PAPER ONE: SYSTEMATIC REVIEW
The Efficacy of Interventions that Facilitate Social Participation on Outcomes of Social Participation and Quality of Life in Adults with Acquired Brain Injury

PAPER TWO: EMPIRICAL PAPER
Improving Peer Relationships for Adolescents with Acquired Brain Injury:
Using Intervention Mapping as a Framework to Identify Targets for Intervention

Submitted by Mr Scott Ankrett, to the University of Exeter as a thesis for the degree of Doctor of Clinical Psychology, May 2020

This thesis is available for Library use on the understanding that it is copyright material and that no quotation from the thesis may be published without proper acknowledgement.

I certify that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

Signature: [Signature]
Acknowledgements

Firstly, I would like to take the opportunity to thank my supervisors, A/Prof Anna Adlam and Dr Janet Smithson, for their valuable input and hard work supporting me to complete this thesis; particularly during the current COVID circumstances. Thank you.

I would also like to thank Louise Wilkinson and Penny Weekes for their support in the recruitment process. I have enjoyed my increasingly active role with Penny and meeting some amazing parents and adolescents. I also extend my greatest appreciation to all of those who participated in my empirical study.

Finally, I want to thank my partner, Kathryn, for all of her emotional support and humour throughout the Doctorate in Clinical Psychology. You help me when I doubt myself and remind me of my passion for the profession. Thank you.
## Table of Contents

PAPER ONE: SYSTEMATIC REVIEW ........................................................................ 9

Abstract ............................................................................................................. 10

Introduction ......................................................................................................... 12

Rationale and Aims for Review ........................................................................... 16

Methods ............................................................................................................... 18

- ELIGIBILITY CRITERIA .................................................................................. 18
- INFORMATION SOURCES .............................................................................. 21
- SEARCH STRATEGY ....................................................................................... 21
- STUDY SELECTION ......................................................................................... 22
- APPRAISING QUALITY AND RISK OF BIAS IN STUDIES ......................... 23
- DATA SYNTHESIS ......................................................................................... 24

Results ............................................................................................................... 25

- CHARACTERISTICS OF INCLUDED STUDIES ........................................ 40
- CRITICAL APPRAISAL: INTERVENTION METHOD AND EFFICACY ON TARGET OUTCOMES .......................................................................................... 41

Discussion .......................................................................................................... 45

- QUESTION ONE: EFFICACY OF INTERVENTIONS ON TARGET OUTCOMES .......... 45
- QUESTION TWO: DOES INCREASED SOCIAL PARTICIPATION RESULT IN IMPROVED QoL? .................................................................................................................. 46
- QUESTION THREE: PSYCHOLOGICAL PROCESSES THAT SUPPORT SOCIAL PARTICIPATION AND QoL .................................................................................. 47
- STRENGTHS AND LIMITATIONS OF CURRENT REVIEW .......................... 48
- CLINICAL AND THEORETICAL IMPLICATIONS ........................................... 49
1.5 RESTRICTED INDEPENDENCE AT A TIME FOR GROWTH .................................................. 98
1.6 LOSS OF PAST SELF ........................................................................................................ 100
1.7 CHALLENGES WITH ACQUIRED STATUS ..................................................................... 101
2.1 BUILDING UNDERSTANDING ......................................................................................... 102
2.2 MEANINGFUL SOCIAL CONNECTION ............................................................................. 102
2.3 SUPPORT FOR THE JOURNEY ......................................................................................... 103
2.4 EMPOWERMENT .............................................................................................................. 104
LOGIC MODEL OF PEER RELATIONSHIP DIFFICULTIES ..................................................... 105

Discussion .......................................................................................................................... 108
THEORETICAL IMPLICATIONS ............................................................................................... 110
CLINICAL IMPLICATIONS ...................................................................................................... 112
STRENGTHS AND LIMITATIONS ......................................................................................... 113

Conclusion .......................................................................................................................... 115
References ............................................................................................................................ 116
Appendices ............................................................................................................................ 126
List of Tables

Systematic Review

Table 1. PICOS Eligibility Criteria for the Inclusion and Exclusions of Studies in the Review ................................................................................................................. 19
Table 2. Key Search Terms used in Review ........................................................................ 22
Table 3. Summary of Studies Included for Analysis in Alphabetical Order. ...... 27
Table 4 Recommendations for Future Research ................................................................. 50

