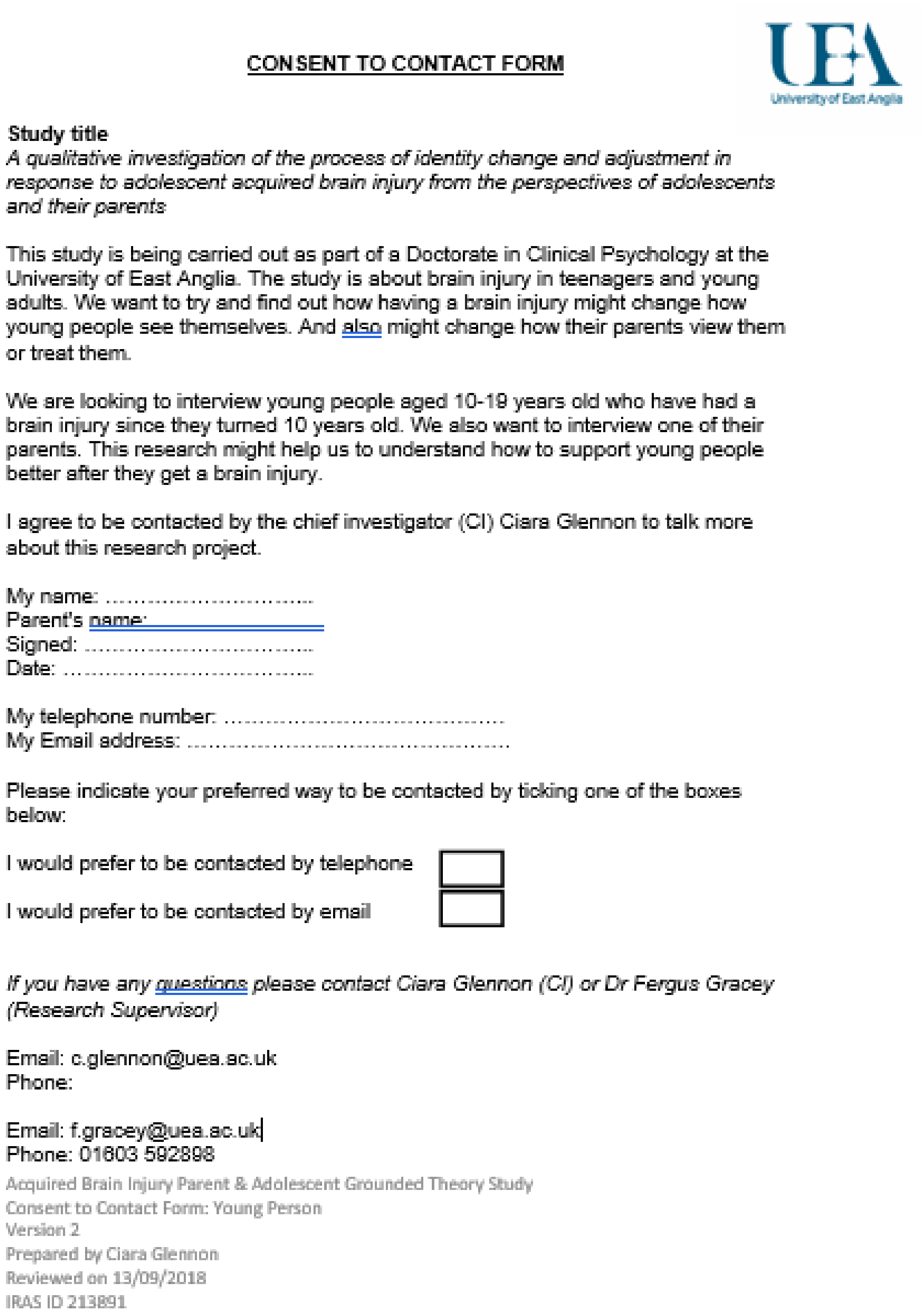
I would prefer to be contacted by email ☐

If you have any questions please contact Ciara Glennon (CI) or Dr Fergus Gracey (Research Supervisor)

Email: c.glennon@uea.ac.uk	Email: f.gracey@uea.ac.uk
Phone:	Phone: 01603 592898

Acquired Brain Injury Parent & Adolescent Grounded Theory Study
Consent to Contact Form: Parent
Version 2
Prepared by Ciara Glennon
Reviewed on 13/09/2018
IRAS ID 213891

Appendix M - Consent to Contact Form- Adolescent- Empirical Paper



CONSENT TO CONTACT FORM

Study title
A qualitative investigation of the process of identity change and adjustment in response to adolescent acquired brain injury from the perspectives of adolescents and their parents

This study is being carried out as part of a Doctorate in Clinical Psychology at the University of East Anglia. The study is about brain injury in teenagers and young adults. We want to try and find out how having a brain injury might change how young people see themselves. And also might change how their parents view them or treat them.

We are looking to interview young people aged 10-19 years old who have had a brain injury since they turned 10 years old. We also want to interview one of their parents. This research might help us to understand how to support young people better after they get a brain injury.

I agree to be contacted by the chief investigator (CI) Ciara Glennon to talk more about this research project.

My name: …………………………..
Parent's name: ______________
Signed: ……………………………..
Date: ………………………………..

My telephone number: ……………………………………
My Email address: ……………………………………………

Please indicate your preferred way to be contacted by ticking one of the boxes below:

I would prefer to be contacted by telephone ☐

I would prefer to be contacted by email ☐

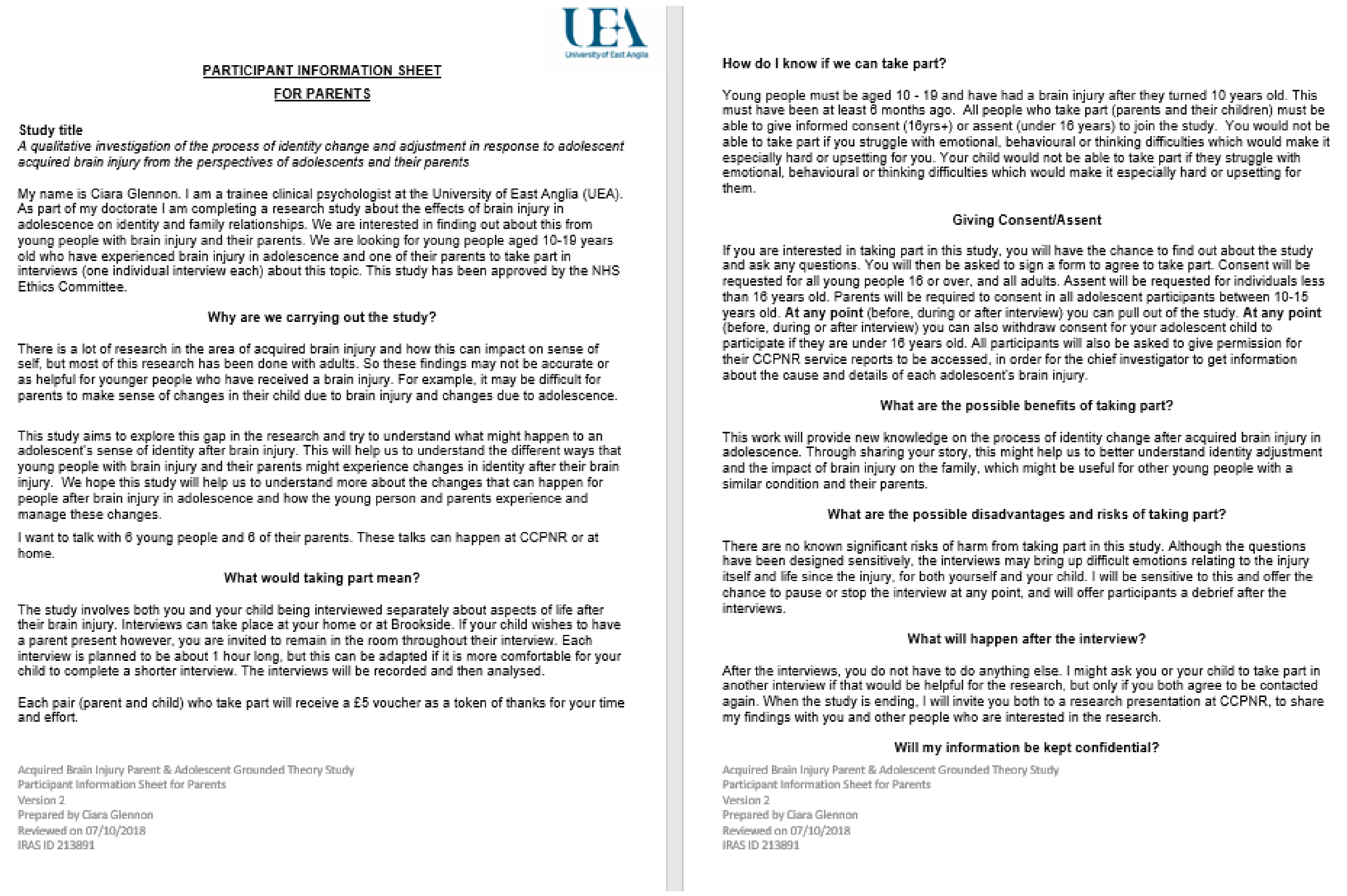
If you have any questions please contact Ciara Glennon (CI) or Dr Fergus Gracey (Research Supervisor)

Email: c.glennon@uea.ac.uk
Phone:

Email: f.gracey@uea.ac.uk
Phone: 01603 592898

Acquired Brain Injury Parent & Adolescent Grounded Theory Study
Consent to Contact Form: Young Person
Version 2
Prepared by Ciara Glennon
Reviewed on 13/09/2018
IRAS ID 213891

Appendix N - Participant information sheets- Parents- Empirical Paper



PARTICIPANT INFORMATION SHEET
FOR PARENTS

Study title
A qualitative investigation of the process of identity change and adjustment in response to adolescent acquired brain injury from the perspectives of adolescents and their parents

My name is Ciara Glennon. I am a trainee clinical psychologist at the University of East Anglia (UEA). As part of my doctorate I am completing a research study about the effects of brain injury in adolescence on identity and family relationships. We are interested in finding out about this from young people with brain injury and their parents. We are looking for young people aged 10-19 years old who have experienced brain injury in adolescence and one of their parents to take part in interviews (one individual interview each) about this topic. This study has been approved by the NHS Ethics Committee.

Why are we carrying out the study?

There is a lot of research in the area of acquired brain injury and how this can impact on sense of self, but most of this research has been done with adults. So these findings may not be accurate or as helpful for younger people who have received a brain injury. For example, it may be difficult for parents to make sense of changes in their child due to brain injury and changes due to adolescence.

This study aims to explore this gap in the research and try to understand what might happen to an adolescent's sense of identity after brain injury. This will help us to understand the different ways that young people with brain injury and their parents might experience changes in identity after their brain injury. We hope this study will help us to understand more about the changes that can happen for people after brain injury in adolescence and how the young person and parents experience and manage these changes.

I want to talk with 6 young people and 6 of their parents. These talks can happen at CCPNR or at home.

What would taking part mean?

The study involves both you and your child being interviewed separately about aspects of life after their brain injury. Interviews can take place at your home or at Brookside. If your child wishes to have a parent present however, you are invited to remain in the room throughout their interview. Each interview is planned to be about 1 hour long, but this can be adapted if it is more comfortable for your child to complete a shorter interview. The interviews will be recorded and then analysed.

Each pair (parent and child) who take part will receive a £5 voucher as a token of thanks for your time and effort.

How do I know if we can take part?

Young people must be aged 10 - 19 and have had a brain injury after they turned 10 years old. This must have been at least 6 months ago. All people who take part (parents and their children) must be able to give informed consent (16yrs+) or assent (under 16 years) to join the study. You would not be able to take part if you struggle with emotional, behavioural or thinking difficulties which would make it especially hard or upsetting for you. Your child would not be able to take part if they struggle with emotional, behavioural or thinking difficulties which would make it especially hard or upsetting for them.

Giving Consent/Assent

If you are interested in taking part in this study, you will have the chance to find out about the study and ask any questions. You will then be asked to sign a form to agree to take part. Consent will be requested for all young people 16 or over, and all adults. Assent will be requested for individuals less than 16 years old. Parents will be required to consent in all adolescent participants between 10-15 years old. **At any point** (before, during or after interview) you can pull out of the study. **At any point** (before, during or after interview) you can also withdraw consent for your adolescent child to participate if they are under 16 years old. All participants will also be asked to give permission for their CCPNR service reports to be accessed, in order for the chief investigator to get information about the cause and details of each adolescent's brain injury.

What are the possible benefits of taking part?

This work will provide new knowledge on the process of identity change after acquired brain injury in adolescence. Through sharing your story, this might help us to better understand identity adjustment and the impact of brain injury on the family, which might be useful for other young people with a similar condition and their parents.

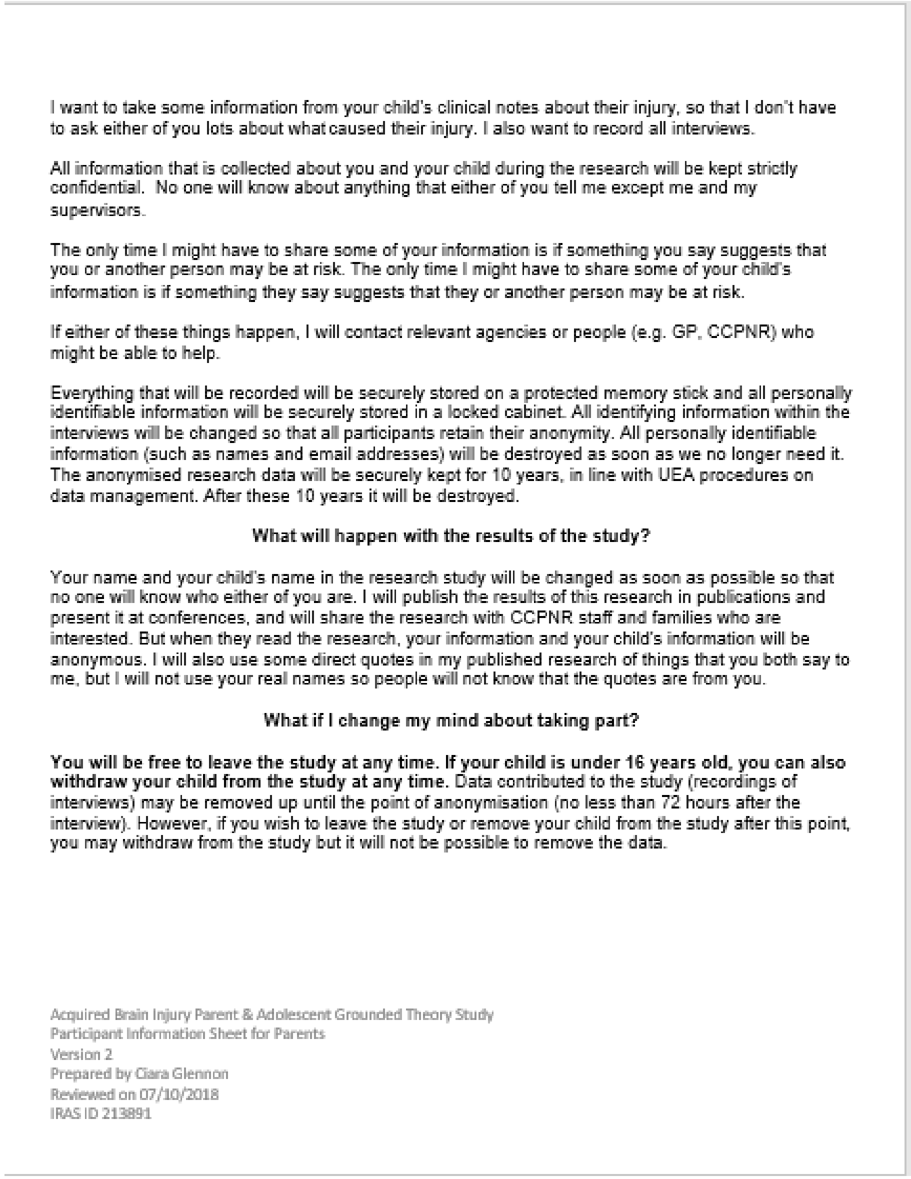
What are the possible disadvantages and risks of taking part?

There are no known significant risks of harm from taking part in this study. Although the questions have been designed sensitively, the interviews may bring up difficult emotions relating to the injury itself and life since the injury, for both yourself and your child. I will be sensitive to this and offer the chance to pause or stop the interview at any point, and will offer participants a debrief after the interviews.

What will happen after the interview?

After the interviews, you do not have to do anything else. I might ask you or your child to take part in another interview if that would be helpful for the research, but only if you both agree to be contacted again. When the study is ending, I will invite you both to a research presentation at CCPNR, to share my findings with you and other people who are interested in the research.

Will my information be kept confidential?



I want to take some information from your child's clinical notes about their injury, so that I don't have to ask either of you lots about what caused their injury. I also want to record all interviews.

All information that is collected about you and your child during the research will be kept strictly confidential. No one will know about anything that either of you tell me except me and my supervisors.

The only time I might have to share some of your information is if something you say suggests that you or another person may be at risk. The only time I might have to share some of your child's information is if something they say suggests that they or another person may be at risk.

If either of these things happen, I will contact relevant agencies or people (e.g. GP, CCPNR) who might be able to help.

Everything that will be recorded will be securely stored on a protected memory stick and all personally identifiable information will be securely stored in a locked cabinet. All identifying information within the interviews will be changed so that all participants retain their anonymity. All personally identifiable information (such as names and email addresses) will be destroyed as soon as we no longer need it. The anonymised research data will be securely kept for 10 years, in line with UEA procedures on data management. After these 10 years it will be destroyed.

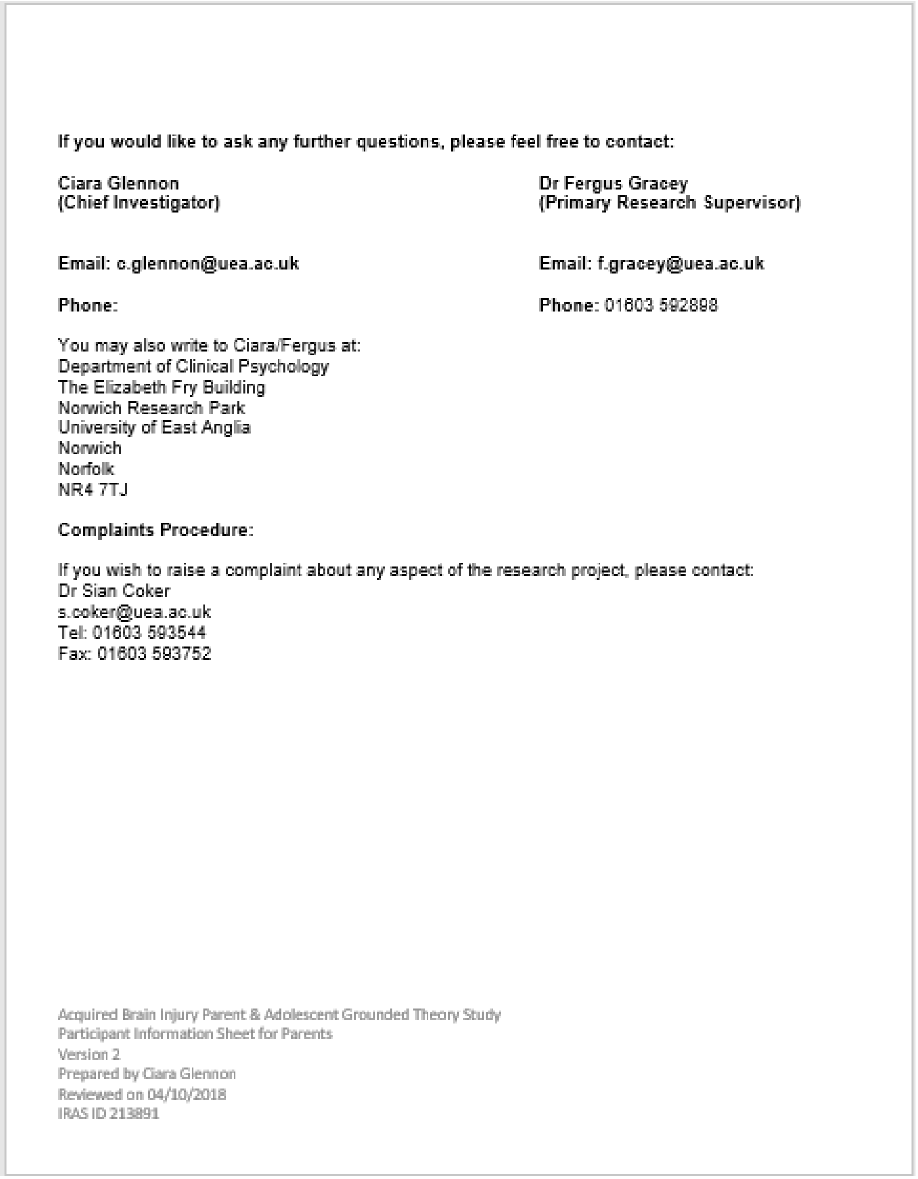
What will happen with the results of the study?

Your name and your child's name in the research study will be changed as soon as possible so that no one will know who either of you are. I will publish the results of this research in publications and present it at conferences, and will share the research with CCPNR staff and families who are interested. But when they read the research, your information and your child's information will be anonymous. I will also use some direct quotes in my published research of things that you both say to me, but I will not use your real names so people will not know that the quotes are from you.

What if I change my mind about taking part?

You will be free to leave the study at any time. If your child is under 16 years old, you can also withdraw your child from the study at any time. Data contributed to the study (recordings of interviews) may be removed up until the point of anonymisation (no less than 72 hours after the interview). However, if you wish to leave the study or remove your child from the study after this point, you may withdraw from the study but it will not be possible to remove the data.

Acquired Brain Injury Parent & Adolescent Grounded Theory Study
Participant Information Sheet for Parents
Version 2
Prepared by Ciara Glennon
Reviewed on 07/10/2018
IRAS ID 213891



If you would like to ask any further questions, please feel free to contact:

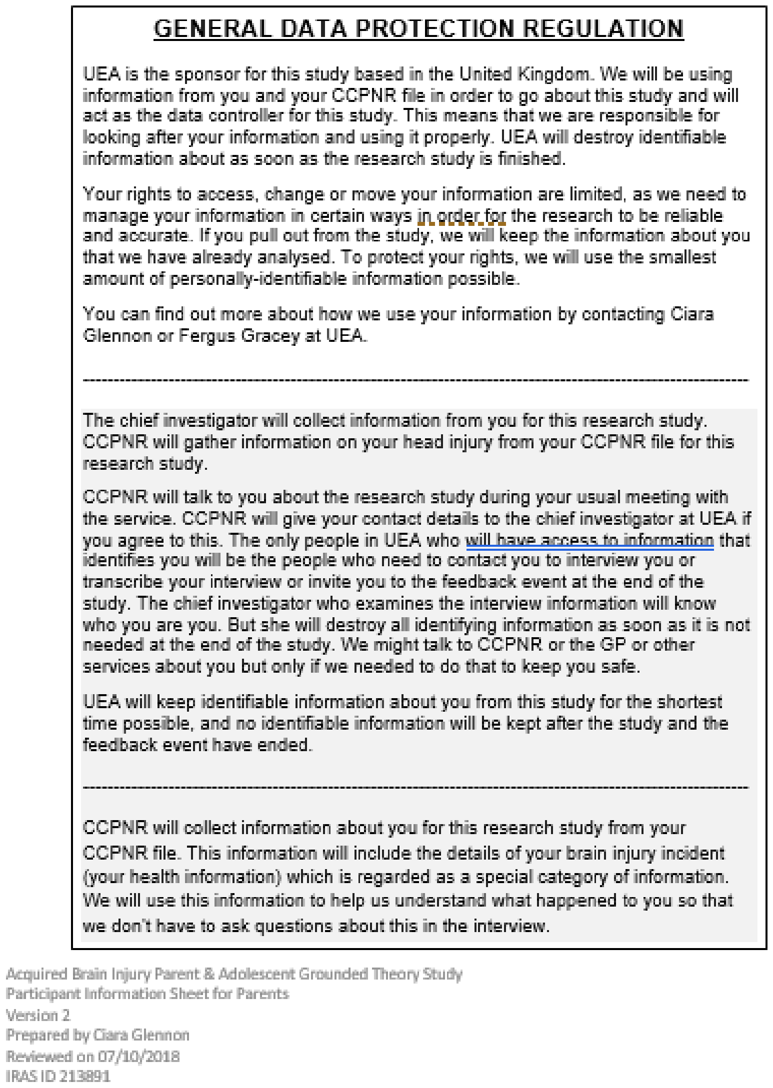
Ciara Glennon **(Chief Investigator)**	**Dr Fergus Gracey** **(Primary Research Supervisor)**
Email: c.glennon@uea.ac.uk	**Email:** f.gracey@uea.ac.uk
Phone:	**Phone:** 01603 592898

You may also write to Ciara/Fergus at:
Department of Clinical Psychology
The Elizabeth Fry Building
Norwich Research Park
University of East Anglia
Norwich
Norfolk
NR4 7TJ

Complaints Procedure:

If you wish to raise a complaint about any aspect of the research project, please contact:
Dr Sian Coker
s.coker@uea.ac.uk
Tel: 01603 593544
Fax: 01603 593752

Acquired Brain Injury Parent & Adolescent Grounded Theory Study
Participant Information Sheet for Parents
Version 2
Prepared by Ciara Glennon
Reviewed on 04/10/2018
IRAS ID 213891



GENERAL DATA PROTECTION REGULATION

UEA is the sponsor for this study based in the United Kingdom. We will be using information from you and your CCPNR file in order to go about this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. UEA will destroy identifiable information about as soon as the research study is finished.

Your rights to access, change or move your information are limited, as we need to manage your information in certain ways in order for the research to be reliable and accurate. If you pull out from the study, we will keep the information about you that we have already analysed. To protect your rights, we will use the smallest amount of personally-identifiable information possible.

You can find out more about how we use your information by contacting Ciara Glennon or Fergus Gracey at UEA.

The chief investigator will collect information from you for this research study. CCPNR will gather information on your head injury from your CCPNR file for this research study.

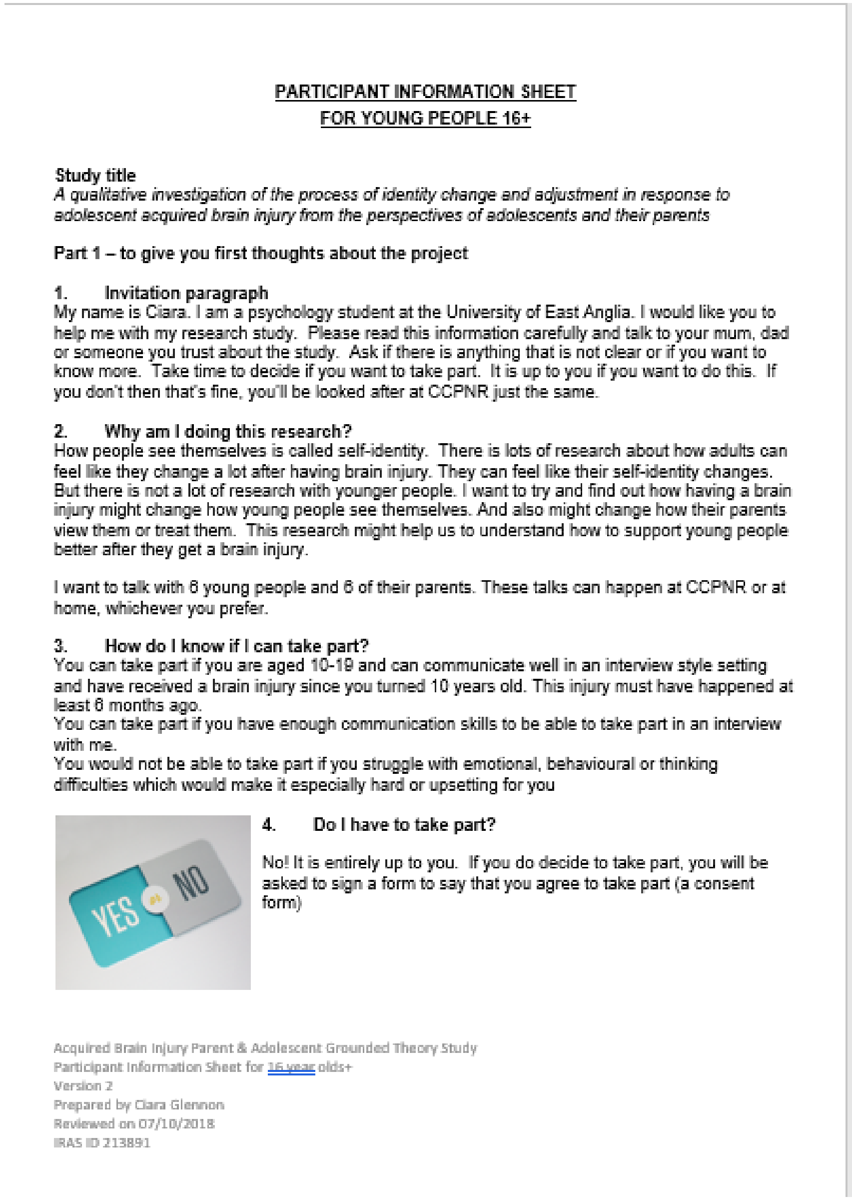
CCPNR will talk to you about the research study during your usual meeting with the service. CCPNR will give your contact details to the chief investigator at UEA if you agree to this. The only people in UEA who will have access to information that identifies you will be the people who need to contact you to interview you or transcribe your interview or invite you to the feedback event at the end of the study. The chief investigator who examines the interview information will know who you are you. But she will destroy all identifying information as soon as it is not needed at the end of the study. We might talk to CCPNR or the GP or other services about you but only if we needed to do that to keep you safe.