Empirical Paper

Table 1. Mediators and Cognitive Determinants Outlined by the SOCIAL Model .......................................................................................................................... 76
Table 2. Parent and Adolescent Stakeholders ........................................................................ 83
Table 3. Adults with ABI Stakeholders ................................................................................ 83
Table 4. Practitioner Stakeholders ....................................................................................... 84
Table 5. Steps for Thematic Analysis (Braun & Clarke, 2006) ......................................... 87
Table 6. Domains and Themes ............................................................................................ 92
List of Figures

**Systematic Review**

Figure 1. The formulas used for calculating ES (Hedges g) for included studies.
.................................................................................................................................................. 25

Figure 2. Results of search strategy and screening process for systematic review using PRISMA flow diagram......................................................................................................................... 26

**Empirical Paper**

Figure 1. A version of the SOCIAL model re-created with the original author’s permission (Beauchamp & Anderson, 2010).................................................................................. 75

Figure 2. Logic Model of Peer Relationship Difficulties for Adolescents with ABI (6th Revision). .................................................................................................................................................. 107
Tables of Appendices

Systematic Review
Appendix A: Quality Appraisal Scores for Included Studies......................... 66
Appendix B: Journal of the International Neuropsychological Society Publication Guidelines ................................................................. 68

Empirical Paper
Appendix A: Steps of Intervention Mapping ............................................ 126
Appendix B: Consent to Contact Forms .................................................. 127
Appendix C: Adult Stakeholder Participant Information Sheet (Focus Groups) ................................................................................................. 131
Appendix D: Young Person Participation Information Sheet (Focus Group) ... 135
Appendix E: Parent Participant Information Sheet (Focus Group).............. 139
Appendix F: Adult Stakeholder Participant Information Sheet (Interviews) .... 143
Appendix G: Young Person Participation Information Sheet (Interviews) ...... 147
Appendix H: Parent Participant Information Sheet ..................................... 152
Appendix I: Consent to Participate Sheets ................................................ 157
Appendix J: Ethical Approval Confirmation ............................................... 165
Appendix K: Planning Group Survey ....................................................... 166
Appendix L: Logic Model of the Problem (1st Draft) for Focus Groups and Interviews ......................................................................................... 170
Appendix M: Focus Group Schedule for Adolescents ............................... 171
Appendix N: Reflections Following Piloting of Schedule ............................ 178
Appendix O: Theme Summary for Stakeholder Feedback ......................... 180
Appendix P: Domain One Theme Building Tables ................................... 182
The Efficacy of Interventions that Facilitate Social Participation on Outcomes of Social Participation and Quality of Life in Adults with Acquired Brain Injury: A Systematic Review

Trainee Name: Scott Ankrett

Primary Research Supervisor: Professor Anna Adlam
Associate Professor/Clinical Psychologist
Co-Director for Postgraduate Research for Psychology
University of Exeter

Secondary Research Supervisor: Dr Janet Smithson
Senior Lecturer in Psychology
University of Exeter

Target Journal: Journal of the International Neuropsychological Society

Word Count: 6141 words (excluding abstract, tables, figures, and captions)

Submitted in partial fulfilment of requirements for the Doctorate Degree in Clinical Psychology, University of Exeter
Abstract

Background and aims. Social participation is a key determinant for health and wellbeing across the lifespan, and is a frequent goal for rehabilitation. Acquired brain injury (ABI) is a leading cause of death and disability worldwide that can result in persistent difficulties within cognitive, emotional, behavioural, physical, and social domains that contribute to chronic disability and restricted participation. Consequently, survivors are at higher risk of social isolation and reduced quality of life (QoL). The social participatory goals of rehabilitation are increasingly advocated for to support QoL and minimise disability post-ABI. The aim of this review was to explore the efficacy of interventions that facilitate social participation on outcomes of social participation and QoL in adult survivors of ABI. The synthesis of available evidence might support rehabilitation professionals to consider how to improve such outcomes in post-acute settings.

Methods. A systematic review was conducted to locate, appraise, and synthesise evidence relating to the review questions. Appropriate intervention studies were identified using a pre-determined search strategy. These were then assessed for inclusion against pre-defined eligibility criteria to investigate the efficacy of their interventions on the target outcomes for this review, social participation and QoL.