UEA will keep identifiable information about you from this study for the shortest time possible, and no identifiable information will be kept after the study and the feedback event have ended.

CCPNR will collect information about you for this research study from your CCPNR file. This information will include the details of your brain injury incident (your health information) which is regarded as a special category of information. We will use this information to help us understand what happened to you so that we don't have to ask questions about this in the interview.

Acquired Brain Injury Parent & Adolescent Grounded Theory Study
Participant Information Sheet for Parents
Version 2
Prepared by Ciara Glennon
Reviewed on 07/10/2018
IRAS ID 213891

Appendix O - Participant information sheets- Adolescents 16+ yrs. - Empirical Paper



PARTICIPANT INFORMATION SHEET
FOR YOUNG PEOPLE 16+

Study title
A qualitative investigation of the process of identity change and adjustment in response to adolescent acquired brain injury from the perspectives of adolescents and their parents

Part 1 – to give you first thoughts about the project

1. Invitation paragraph
My name is Ciara. I am a psychology student at the University of East Anglia. I would like you to help me with my research study. Please read this information carefully and talk to your mum, dad or someone you trust about the study. Ask if there is anything that is not clear or if you want to know more. Take time to decide if you want to take part. It is up to you if you want to do this. If you don't then that's fine, you'll be looked after at CCPNR just the same.

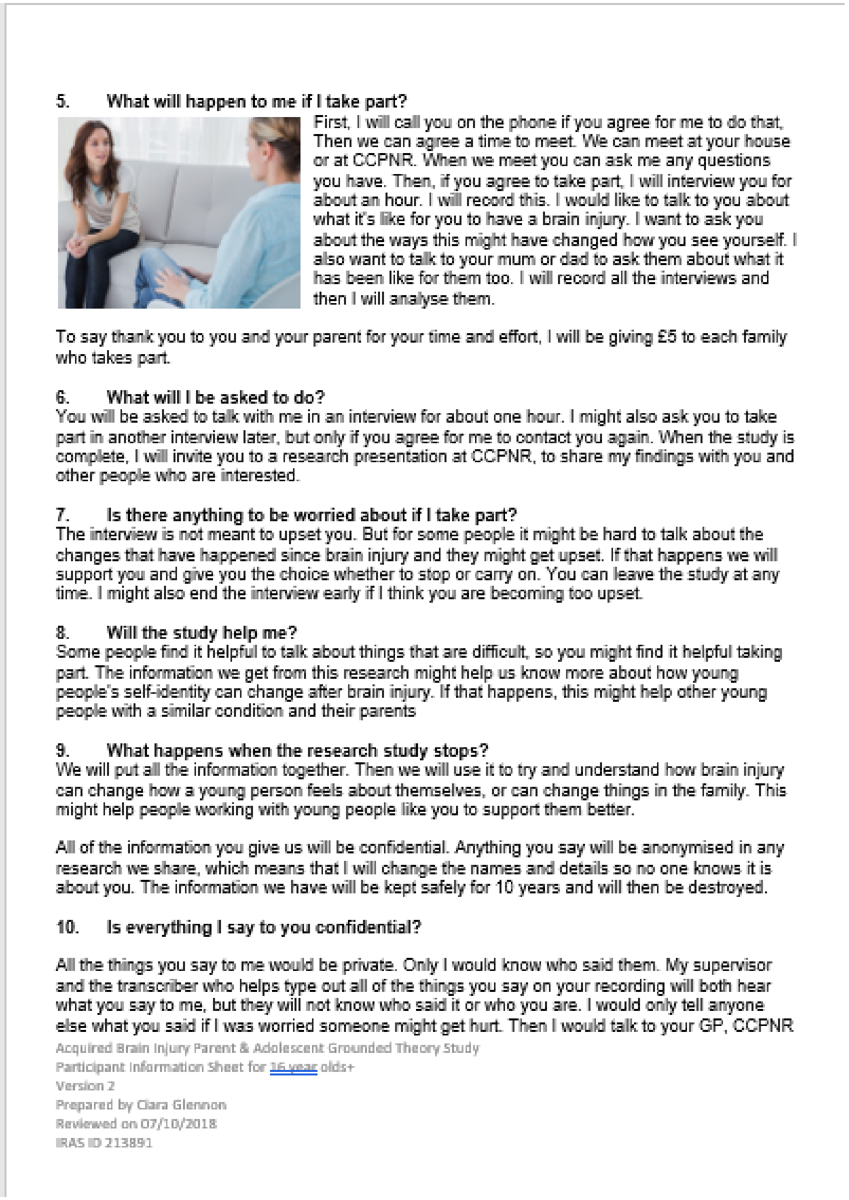
2. Why am I doing this research?
How people see themselves is called self-identity. There is lots of research about how adults can feel like they change a lot after having brain injury. They can feel like their self-identity changes. But there is not a lot of research with younger people. I want to try and find out how having a brain injury might change how young people see themselves. And also might change how their parents view them or treat them. This research might help us to understand how to support young people better after they get a brain injury.

I want to talk with 6 young people and 6 of their parents. These talks can happen at CCPNR or at home, whichever you prefer.

3. How do I know if I can take part?
You can take part if you are aged 10-19 and can communicate well in an interview style setting and have received a brain injury since you turned 10 years old. This injury must have happened at least 6 months ago.
You can take part if you have enough communication skills to be able to take part in an interview with me.
You would not be able to take part if you struggle with emotional, behavioural or thinking difficulties which would make it especially hard or upsetting for you

4. Do I have to take part?

No! It is entirely up to you. If you do decide to take part, you will be asked to sign a form to say that you agree to take part (a consent form)



5. What will happen to me if I take part?
First, I will call you on the phone if you agree for me to do that. Then we can agree a time to meet. We can meet at your house or at CCPNR. When we meet you can ask me any questions you have. Then, if you agree to take part, I will interview you for about an hour. I will record this. I would like to talk to you about what it's like for you to have a brain injury. I want to ask you about the ways this might have changed how you see yourself. I also want to talk to your mum or dad to ask them about what it has been like for them too. I will record all the interviews and then I will analyse them.

To say thank you to you and your parent for your time and effort, I will be giving £5 to each family who takes part.

6. What will I be asked to do?
You will be asked to talk with me in an interview for about one hour. I might also ask you to take part in another interview later, but only if you agree for me to contact you again. When the study is complete, I will invite you to a research presentation at CCPNR, to share my findings with you and other people who are interested.

7. Is there anything to be worried about if I take part?
The interview is not meant to upset you. But for some people it might be hard to talk about the changes that have happened since brain injury and they might get upset. If that happens we will support you and give you the choice whether to stop or carry on. You can leave the study at any time. I might also end the interview early if I think you are becoming too upset.

8. Will the study help me?
Some people find it helpful to talk about things that are difficult, so you might find it helpful taking part. The information we get from this research might help us know more about how young people's self-identity can change after brain injury. If that happens, this might help other young people with a similar condition and their parents

9. What happens when the research study stops?
We will put all the information together. Then we will use it to try and understand how brain injury can change how a young person feels about themselves, or can change things in the family. This might help people working with young people like you to support them better.

All of the information you give us will be confidential. Anything you say will be anonymised in any research we share, which means that I will change the names and details so no one knows it is about you. The information we have will be kept safely for 10 years and will then be destroyed.

10. Is everything I say to you confidential?

All the things you say to me would be private. Only I would know who said them. My supervisor and the transcriber who helps type out all of the things you say on your recording will both hear what you say to me, but they will not know who said it or who you are. I would only tell anyone else what you said if I was worried someone might get hurt. Then I would talk to your GP, CCPNR or whichever agency could help you the best. I would always try talk to you if I was going to tell anyone else about things that you say.

11. What happens to my information?

I want to take some information from your clinical notes about your injury, so that I don't have to ask you lots about what caused your injury. I also want to record your interview. All information that is collected about you during the research will be kept strictly confidential. No one will know about anything you tell me except me and my supervisors. The only time I might have to share some of your information is if something you say suggests that you or another person are or may be at risk. If that happens I will need to contact your GP, CCPNR or other people who might be able to help. I will always try talk to you first if this is happening.

Your name in the research study will be changed as soon as possible so that no one will know who you are. I will publish the results of this research in publications and present it at conferences, and will share the research with CCPNR staff and families who are interested. But when they read the research, your information will be anonymous. I will also use some direct quotes in my published research of things that you say to me, but I will not use your real name so people will not know that the quotes are from you.

All your personal information will be kept strictly confidential and be securely stored, and only the CI and primary research supervisor will be able to access this. Any identifiable information (like your name and email address) will be destroyed as soon as we no longer need it. Your interview data will only be identifiable by your pseudonym. The anonymised research data will be securely kept for **10 years**, in line with UEA procedures on data management. After these 10 years it will be destroyed.

12. What if I change my mind about taking part?

At any point, you can change your mind and leave the study. If you leave the study, this will not affect the care you receive from CCPNR.

However, if it is more than 72 hours (3 days) after your interview and I have already analysed the things you have said to me, then it will be impossible to take your information back out of the study. If that happens, it will be kept in the study but it will be completely anonymous.

13. What if there is a problem or something goes wrong?

If you want to make a complaint or have any concerns about this study you can contact:
Dr Sian Coker, University of East Anglia
s.coker@uea.ac.uk
Tel: 01603 593544

14. What will happen to the results of the research study?

When the study has finished we will present our findings to you and your parents, CCPNR, and other people who are interested. We will not use your real name so no one will know what things you have said. We will put the results in presentations and a psychology journal so that other professionals who work with young people with ABI can learn from it.

15. Who is organising and funding the research?

I am doing this research as part of my studies at the University of East Anglia, where I am training to become a clinical psychologist. My supervisor, Fergus Gracey, will be overseeing all parts of this project. The research is being paid for by the University of East Anglia.

16. Who has checked the study?

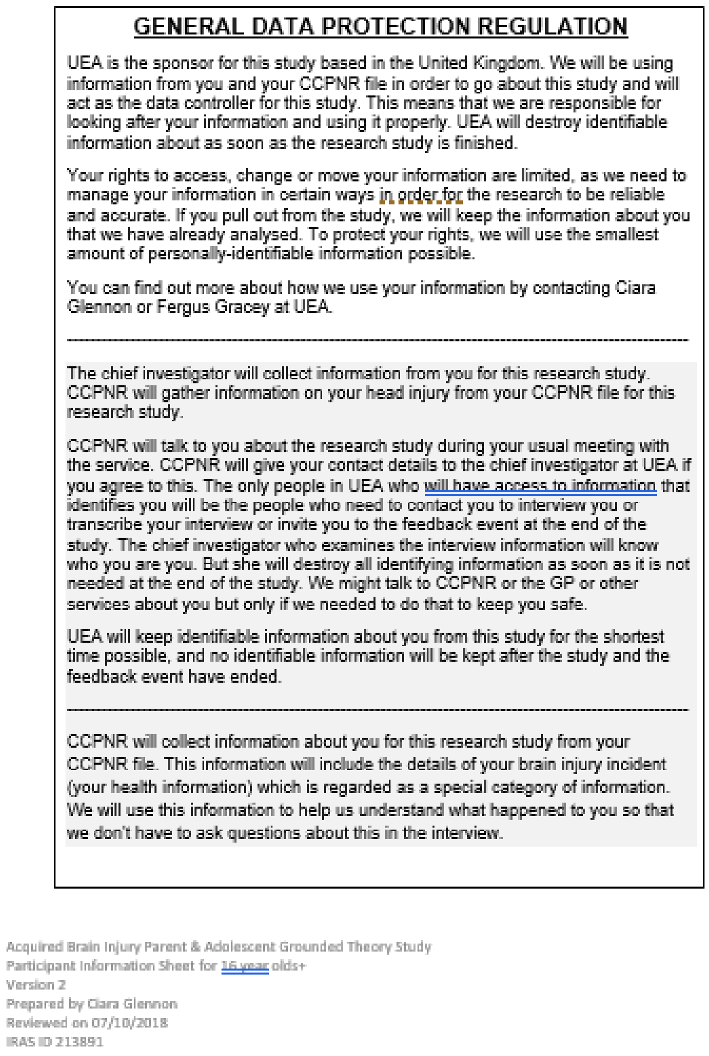
Before any research goes ahead it has to be checked by a Research Ethics Committee. This is a group of people who make sure that the research is OK to do. This study has been checked by lecturers at UEA, by my supervisors, and by the NHS Ethics Committee.

Thank you for taking the time to read this – please ask any questions if you need to.

Contact for further information

If you would like any further information about this study you could contact me or my supervisor:

Ciara Glennon (Chief Investigator)	Dr Fergus Gracey (Primary Research Supervisor)
Email: c.glennon@uea.ac.uk Tel:	Email: f.gracey@uea.ac.uk Tel: 01603 592896



GENERAL DATA PROTECTION REGULATION

UEA is the sponsor for this study based in the United Kingdom. We will be using information from you and your CCPNR file in order to go about this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. UEA will destroy identifiable information about as soon as the research study is finished.

Your rights to access, change or move your information are limited, as we need to manage your information in certain ways in order for the research to be reliable and accurate. If you pull out from the study, we will keep the information about you that we have already analysed. To protect your rights, we will use the smallest amount of personally-identifiable information possible.

You can find out more about how we use your information by contacting Ciara Glennon or Fergus Gracey at UEA.

The chief investigator will collect information from you for this research study. CCPNR will gather information on your head injury from your CCPNR file for this research study.