Results. Of the 1119 possible articles identified in the initial search, 12 studies met the inclusion criteria for this review. Data were then extracted and methodologies were critically appraised. Intervention programmes were grouped according to intervention methods, and included peer-mentoring, community integration, leisure activities, outpatient neuropsychological rehabilitation, intensive cognitive rehabilitation, and health-promotion. Seven of the 12 studies found statistically significant differences on at least one target outcome following intervention. Four of
these identified efficacy on both social participation and QoL, and varied in methodological design and quality.

**Conclusion.** Currently, there is limited evidence for the efficacy of interventions that facilitate social participation on outcomes of social participation and QoL for adults with ABI. The varying objectives, quality, and potential bias of the 12 included studies limits the conclusions that can be drawn. Social participatory interventions appear to have objective and subjective benefits for adults post-ABI. Appropriate intervention methods (i.e., delivery and focus) to support target outcomes is uncertain from the limited literature included in this review. However, interventions that showed efficacy on both target outcomes (four of the 12) were multifaceted and intensive. Rehabilitation of social participation to support social participation and QoL post-ABI may benefit from supporting participants to develop the skills and self-belief needed to actively participate in social activities that are important to them, however, further evidence is needed. Considerations for future research and clinical implications are outlined.
**Introduction**

The World Health Organisation (WHO; 2001) conceptualises disability as impairment, activity limitations, and restrictions in participation. Accordingly, the British Society of Rehabilitation Medicine (BSRM) and the Royal College of Physicians (RCP) in the United Kingdom (UK) define rehabilitation as “a process of active change by which a person who has become disabled acquires the knowledge and skills needed for optimal physical, psychological, and social function” and that services should consider “the use of all means to minimise the impact of disabling conditions and to assist disabled people to achieve their desired level of autonomy and participation in society” (BSRM & RCP, 2003, p. 7).

Social participation is defined as “…a person’s involvement in activities that provide interactions with others in society or the community” (Levasseur, Richard, Gauvin, & Raymond, 2010, p. 2148). This definition was established to address the lack of consensus within the health literature, which often uses similar concepts interchangeably to describe social participation. These include social engagement (i.e., participation in social activities; Bassuk, Glass, & Berkman, 1999), community integration (i.e., engagement in activities in home, social, and productive environments; Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993), and social integration (i.e., mutual engagement in social activities with others; Lefebvre, Cloutier, & Levert, 2008).

To support the definition and conceptualisation of social participation, Levasseur et al. (2010) conducted an inventory and content analysis across 43 identified definitions of social participation across a broad range of disciplines. They proposed a taxonomy comprising of six levels containing the different types of social activities that contribute to social participation: (1) doing an activity in preparation for
connecting with others; (2) being with others but feeling alone; (3) interacting with others without doing a specific activity; (4) doing an activity with others; (5) helping others; and (6) contributing to society. This suggests that a person’s social participation can be viewed on a continuum from passive to very active (Levasseur et al., 2010; Piškur et al., 2014).

Social participation is a fundamental determinant for health and wellbeing (Levasseur et al., 2010), viewed as important for children’s development, positive adult mental health, and healthy aging in the elderly (WHO, 2002). Regarded as a key outcome in rehabilitation (Gerber, Garago, & McMackin, 2016; Piškur et al., 2014), social participation has been separated into objective and subjective outcomes. Some authors refer to it as the number (objective) of social contact hours an individual receives (Shattuck, Orsmond, Wagner, & Cooper, 2011). Others, view social participation as the amount of meaningful (subjective) experiences an individual has with others (Boutot & Bryant, 2005). Thus, one may not engage in many social activities but regards these as meaningful for wellbeing (Piškur et al., 2014).

Social participation is a particular concern following acquired brain injury (ABI), a leading cause of death and disability worldwide (Jolliffe, Lannin, Cadilhac, & Hoffman, 2018; Menon & Bryant, 2019). In the UK alone, there were 348,453 recorded hospital admissions for ABI between 2016 and 2017, approximately 954 admissions per day (Headway, 2018). Moreover, prevalence rates are likely to be an underestimation due to inconsistent recording procedures and those not requiring admission being omitted from figures. ABI can result from a variety of mechanisms that result in damage to the structural integrity of the brain. These include traumatic brain injuries (TBI), caused by road traffic accidents, falls, or assaults; or non-traumatic injuries, caused by stroke, brain tumour, hypoxic injuries, or infections (Barber et al.,
Enhancements in medical science have increased the survival rates for people with severe ABI (Holloway & Tasker, 2019), and the sequela that contribute to chronic disability are increasingly recognised.

Survivors may experience far reaching impairments in cognitive, emotional, behavioural, physical, and social domains. There is evidence to show difficulties with attention (Sinclair, Ponsford, Rajaratnam, & Anderson, 2013), executive functioning (Niemeier, Marwitz, Lesher, Walker, & Bushnik, 2007), insight and awareness (Fleming, Strong, & Ashton, 1996), memory (Hutchinson & Marquardt, 1997), identity (Carroll & Coetzer, 2011), mood (Gould, Ponsford, Johnston, & Schönberger, 2011), lability, aggression, disinhibition (Eames & Wood, 2003), mobility (Cubis et al., 2018), and interpersonal relationships (Yeates, 2013) following ABI. Similarly, individuals can experience significant losses in life roles as well as restricted participation in domestic, vocational, community, and leisure activities (Brown, Gordon, & Spielman, 2003; Goverover, Genova, Smith, Chiaravalloti, & Lengenfelder, 2017).

Post-ABI, individuals are more likely to experience increased social isolation, loneliness, and depression (Bombardier et al., 2010; Douglas, Dyson, & Foreman, 2006; Salas, Casassus, Rowlands, Pimm, & Flanagan, 2018). Unsurprisingly, quality of life (QoL) and satisfaction with functioning is often affected post-ABI, resulting in deteriorating mental health and further restricted participation (Goverover et al., 2017; Kalpakjian, Lam, Toussaint, & Merbitz, 2004). In addition to the impact of ABI, community and cultural factors may also influence social participation post-injury. These include social economic status and access to community resources (Ashida, Kondo, & Kondo, 2016), living in rural areas (Douglas, Dyson, & Foreman, 2006), engagement in health promoting behaviours (Hyyppä & Mäki, 2003), religion and
ethnicity (Tam & Neysmith, 2006), and family and community views towards disability (Saetermoe, Scattone, & Kim, 2001).

Adults with TBI have previously reported significantly less social participation in leisure and recreational activities (Fleming et al., 2011; McLean, Jarus, Hubley, & Jongbloed, 2014), reduced friendship quality, and higher social isolation when compared to non-injured adults (Flynn, Mutlu, Duff, & Turkstra, 2018). Furthermore, Cubis et al. (2018) identified that those who perceived higher levels of functional and cognitive impairment following brain tumours were more likely to experience a loss in social group membership and poorer psychological wellbeing.

WHO (1998) define QoL as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (p. 1570). Accordingly, if participation in social activities is of value to individuals, unfulfillment in this area is likely to affect life satisfaction. Indeed, social support and community integration has previously been shown to be significantly associated with QoL measures (Kalpakijan et al., 2004), and participation in leisure activities has been significantly associated with increased satisfaction with life (Pierce & Hanks, 2006).

Similarly, health-related QoL (HRQoL) gives reference to subjective perspectives on the impact of a health condition on wellbeing and functioning within physical, psychological, social, and domestic domains (Cella et al., 2012). Such experiences are likely to be key drivers for rehabilitation and contribute to overall value of treatment for individuals. The Quality of Life after Brain Injury Instrument (QOLIBRI; von Steinbüchel et al., 2010), a measure of HRQoL, has previously shown positive relationships with the social aspects of the Community Integration Questionnaire (CIQ; Willer et al., 1993) in ABI populations (Gerber et al., 2016). The CIQ is an objective
measure of a person’s level of integration in home, social, and productive activities (Willer et al., 1993), and is frequently used to measure social participation in ABI populations (Gerber et al., 2016).

The relationship between social participation and QoL has previously been recognised (Geber et al., 2016), particularly on subjective measures of social participation. McLean et al. (2014) identified that enjoyment and satisfaction with performance in social activities were significantly associated with QoL in their sample with TBI, but the diversity and frequency of activities were not. Subsequently, it has been concluded that rehabilitation should focus on supporting individuals to engage in meaningful social activities to maximise QoL and minimise disability (Cicerone, 2004; Eriksson, Kottorp, Borg, & Tham, 2009; McColl, 2007; McLean et al., 2014). Whilst it has been suggested that QoL may improve with increased meaningful social participation (Govorover et al., 2017; McLean et al., 2014), the causal relationship between the two outcomes is yet to be explored.