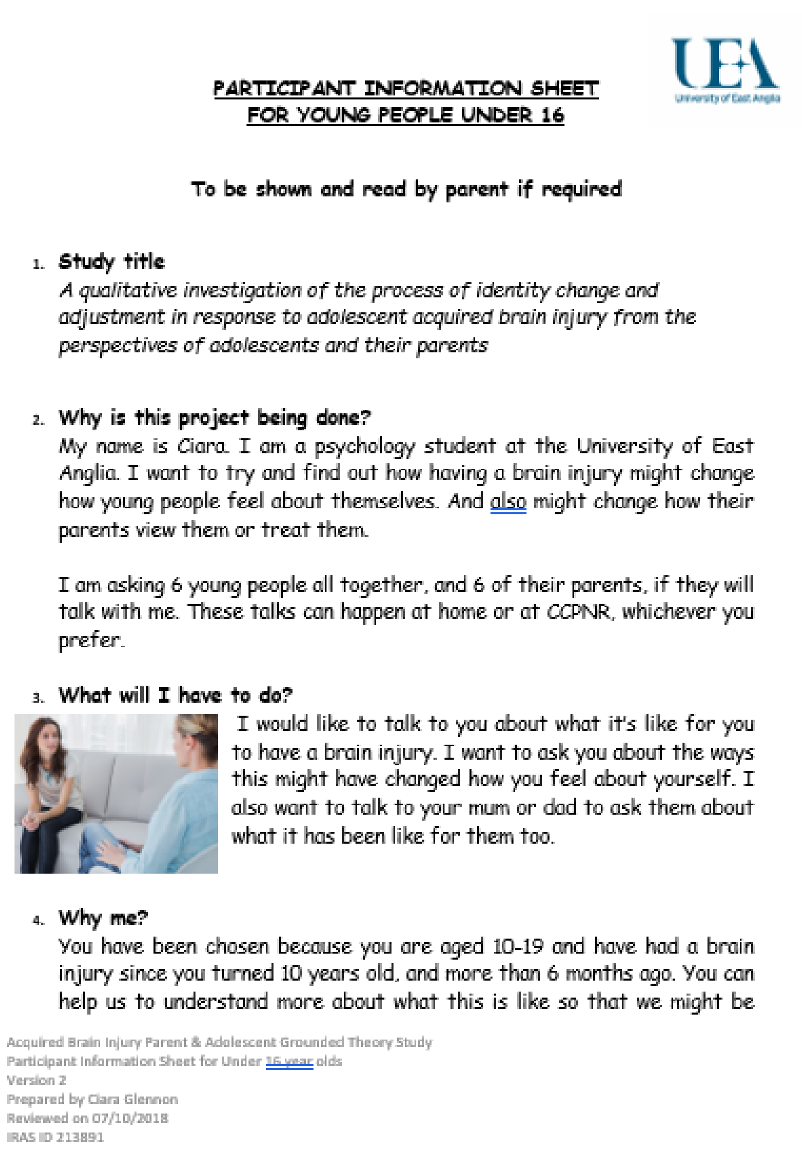
CCPNR will talk to you about the research study during your usual meeting with the service. CCPNR will give your contact details to the chief investigator at UEA if you agree to this. The only people in UEA who will have access to information that identifies you will be the people who need to contact you to interview you or transcribe your interview or invite you to the feedback event at the end of the study. The chief investigator who examines the interview information will know who you are you. But she will destroy all identifying information as soon as it is not needed at the end of the study. We might talk to CCPNR or the GP or other services about you but only if we needed to do that to keep you safe.

UEA will keep identifiable information about you from this study for the shortest time possible, and no identifiable information will be kept after the study and the feedback event have ended.

CCPNR will collect information about you for this research study from your CCPNR file. This information will include the details of your brain injury incident (your health information) which is regarded as a special category of information. We will use this information to help us understand what happened to you so that we don't have to ask questions about this in the interview.

Acquired Brain Injury Parent & Adolescent Grounded Theory Study
Participant Information Sheet for 16 year olds+
Version 2
Prepared by Ciara Glennon
Reviewed on 07/10/2018
IRAS ID 213891

Appendix P - Participant information sheets- Adolescents under 16 yrs. - EP



PARTICIPANT INFORMATION SHEET
FOR YOUNG PEOPLE UNDER 16

To be shown and read by parent if required

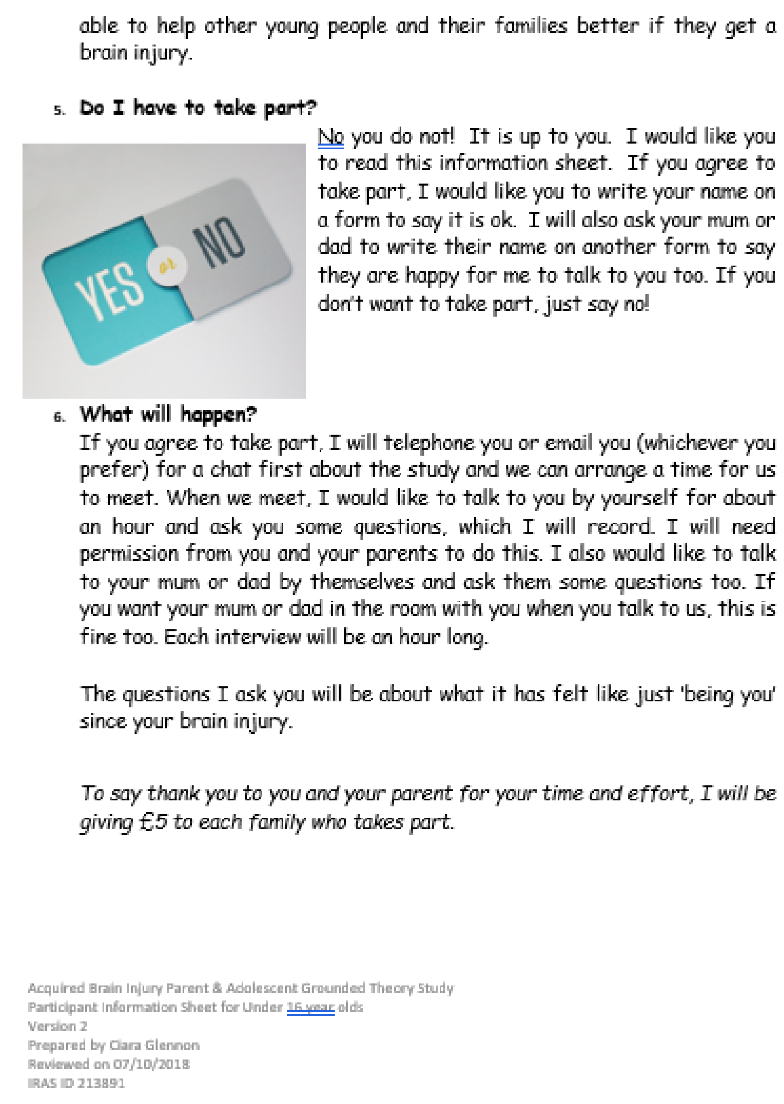
1. **Study title**
   A qualitative investigation of the process of identity change and adjustment in response to adolescent acquired brain injury from the perspectives of adolescents and their parents

2. **Why is this project being done?**
   My name is Ciara. I am a psychology student at the University of East Anglia. I want to try and find out how having a brain injury might change how young people feel about themselves. And also might change how their parents view them or treat them.

   I am asking 6 young people all together, and 6 of their parents, if they will talk with me. These talks can happen at home or at CCPNR, whichever you prefer.

3. **What will I have to do?**
   I would like to talk to you about what it's like for you to have a brain injury. I want to ask you about the ways this might have changed how you feel about yourself. I also want to talk to your mum or dad to ask them about what it has been like for them too.

4. **Why me?**
   You have been chosen because you are aged 10-19 and have had a brain injury since you turned 10 years old, and more than 6 months ago. You can help us to understand more about what this is like so that we might be able to help other young people and their families better if they get a brain injury.



5. **Do I have to take part?**
   No you do not! It is up to you. I would like you to read this information sheet. If you agree to take part, I would like you to write your name on a form to say it is ok. I will also ask your mum or dad to write their name on another form to say they are happy for me to talk to you too. If you don't want to take part, just say no!

6. **What will happen?**
   If you agree to take part, I will telephone you or email you (whichever you prefer) for a chat first about the study and we can arrange a time for us to meet. When we meet, I would like to talk to you by yourself for about an hour and ask you some questions, which I will record. I will need permission from you and your parents to do this. I also would like to talk to your mum or dad by themselves and ask them some questions too. If you want your mum or dad in the room with you when you talk to us, this is fine too. Each interview will be an hour long.

   The questions I ask you will be about what it has felt like just 'being you' since your brain injury.

   To say thank you to you and your parent for your time and effort, I will be giving £5 to each family who takes part.

7. **What else might happen?**

The questions I will ask are not meant to be upsetting. But some people might find it hard or might feel upset thinking about their life after brain injury.
If you become upset, you will be able to take a break or completely stop the interview. I will ask you if you want to continue or want to stop the interview. I might also decide to stop the interview myself if it looks like that might be the best way to help you.

8. **What happens when the research study stops?**

We will collect all the information together. Then we will use it to try and understand how brain injury can change how a young person feels about themselves or can change things in the family. We will put this research in presentations and a psychology journal. This might help people working with young people like you to support them better.

9. **What if I change my mind about taking part?**

You can change your mind and you can leave the study at any time! Just tell your mum or dad at any time, or you can contact us and tell us. Your parent can also still change their mind later and ask to take you out of the study. You will still have the same care from CCPNR.

If you leave the study more than 3 days after the interview, and I have started studying the interview information, you will not be able to remove this data. But it will be anonymous.

10. **What if I wish to complain about the study?**

If you want to complain you or your mum or dad can talk to
Sian Coker at the University of East Anglia.
s.coker@uea.ac.uk
Tel: 01603 593544

11. **Will anyone else know I'm doing this?**

The people in my research team and the staff at CCPNR will know you are taking part. And if you say it's OK, I will also tell your GP. No one else will know because we will not use your name or address. You will get a number which will be used instead.

12. **What happens to my information?**

All of the information you give us will be confidential. When I collect your information I will make sure it is stored in a safe place and only the people doing the research study can look at it. Your personal information like name and contact details will be kept securely and stored separately from the things that you say to me in the interview. After myself and a transcriber type up the things you say to me in the interview, I will change your name, so no one will know the things that you have said except us and my primary supervisor. They will be anonymous.

The only time I might have to share some of your information is if something you say suggests that you or another person are or may be at risk. If that happens I will talk about it with my supervisor and we might need to contact your GP, CCPNR or other people who might be able to help. I will always try talk to you first if this is happening.

13. **What will happen to the results of the research study?**

When the study has finished we will present the things we have found out to you and your parents, CCPNR, and other people who are interested. We will not use your real name so no one will know what things you have said. We will put the results in presentations and a psychology journal so that other professionals who work with young people with ABI can learn from it. I will use some direct quotes in my published research of things that you say to me, but I will not use your real name so people will not know that the quotes are from you.

14. **Did anyone else check the study is OK to do?**

This study has been checked by several people, to make sure it is alright.

15. **How can I find out more about this study?**
Your mum or dad may be able to answer your questions. You can also do this by asking me or my supervisor, Fergus Gracey, at the University of East Anglia. Or you can ask Suzanna at CCPNR.

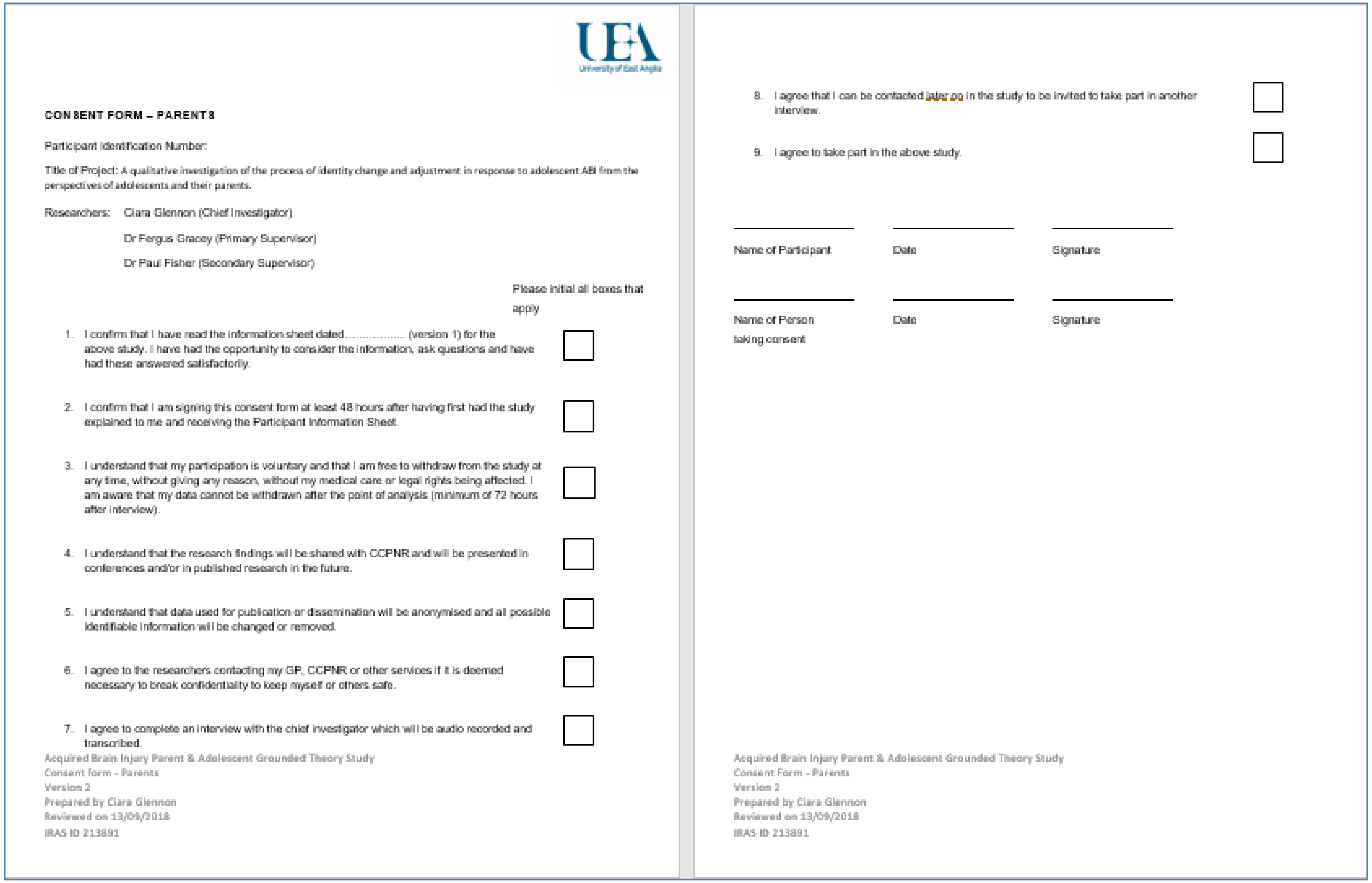
Thank you for taking the time to read this - please ask any questions if you need to

GENERAL DATA PROTECTION REGULATION (GDPR)

This study follows the GDPR rules about how to keep information safe and private. If you want to know more about this, you can ask me or my supervisor, Fergus Gracey, at the University of East Anglia.