**Rationale and Aims for Review**

Rehabilitation aims to maximise an individual’s ability to participate in valued activities and increase wellbeing, despite the presence of impairments (BSRM & RCP, 2003; Hart & Evans, 2006). Accordingly, rehabilitation goals need to focus on what is important to the individual with ABI (Wilson, 2017). The chronic consequences of ABI can have significant implications for social participation and QoL, and the social goals for rehabilitation are becoming increasingly recognised (Gerber et al., 2016).

There is a rationale to review the efficacy of interventions that facilitate social participation for adults with ABI on outcomes of social participation and QoL. Furthermore, it seems pertinent to identify suitable methods (i.e., intervention delivery
and focus) within the evidence-base to achieve this. A synthesis of available evidence could support rehabilitation professionals to: (a) understand the interplay between social participation and QoL; (b) consider how best to support these outcomes in post-acute rehabilitation; and (c) review outlined considerations for future intervention research.

A limited number of systematic reviews have been conducted to explore the efficacy of community, leisure, and social participation interventions in ABI populations. Tate, Wakim, and Genders (2015) reviewed the efficacy of community-based social activity programmes for people with TBI on outcomes of mood and QoL, but not social participation. The authors only found two studies with sufficient scientific rigour to show efficacy of the interventions on target outcomes. The limited number of available studies was recognised and it was concluded that interventions need to be specific, structured, goal-driven, intensive, and conducted over a period of months. More recently, Lee, Heffron, and Mirza (2019) explored the efficacy of interventions focusing on community and leisure participation for individuals following stroke. They also recognised the limited number of available studies to show an effect on measures of participation, depression, and HRQoL. It was recommended that future interventions should focus on social participation and community activities beyond leisure.

This review aims to extend the work of Tate et al. (2015) and Lee et al. (2019) to explore the efficacy of interventions that facilitate social participation on outcomes of social participation and QoL in adults with ABI. As recognised by Levasseur et al. (2010), the ABI literature equally uses interchangeable terms, such as social participation (McLean et al., 2014), leisure activities (Fleming et al., 2011), and community integration (Gerber et al., 2016); with the latter concerning itself with a
person’s activity, and physical and social inclusion in community life (Winkler, Unsworth, & Sloan, 2006). Community integration has largely been replaced by ‘participation’ in rehabilitation literature (McLean et al., 2014).

For this review, social participation was defined as ‘any engagement in activities that provides interaction with others within society or a community’ (Levasseur et al., 2010). The use of this definition will allow for the inclusion of intervention studies using terms such as community integration, leisure activities, and peer-mentors, both in an individual and group setting, if all other inclusion criteria is met. This review aimed to answer the following questions:

1. What is the efficacy of interventions that facilitate social participation on outcomes of social participation and QoL in adult survivors of ABI?
2. Does increased social participation result in improved QoL post-ABI?
3. What are the psychological processes that support social participation and QoL post-ABI?

Methods

A systematic review aims to locate, appraise, and synthesise empirical evidence relating to specific research questions to provide evidence-based answers (Boland, Cherry, & Dixon, 2017). This review adhered to the guidelines provided by the Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocol (PRISMA-P; Moher et al., 2015).

Eligibility Criteria

The population, intervention, comparator, outcome, and study type (PICOS) framework was used to determine eligibility criteria (Table 1) for study characteristics, as recommended by the PRISMA-P checklist (Moher et al., 2015).
Table 1

PICOS Eligibility Criteria for the Inclusion and Exclusions of Studies in the Review

<table>
<thead>
<tr>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Population</strong></td>
<td><strong>Exclusion</strong></td>
</tr>
<tr>
<td>• Adult population (&gt;18 years)</td>
<td>• Non-adult populations</td>
</tr>
<tr>
<td>• Population with ABI (various aetiologies, may include stroke if population referred to as ABI)</td>
<td>(specified children or adolescent population / or older adult population)</td>
</tr>
<tr>
<td>• Population exclusively referred to as stroke</td>
<td>• Population without ABI (i.e., progressive neurological conditions/ neurodevelopmental or learning/ intellectual disabilities)</td>
</tr>
<tr>
<td>• Population with primary mental health needs/ focus</td>
<td>• Population with primary mental health needs/ focus</td>
</tr>
<tr>
<td><strong>Intervention</strong></td>
<td><strong>Comparison</strong></td>
</tr>
<tr>
<td>• Studies or interventions facilitating/ increasing social participation for participants (i.e., supporting inclusion in activities with others)</td>
<td>n/a</td>
</tr>
<tr>
<td>• Studies without a primary focus increasing social participation for participants (i.e., return to work, individual self-help)</td>
<td>n/a</td>
</tr>
<tr>
<td><strong>Comparison</strong></td>
<td><strong>Outcomes</strong></td>
</tr>
<tr>
<td>n/a</td>
<td>• Studies that report social participation (including community integration, leisure satisfaction) and QoL as separate outcomes</td>
</tr>
<tr>
<td><strong>Outcomes</strong></td>
<td>• Studies that do not report outcomes relating to social participation or QoL</td>
</tr>
<tr>
<td>• Studies that report outcomes relating to social participation and QoL/ HRQoL</td>
<td>• Studies that only report outcomes relating to social participation or QoL</td>
</tr>
<tr>
<td>• QoL may be reported as subjective well-being or satisfaction with life</td>
<td>• Studies that only report outcomes in mood domains</td>
</tr>
<tr>
<td>• Studies may report additional outcomes, as well as social participation and QoL</td>
<td></td>
</tr>
</tbody>
</table>
Study designs
- Peer-reviewed articles
- Quantitative studies
- Randomised controlled trials (RCT)
- Longitudinal/prospective studies
- Single-case experimental designs (SCEDs)
- Qualitative studies
- Clinical case studies
- ‘Grey literature’ (due to time restrictions)
- Discussion or opinion papers
- Conference abstracts
- Book chapters
- Papers published in foreign language with no available English translation
- Study proposals

**Population.** Identified participants were adults (>18 years) with ABI. Studies that outlined a minimum inclusion age of 16 years were included if the sample was stated to be adults and the reported mean age suggested the majority of participants to be above the age of 18 years. The term “stroke” was excluded from the search strategy due to the recent review by Lee et al. (2019) with this population in this topic area. Participants with stroke aetiologies were only included if studies identified the sample to be exclusively ABI.

**Intervention.** Studies were included if the intervention promoted engagement in activities in a social, group, or community setting; in line with the definition of social participation. Studies were included if they referred to community integration, leisure activities, or peer-mentoring and aimed to increase participation with others.

**Comparator.** No restrictions were placed upon comparator criteria, allowing for the inclusion of randomised controlled trials (RCT), and within prospective and single-case experimental designs.

**Outcome.** Studies were included if they measured outcomes relating to both social participation (including community integration, leisure satisfaction) and QoL (including HRQoL). Studies that only reported one of these outcomes were excluded.
due to the review questions. Studies may also refer to QoL as subjective well-being or satisfaction with life (Skevington & Böhnke, 2018).

**Study designs.** Only peer-reviewed studies were included in this review. Due to time constraints and the large number of possible articles identified from searching the ProQuest database, grey literature was not included.

**Information Sources**

The following electronic databases were searched to identify eligible studies: PsycINFO, Medline, Embase, CINAHL, Web of Science, Psychology and Behavioural Collections, and the Cochrane Library. Studies were also added from initial scoping searches and reference lists within publications were hand-searched for further relevant papers, as recommended by the National Institute for Health and Care Excellence (NICE, 2012).

**Search Strategy**

The Cochrane database and the International Prospective Register of Systematic Reviews were checked to confirm that the review questions had not yet been investigated. An initial scoping search was conducted to provide an overview of the available literature and relevance to the review questions. The reading of key texts and previous reviews allowed for the generation of further specific search terms (Lee et al., 2019; Levasseur et al., 2010; Tate et al., 2015). Final search terms were refined with consultation and supervision from researchers and clinicians, as recommended by the Cochrane Online Library guidance (Thomas, Kneale, McKenzie, Brennan, & Bhaumik, 2019).

The search terms in Table 2 were used to search for relevant studies across the identified databases. Using these terms in conjunction with Boolean operators and truncation symbols optimised the search strategy (Higgins & Green, 2011). All
databases were searched in December 2019 and all identified citations were exported into the reference management software, Mendeley.