Or you can ask Suzanna at CCPNR.

Appendix Q - Consent Forms- Parent sheets- for self - Empirical Paper



CONSENT FORM – PARENTS

Participant Identification Number:

Title of Project: A qualitative investigation of the process of identity change and adjustment in response to adolescent ABI from the perspectives of adolescents and their parents.

Researchers: Clara Glennon (Chief Investigator)
Dr Fergus Gracey (Primary Supervisor)
Dr Paul Fisher (Secondary Supervisor)

Please initial all boxes that apply

1. I confirm that I have read the information sheet dated……………… (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I confirm that I am signing this consent form at least 48 hours after having first had the study explained to me and receiving the Participant Information Sheet. ☐
3. I understand that my participation is voluntary and that I am free to withdraw from the study at any time, without giving any reason, without my medical care or legal rights being affected. I am aware that my data cannot be withdrawn after the point of analysis (minimum of 72 hours after interview). ☐
4. I understand that the research findings will be shared with CCPNR and will be presented in conferences and/or in published research in the future. ☐
5. I understand that data used for publication or dissemination will be anonymised and all possible identifiable information will be changed or removed. ☐
6. I agree to the researchers contacting my GP, CCPNR or other services if it is deemed necessary to break confidentiality to keep myself or others safe. ☐
7. I agree to complete an interview with the chief investigator which will be audio recorded and transcribed. ☐

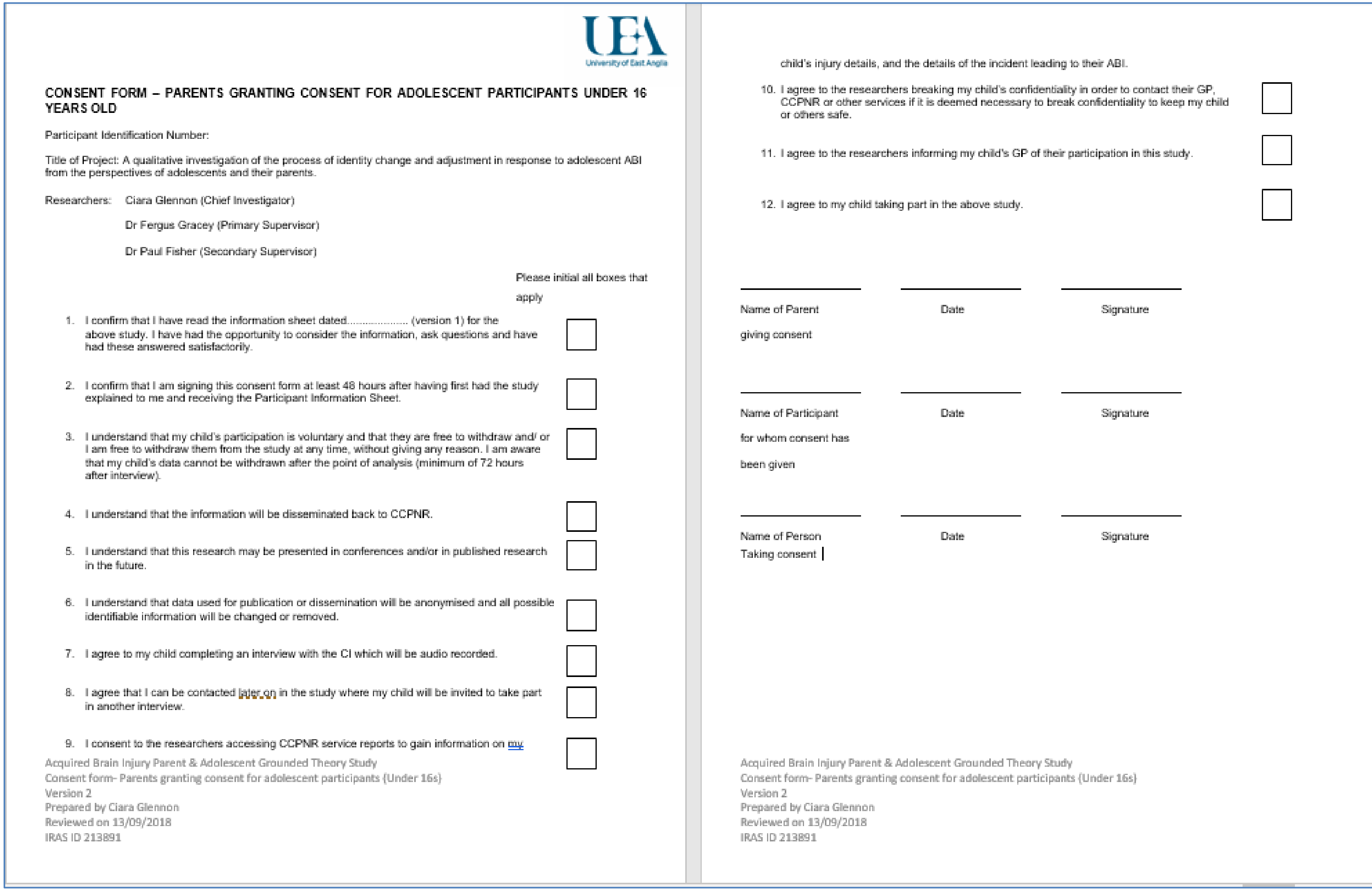
Acquired Brain Injury Parent & Adolescent Grounded Theory Study
Consent form – Parents
Version 2
Prepared by Clara Glennon
Reviewed on 13/09/2018
IRAS ID 213891

8. I agree that I can be contacted later on in the study to be invited to take part in another interview. ☐
9. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Acquired Brain Injury Parent & Adolescent Grounded Theory Study
Consent Form – Parents
Version 2
Prepared by Clara Glennon
Reviewed on 13/09/2018
IRAS ID 213891

Appendix R- Consent Forms- Parent sheets- for consenting in child- Empirical Paper



University of East Anglia

CONSENT FORM – PARENTS GRANTING CONSENT FOR ADOLESCENT PARTICIPANTS UNDER 16 YEARS OLD

Participant Identification Number:

Title of Project: A qualitative investigation of the process of identity change and adjustment in response to adolescent ABI from the perspectives of adolescents and their parents.

Researchers: Ciara Glennon (Chief Investigator)
Dr Fergus Gracey (Primary Supervisor)
Dr Paul Fisher (Secondary Supervisor)

Please initial all boxes that apply

1. I confirm that I have read the information sheet dated.................... (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I confirm that I am signing this consent form at least 48 hours after having first had the study explained to me and receiving the Participant Information Sheet. ☐
3. I understand that my child's participation is voluntary and that they are free to withdraw and/ or I am free to withdraw them from the study at any time, without giving any reason. I am aware that my child's data cannot be withdrawn after the point of analysis (minimum of 72 hours after interview). ☐
4. I understand that the information will be disseminated back to CCPNR. ☐
5. I understand that this research may be presented in conferences and/or in published research in the future. ☐
6. I understand that data used for publication or dissemination will be anonymised and all possible identifiable information will be changed or removed. ☐
7. I agree to my child completing an interview with the CI which will be audio recorded. ☐
8. I agree that I can be contacted later on in the study where my child will be invited to take part in another interview. ☐
9. I consent to the researchers accessing CCPNR service reports to gain information on my ☐

Acquired Brain Injury Parent & Adolescent Grounded Theory Study
Consent form- Parents granting consent for adolescent participants (Under 16s)
Version 2
Prepared by Ciara Glennon
Reviewed on 13/09/2018
IRAS ID 213891

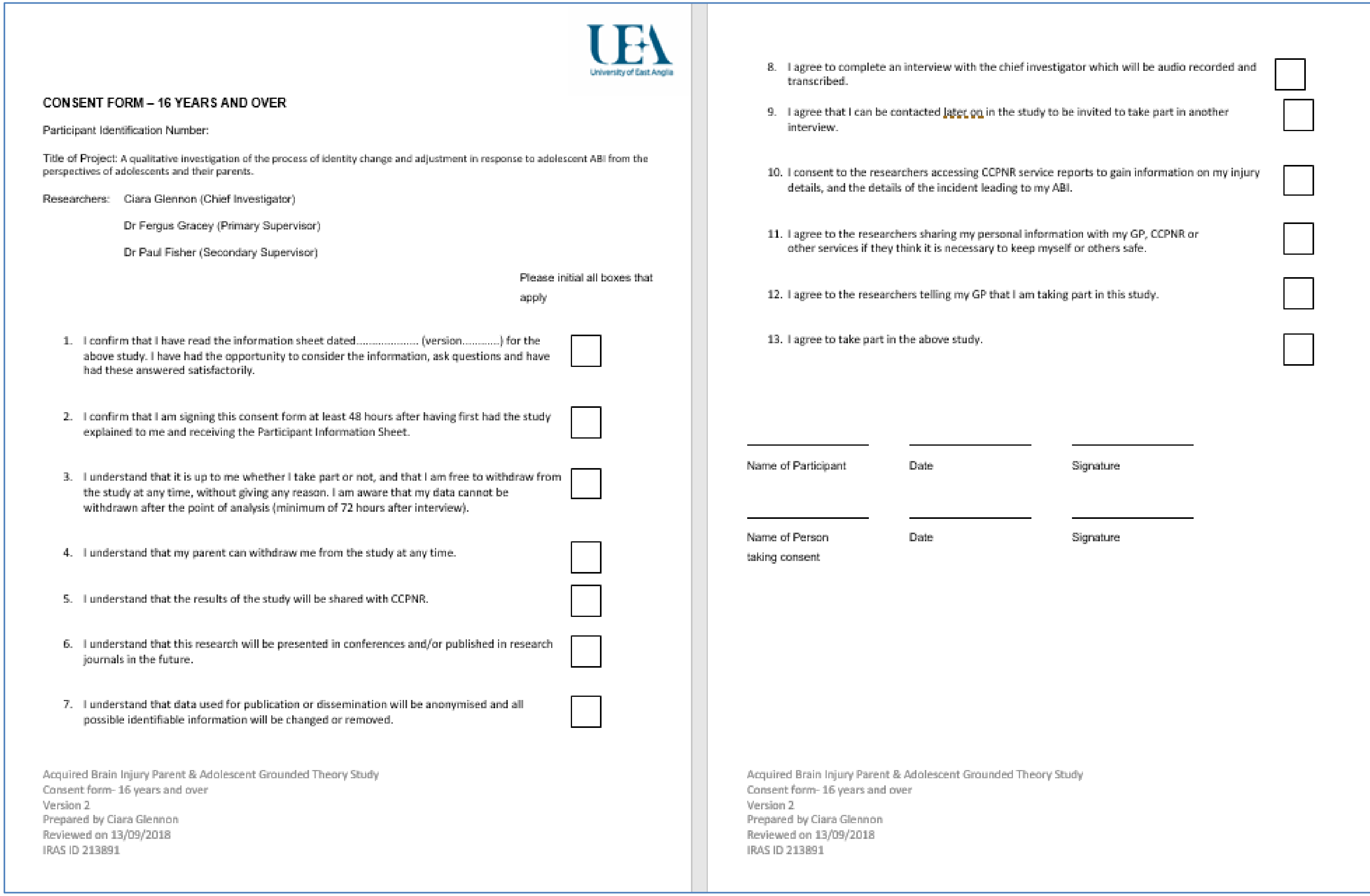
child's injury details, and the details of the incident leading to their ABI.

10. I agree to the researchers breaking my child's confidentiality in order to contact their GP, CCPNR or other services if it is deemed necessary to break confidentiality to keep my child or others safe. ☐
11. I agree to the researchers informing my child's GP of their participation in this study. ☐
12. I agree to my child taking part in the above study. ☐

Name of Parent giving consent	Date	Signature
Name of Participant for whom consent has been given	Date	Signature
Name of Person Taking consent	Date	Signature

Acquired Brain Injury Parent & Adolescent Grounded Theory Study
Consent form- Parents granting consent for adolescent participants (Under 16s)
Version 2
Prepared by Ciara Glennon
Reviewed on 13/09/2018
IRAS ID 213891

Appendix S - Consent Forms- YPs 16+ - Empirical Paper



CONSENT FORM – 16 YEARS AND OVER

Participant Identification Number:

Title of Project: A qualitative investigation of the process of identity change and adjustment in response to adolescent ABI from the perspectives of adolescents and their parents.

Researchers: Ciara Glennon (Chief Investigator)
Dr Fergus Gracey (Primary Supervisor)
Dr Paul Fisher (Secondary Supervisor)

Please initial all boxes that apply

1. I confirm that I have read the information sheet dated..................... (version............) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I confirm that I am signing this consent form at least 48 hours after having first had the study explained to me and receiving the Participant Information Sheet. ☐
3. I understand that it is up to me whether I take part or not, and that I am free to withdraw from the study at any time, without giving any reason. I am aware that my data cannot be withdrawn after the point of analysis (minimum of 72 hours after interview). ☐
4. I understand that my parent can withdraw me from the study at any time. ☐
5. I understand that the results of the study will be shared with CCPNR. ☐
6. I understand that this research will be presented in conferences and/or published in research journals in the future. ☐
7. I understand that data used for publication or dissemination will be anonymised and all possible identifiable information will be changed or removed. ☐

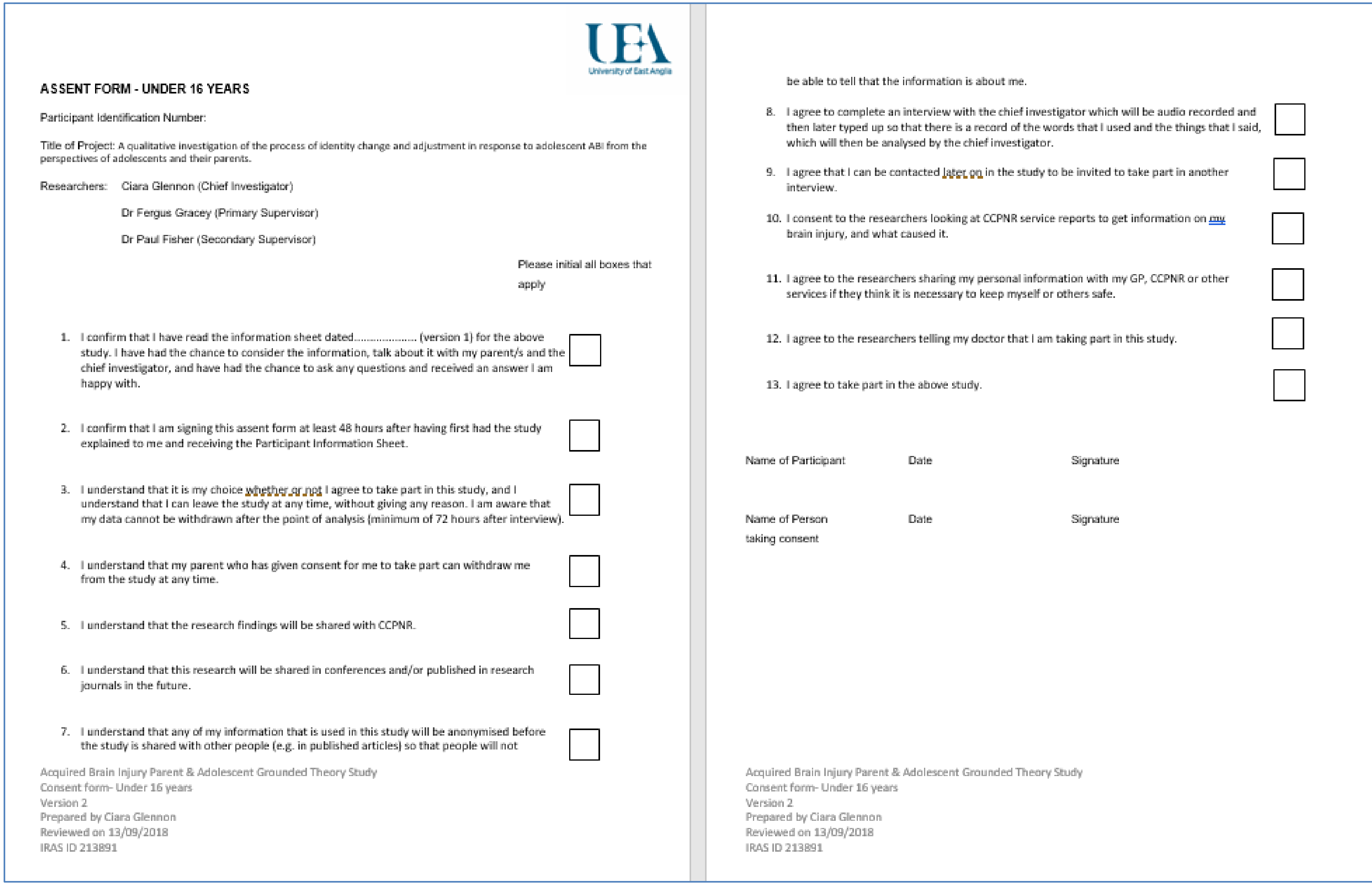
Acquired Brain Injury Parent & Adolescent Grounded Theory Study
Consent form- 16 years and over
Version 2
Prepared by Ciara Glennon
Reviewed on 13/09/2018
IRAS ID 213891

8. I agree to complete an interview with the chief investigator which will be audio recorded and transcribed. ☐
9. I agree that I can be contacted later on in the study to be invited to take part in another interview. ☐
10. I consent to the researchers accessing CCPNR service reports to gain information on my injury details, and the details of the incident leading to my ABI. ☐
11. I agree to the researchers sharing my personal information with my GP, CCPNR or other services if they think it is necessary to keep myself or others safe. ☐
12. I agree to the researchers telling my GP that I am taking part in this study. ☐
13. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Acquired Brain Injury Parent & Adolescent Grounded Theory Study
Consent form- 16 years and over
Version 2
Prepared by Ciara Glennon
Reviewed on 13/09/2018
IRAS ID 213891

Appendix T- Assent Forms- YPs under 16 - Empirical Paper



ASSENT FORM - UNDER 16 YEARS

Participant Identification Number:

Title of Project: A qualitative investigation of the process of identity change and adjustment in response to adolescent ABI from the perspectives of adolescents and their parents.

Researchers: Ciara Glennon (Chief Investigator)
Dr Fergus Gracey (Primary Supervisor)
Dr Paul Fisher (Secondary Supervisor)

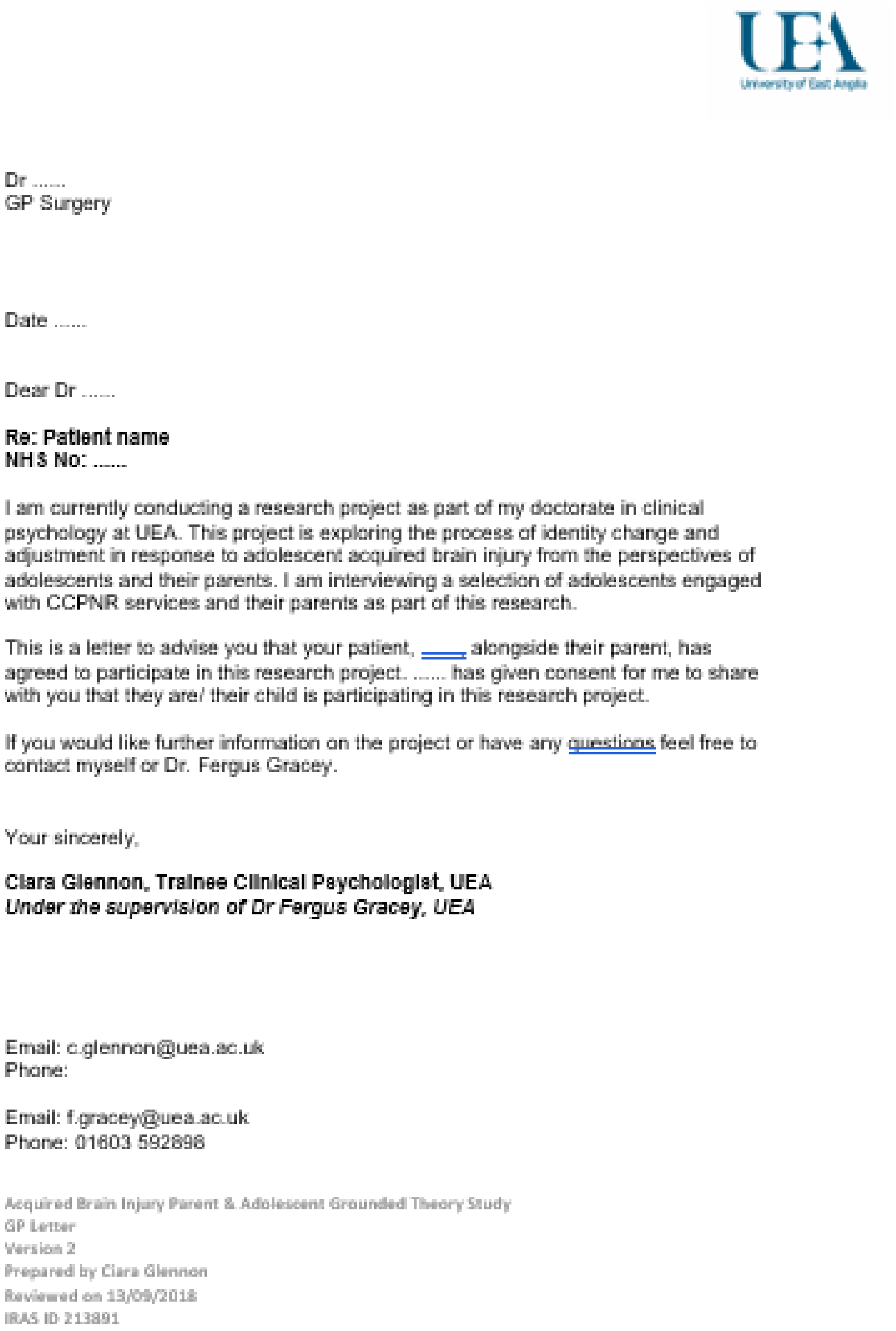
Please initial all boxes that apply

1. I confirm that I have read the information sheet dated.................... (version 1) for the above study. I have had the chance to consider the information, talk about it with my parent/s and the chief investigator, and have had the chance to ask any questions and received an answer I am happy with. ☐
2. I confirm that I am signing this assent form at least 48 hours after having first had the study explained to me and receiving the Participant Information Sheet. ☐
3. I understand that it is my choice whether or not I agree to take part in this study, and I understand that I can leave the study at any time, without giving any reason. I am aware that my data cannot be withdrawn after the point of analysis (minimum of 72 hours after interview). ☐
4. I understand that my parent who has given consent for me to take part can withdraw me from the study at any time. ☐
5. I understand that the research findings will be shared with CCPNR. ☐
6. I understand that this research will be shared in conferences and/or published in research journals in the future. ☐
7. I understand that any of my information that is used in this study will be anonymised before the study is shared with other people (e.g. in published articles) so that people will not be able to tell that the information is about me. ☐
8. I agree to complete an interview with the chief investigator which will be audio recorded and then later typed up so that there is a record of the words that I used and the things that I said, which will then be analysed by the chief investigator. ☐
9. I agree that I can be contacted later on in the study to be invited to take part in another interview. ☐
10. I consent to the researchers looking at CCPNR service reports to get information on my brain injury, and what caused it. ☐
11. I agree to the researchers sharing my personal information with my GP, CCPNR or other services if they think it is necessary to keep myself or others safe. ☐
12. I agree to the researchers telling my doctor that I am taking part in this study. ☐
13. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Acquired Brain Injury Parent & Adolescent Grounded Theory Study
Consent form- Under 16 years
Version 2
Prepared by Ciara Glennon
Reviewed on 13/09/2018
IRAS ID 213891

Appendix U - Health Professional Letter advising of participation in research - Empirical Paper



Dr ......
GP Surgery

Date ......

Dear Dr ......

Re: Patient name
NHS No: ......

I am currently conducting a research project as part of my doctorate in clinical psychology at UEA. This project is exploring the process of identity change and adjustment in response to adolescent acquired brain injury from the perspectives of adolescents and their parents. I am interviewing a selection of adolescents engaged with CCPNR services and their parents as part of this research.

This is a letter to advise you that your patient, _____ alongside their parent, has agreed to participate in this research project. ...... has given consent for me to share with you that they are/ their child is participating in this research project.

If you would like further information on the project or have any questions feel free to contact myself or Dr. Fergus Gracey.

Your sincerely,

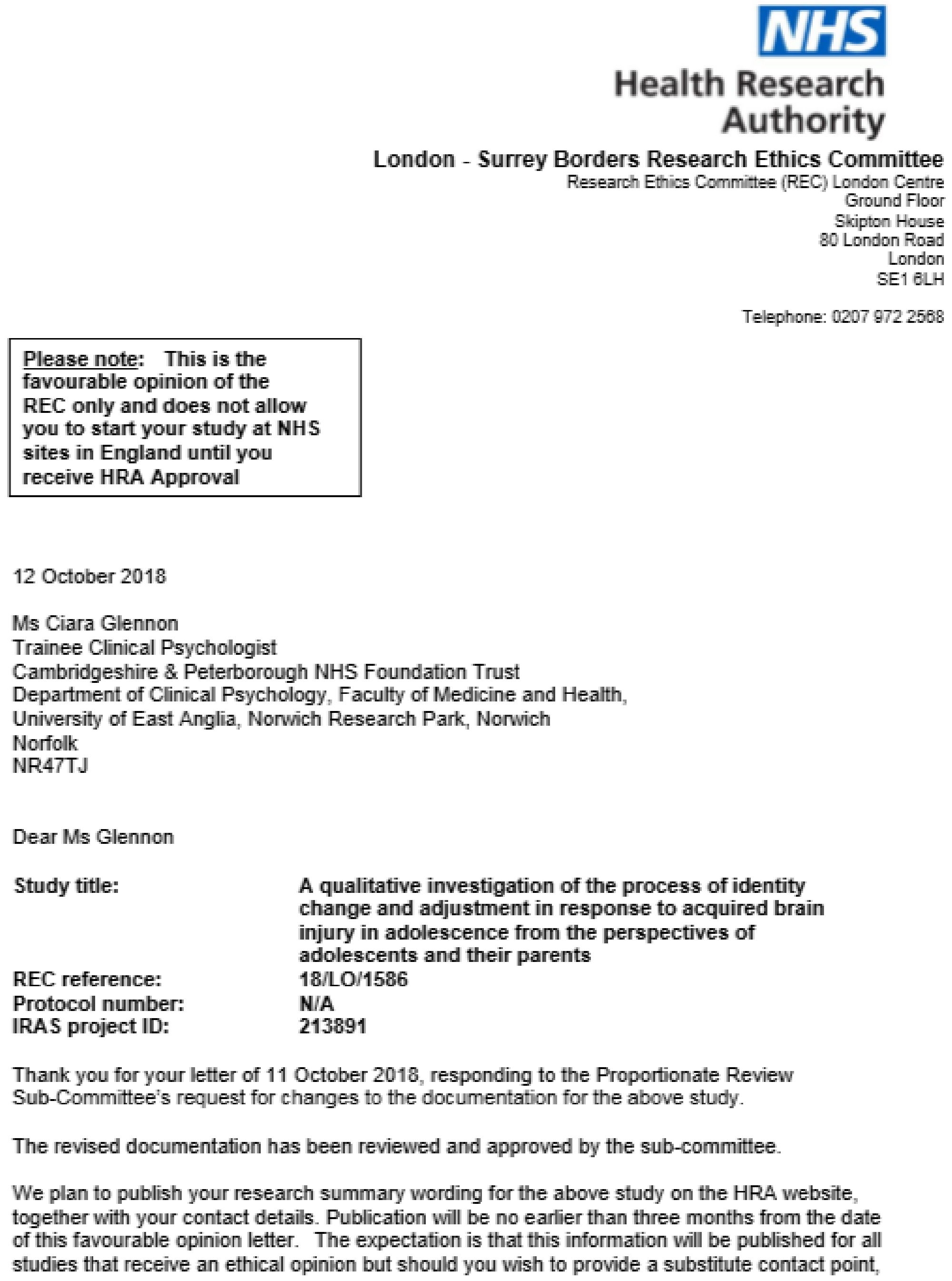
Clara Glennon, Trainee Clinical Psychologist, UEA
Under the supervision of Dr Fergus Gracey, UEA

Email: c.glennon@uea.ac.uk
Phone:

Email: f.gracey@uea.ac.uk
Phone: 01603 592898

Acquired Brain Injury Parent & Adolescent Grounded Theory Study
GP Letter
Version 2
Prepared by Clara Glennon
Reviewed on 13/09/2018
IRAS ID 213891

Appendix V - Ethical Approval - Empirical Paper



NHS
Health Research
Authority
London - Surrey Borders Research Ethics Committee
Research Ethics Committee (REC) London Centre
Ground Floor
Skipton House
80 London Road
London
SE1 6LH

Telephone: 0207 972 2568

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

12 October 2018

Ms Ciara Glennon
Trainee Clinical Psychologist
Cambridgeshire & Peterborough NHS Foundation Trust
Department of Clinical Psychology, Faculty of Medicine and Health,
University of East Anglia, Norwich Research Park, Norwich
Norfolk
NR47TJ

Dear Ms Glennon

Study title:	**A qualitative investigation of the process of identity change and adjustment in response to acquired brain injury in adolescence from the perspectives of adolescents and their parents**
REC reference:	**18/LO/1586**
Protocol number:	**N/A**
IRAS project ID:	**213891**

Thank you for your letter of 11 October 2018, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Covering letter on headed paper [REC Query- response letter]	1	08 October 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor Insurance]	1	18 July 2018
GP/consultant information sheets or letters [GP Letter]	2	13 September 2018
Interview schedules or topic guides for participants [Topic Guides]	1	01 April 2018
IRAS Application Form [IRAS_Form_22082018]		22 August 2018
Letter from sponsor [Letter from sponsor]	1	18 July 2018
Letters of invitation to participant [Participants not invited to interview]	2	13 September 2018
Other [Summary CV for Local Collaborator]	1	11 May 2018
Other [email about student as CI]		28 August 2018
Participant consent form [Consent Forms]	2	13 September 2018
Participant consent form [Consent to Contact Parent]	2	13 September 2018
Participant consent form [Consent to Contact Young Person]	2	13 September 2018
Participant information sheet (PIS) [Parent PIS]	2	07 October 2018
Participant information sheet (PIS) [16+ PIS]	2	07 October 2018
Participant information sheet (PIS) [Under 16s PIS]	2	07 October 2018
Research protocol or project proposal [Project Proposal]	1	13 August 2018
Summary CV for Chief Investigator (CI) [Summary CV for CI]	1	26 March 2018
Summary CV for supervisor (student research) [Summary CV for Primary Supervisor]	1	30 October 2017
Summary CV for supervisor (student research) [Summary CV for Secondary Supervisor]	1	07 March 2014
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Protocol Flowchart]	1	13 August 2018

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

Feedback

You are invited to give your view of the service that you have received from the Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance

We are pleased to welcome researchers and R & D staff at our RES Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

18/LO/1586 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

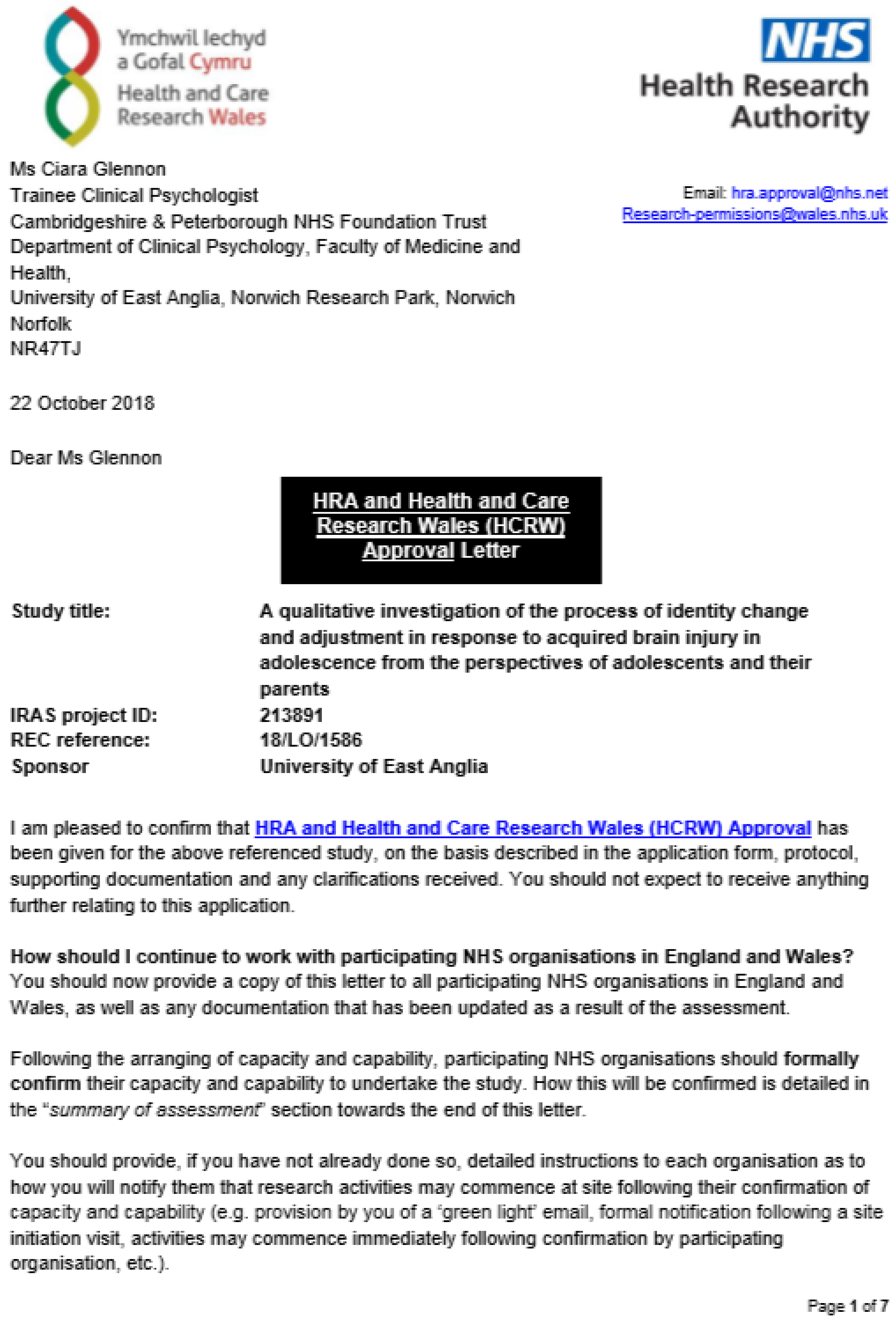
pp Barbara [illegible]

Sir Adrian Baillie
Chair

Email: nrescommittee.london-surreyborders@nhs.net

Enclosures: *"After ethical review – guidance for researchers"*

Appendix W- HRA Approval - Empirical Paper



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

Ms Ciara Glennon
Trainee Clinical Psychologist
Cambridgeshire & Peterborough NHS Foundation Trust
Department of Clinical Psychology, Faculty of Medicine and
Health,
University of East Anglia, Norwich Research Park, Norwich
Norfolk
NR47TJ

22 October 2018

Dear Ms Glennon

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

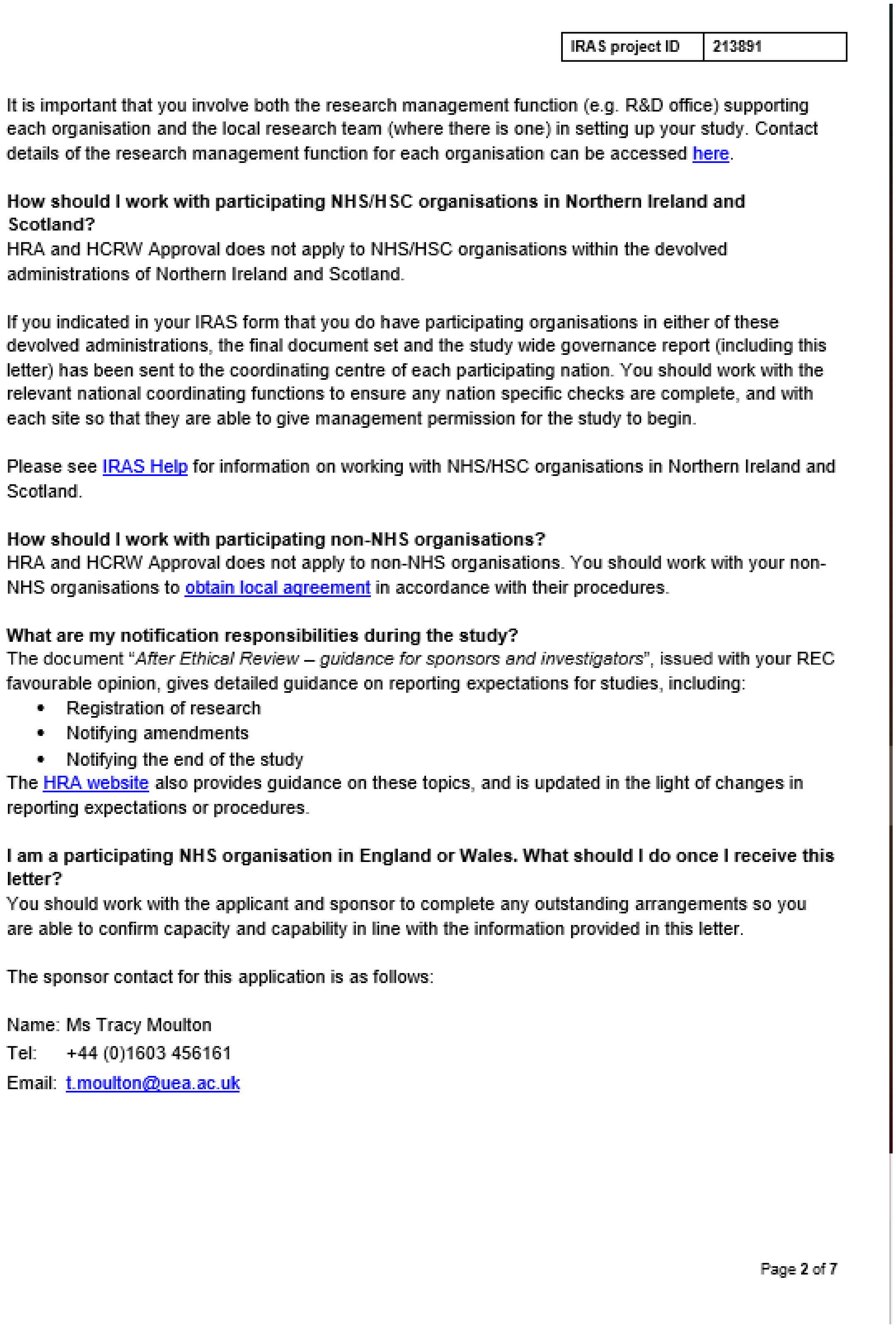
Study title:	**A qualitative investigation of the process of identity change and adjustment in response to acquired brain injury in adolescence from the perspectives of adolescents and their parents**
IRAS project ID:	**213891**
REC reference:	**18/LO/1586**
Sponsor	**University of East Anglia**

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.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).



It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

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 the devolved administrations of 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) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

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 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.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Ms Tracy Moulton
Tel: +44 (0)1603 456161
Email: t.moulton@uea.ac.uk

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

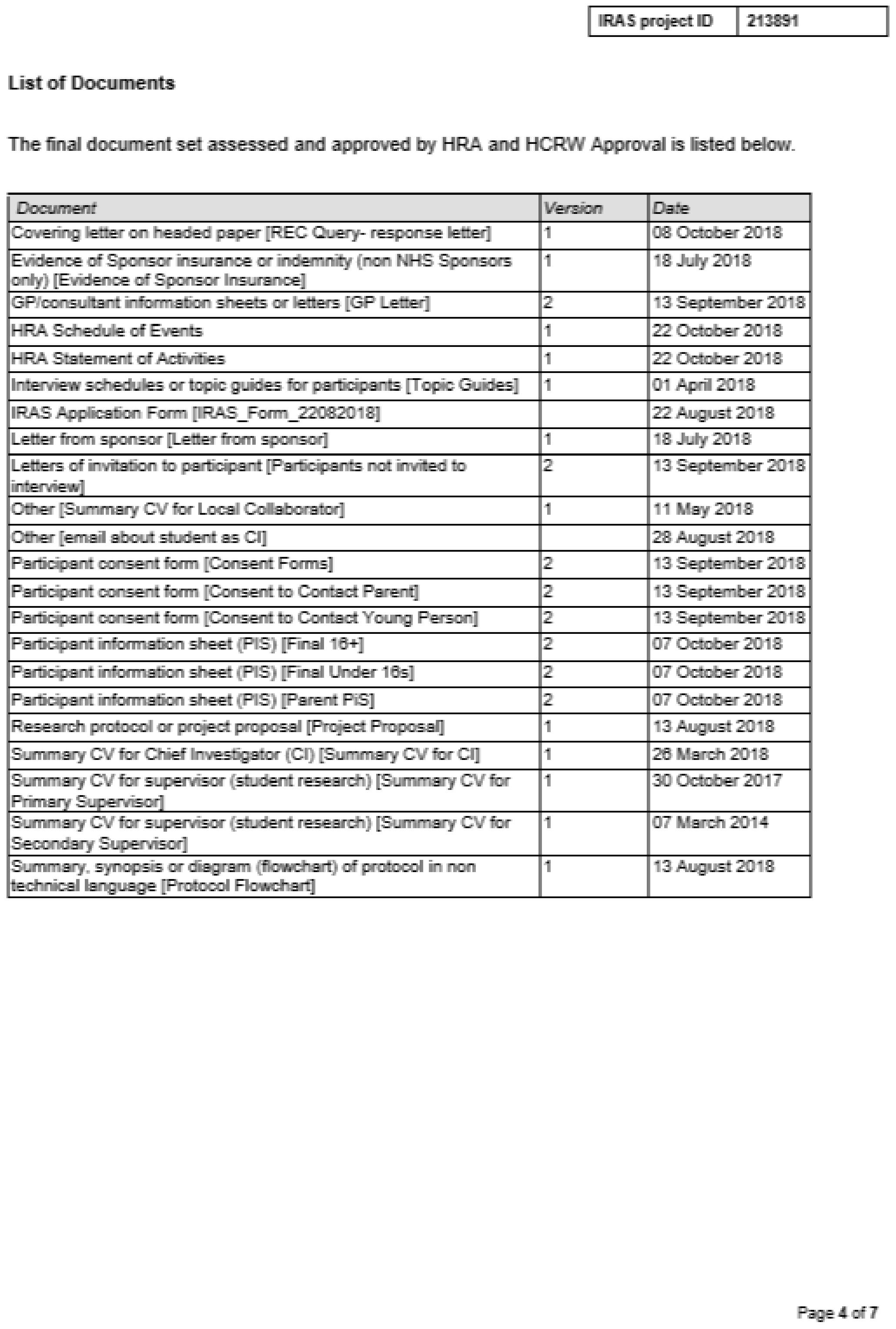
Your IRAS project ID is **213891**. Please quote this on all correspondence.

Yours sincerely

Kevin Ahmed
Assessor

Telephone: 0207 104 8171
Email: hra.approval@nhs.net

Copy to: *Ms Tracy Moulton, Sponsor Contact, University of East Anglia*
Mr Stephen Kelleher, R&D Contact, Cambridgeshire & Peterborough NHS Foundation Trust



IRAS project ID	213891

List of Documents

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

Document	*Version*	*Date*
Covering letter on headed paper [REC Query- response letter]	1	08 October 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor Insurance]	1	18 July 2018
GP/consultant information sheets or letters [GP Letter]	2	13 September 2018
HRA Schedule of Events	1	22 October 2018
HRA Statement of Activities	1	22 October 2018
Interview schedules or topic guides for participants [Topic Guides]	1	01 April 2018
IRAS Application Form [IRAS_Form_22082018]		22 August 2018
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Participant information sheet (PIS) [Final 16+]	2	07 October 2018
Participant information sheet (PIS) [Final Under 16s]	2	07 October 2018
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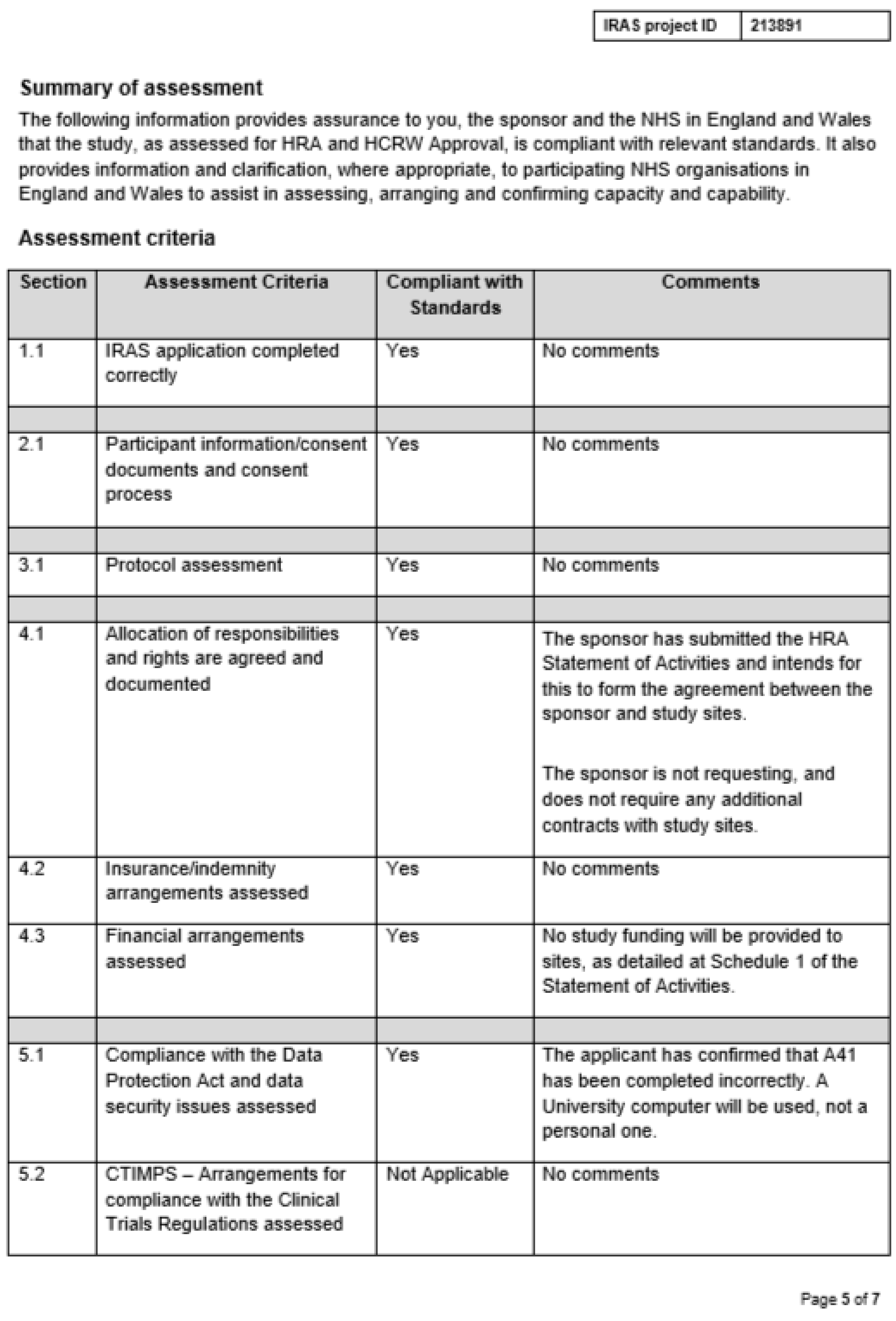


IRAS project ID	213891

Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England and Wales to assist in assessing, arranging and confirming capacity and capability.

Assessment criteria

Section	Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The sponsor has submitted the HRA Statement of Activities and intends for this to form the agreement between the sponsor and study sites. The sponsor is not requesting, and does not require any additional contracts with study sites.
4.2	Insurance/indemnity arrangements assessed	Yes	No comments
4.3	Financial arrangements assessed	Yes	No study funding will be provided to sites, as detailed at Schedule 1 of the Statement of Activities.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	The applicant has confirmed that A41 has been completed incorrectly. A University computer will be used, not a personal one.
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments

IRAS project ID	213891

Section	Assessment Criteria	Compliant with Standards	Comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

Only one NHS organisation is currently participating in the study. Therefore there is only one site type.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England and Wales in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation.

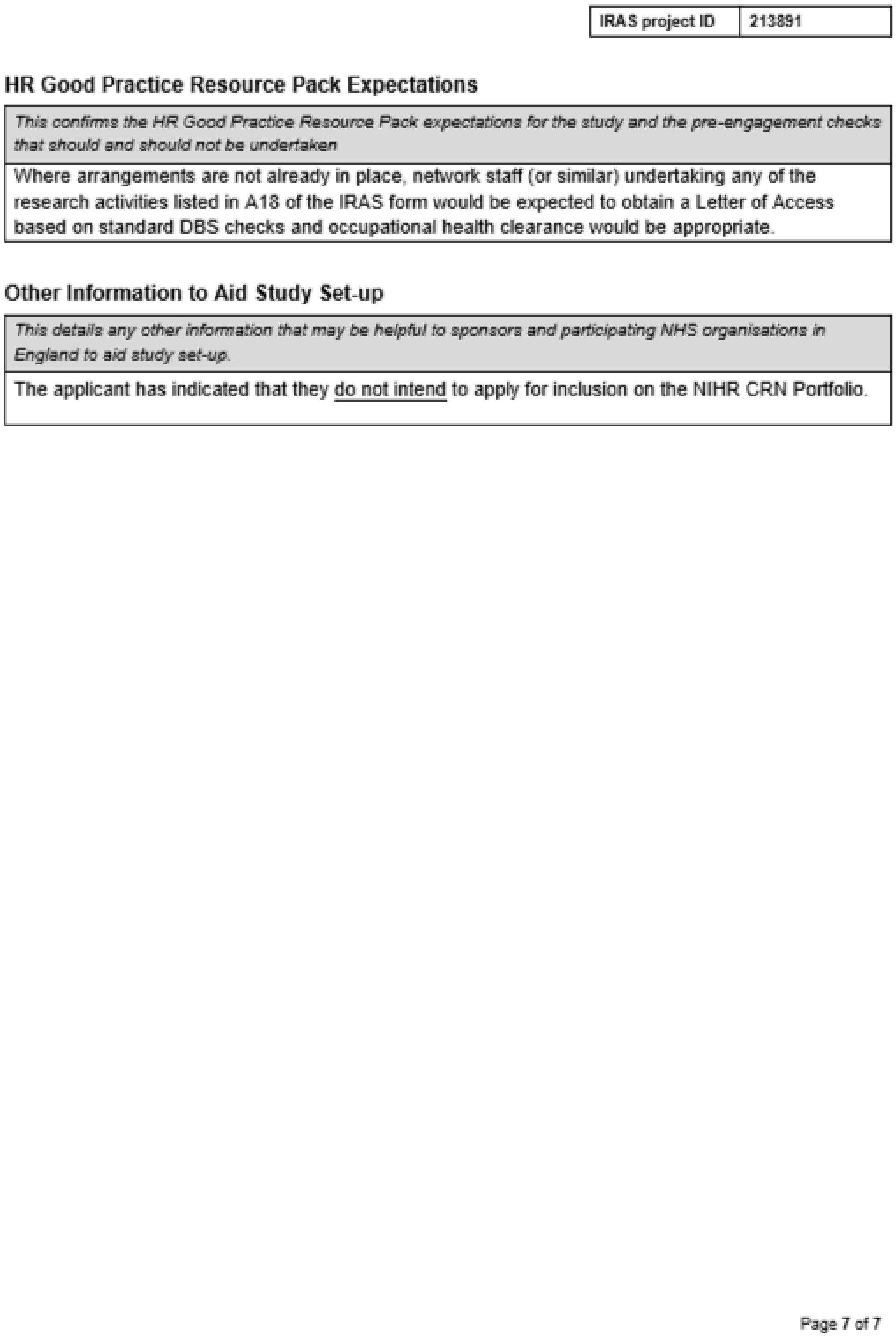
If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS, the HRA or HCRW websites, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net or HCRW at Research-permissions@wales.nhs.uk. We will work with these organisations to achieve a consistent approach to information provision.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A Local Collaborator should be appointed at study sites.

GCP training is not a generic training expectation, in line with the HRA statement on training expectations.



IRAS project ID	**213891**

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken
Where arrangements are not already in place, network staff (or similar) undertaking any of the research activities listed in A18 of the IRAS form would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance would be appropriate.

Other Information to Aid Study Set-up

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

Appendix X - Consolidating Criteria for Reporting Qualitative Studies (COREQ) - Empirical Paper

Developed from:

Tong A, Sainsbury P, Craig J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	**Guide questions/description**	**Reported on Page #**
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group? CG	83
2. Credentials	What were the researcher's credentials? *BA Hons, MSc*	83
3. Occupation	What was their occupation at the time of the study? *Trainee Clinical Psychologist*	Appendix N, O, P
4. Gender	Was the researcher male or female? *Female*	110
5. Experience and training	What experience or training did the researcher have? *This research was being conducted as part of a clinical psychology professional doctorate*	101, Appendix N, O, P
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement? *Yes, all participants had discussed the project by phone or in person prior to interviews*	118
7. Participant knowledge of the interviewer	What did the participants know about the researcher? *Participants knew that the interviewer was a trainee clinical psychologist conducting interviews as part of her research project*	Appendix N, O, P
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? *The interviewer discusses herself in PIS and in reflections on her position in the extended methodology, and final chapter*	110, 145, Appendix N, O, P
Domain 2: study design		
Theoretical framework		
9. Methodological	What methodological orientation was	81

orientation and Theory	stated to underpin the study? *Grounded theory*	
Participant selection		
10. Sampling	How were participants selected? *Purposively*	117
11. Method of approach	How were participants approached? *Approached by staff during routine appointment for consent to contact, and when given, contacted by the lead researcher (either phone or email, depending on preference stated)*	83
12. Sample size	How many participants were in the study? *Twelve*	81
13. Non-participation	How many people refused to participate or dropped out? Reasons? *Believed none. None that the lead researcher was made aware of*	81
Setting		
14. Setting of data collection	Where was the data collected? *In participants homes*	83
15. Presence of non-participants	Was anyone else present besides the participants and researchers? *All interviews were conducted with only interviewee present (x11), apart from one where a young person requested mother stayed in room to help with communication (speech difficulties sometimes made it difficult for him to be comprehended by interviewer)*	83
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date *Demographic data, injury type, and time since injury are presented in table as well as specific family contexts (number of parents in household, additional diagnoses) in EM*	82, 112
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested? *Yes*	Appendix J, K
18. Repeat interviews	Were repeat inter views carried out? If yes, how many? *Only on one occasion, where participants availability restricted completion of initial interview, leading to one participant being interviewed twice.*	83
19. Audio/visual recording	Did the research use audio or visual recording to collect the data? *Yes*	83

20. Field notes	Were field notes made during and/or after the interview or focus group? *Yes*	110
21. Duration	What was the duration of the inter views or focus group? *68-minute average for YPs, 75 minute average for parents*	83
22. Data saturation	Was data saturation discussed?	81
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction? *No, this was considered amongst research team but decided against*	N/A
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data? *One*	112
25. Description of the coding tree	Did authors provide a description of the coding tree? *GT map in Appendix*	Appendix Y
26. Derivation of themes	Were themes identified in advance or derived from the data? *Derived from the data*	119
27. Software	What software, if applicable, was used to manage the data? *Nvivo and Excel*	112
28. Participant checking	Did participants provide feedback on the findings? *This was planned for after study completion, not possible to complete within time frame of the project.*	To occur
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? *Yes*	84-96
30. Data and findings consistent	Was there consistency between the data presented and the findings? *Yes*	114
31. Clarity of major themes	Were major themes clearly presented in the findings? *Yes*	84-96
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes? *GT map in Appendix*	84-96, Appendix Y

Appendix Y – Process elements elicited in the GT

Experience of the now self and other selves- *tension between continuity and change*	Self in relation to self			
	Self in relation to others			
	Self in relation to the unlived life			
Response to experienced continuity/change	I am/am not normal (YP)			
	My child is here/gone (mum)			
Resolving discrepancies	Fitting in (YP)			
	My job is to fix everything (mum)	Preparing		• Instilling a resiliency outlook • Fighting and advocating • Supporting children towards independence and autonomy • Supporting adjustment towards personally meaningful goals
		Protecting	Padding	• Compensation • Mediating relationships
			Presence	
			Holding the psychological load	• Subjugating and Sacrificing • Being the emotional punchbag • Worrying over vulnerability
Adjustment towards a tentative equilibrium	Adjustment, integrating and living with the now self (YP)			
	Changed visions for parent (mum)			