Table 2

*Key Search Terms used in Review*

<table>
<thead>
<tr>
<th>Individual Search Terms (Titles and Abstracts)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. “intervention*” OR “progra*” OR “rehabilitation” OR “treatment” AND</td>
</tr>
<tr>
<td>2. “social participation” OR “participation” OR “social engagement” OR “social integration” OR “re-integration” OR “leisure activities” OR “community activities” OR “social networks” AND</td>
</tr>
<tr>
<td>3. “adult*” OR “adult survivors” OR “adulthood” AND</td>
</tr>
<tr>
<td>4. “traumatic brain injury” OR “TBI” OR “acquired brain injury” OR “ABI” OR “head injury” OR “brain tumo*” OR “CNS infection” OR “meningitis” OR “encephalitis” AND</td>
</tr>
<tr>
<td>5. “quality of life” OR “QoL” OR “health related quality of life” OR “HRQoL” OR “subjective well-being” OR “SWB”</td>
</tr>
</tbody>
</table>

**Study Selection**

All identified articles (titles and abstracts) were initially screened against the outlined PICOS criteria. Studies that were considered appropriate were then included for full text screening to assess their eligibility against the inclusion and exclusion criteria. Six studies were randomly selected at the full text stage to be reviewed by a second-rater. They were asked to make a yes/no decision as to whether the study was to be included or excluded, based on the PICOS criteria. Inclusion criteria was discussed to address any queries. This yielded 100% inter-rater reliability (Cohen’s $K = 1$).
Appraising Quality and Risk of Bias in Studies

As recommended by Moher et al. (2015), the validity and methodology of each full text article was assessed. Consistent with previous systematic reviews exploring interventions conducted with ABI populations (Krasny-Pacini, Chevignard, & Evans, 2014; Mahen, Rous, & Adlam, 2017; Ross, Dorris, & McMillan, 2011), an appraisal checklist was used to assess the quality of quantitative methodology (Mahen et al., 2017). This appraisal tool was developed primarily using the Consolidated Standards of Reporting Trials (CONSORT) guidelines, with further added items specific to ABI that could impact upon the validity of results, such as time since injury (accounting for recovery processes). This checklist has previously been reported to have high inter-rater reliability (Krasny-Pacini et al., 2014; Mahen et al., 2017). Studies that employed mixed-method designs were assessed on the basis of the most prominent methodology. Accordingly, all included studies were assessed using the same appraisal tool.

Studies were assessed against the 27-item criteria. A score of 1 was awarded if the criterion was met, and 0 if it was not met or not possible to ascertain. Consistent with previous reviews (Krasny-Pacini et al., 2014; Mahen et al., 2017; Ross et al., 2011), studies were considered to be “high” quality if they met 75% of the specified criteria. Studies that met between 50% and 74% were deemed to have “moderate” quality, and those that met less than 50% were considered to be “lower” quality. To assess the reliability of the chosen appraisal checklist, an independent researcher rated three (25%) randomly chosen studies using the same checklist. A comparison of quality scores from both researchers yielded an almost perfect agreement (Cohen’s $k = .91$). The appraisal checklist was not used as an assessment tool to exclude
included studies on the basis of their quality, and all studies contributed towards the overall discussion of evidence.

**Data Synthesis**

The synthesis is provided in a narrative format due to the variation in included studies, as recommended by the Centre for Reviews and Dissemination (CRD; 2009). Data were extracted from each full text article based on (1) study population; (2) suitable design; (3) intervention description; (4) outcome measures; and (5) results and conclusions regarding intervention efficacy on target outcomes, social participation and QoL.

Where possible, the effect sizes (ES) on target outcomes were also extracted or calculated using Hedges $g$ (Hedges & Vevea, 1998), adapted by Morris and DeShon (2002). Hedges $g$ was calculated as a standard difference between means and has previously been used in research (Cicerone et al., 2008) and other systematic review articles to investigate efficacy of interventions in ABI populations (Krasny-Pacini et al., 2014; Mahen et al., 2017). Calculating ES allows for the exploration of the magnitude of reported statistical significance that exist between and within experimental groups.

ES was interpreted as small when $g \geq .2$, medium when $g \geq .5$, and large when $g \geq .8$ (Cohen, 1988). Figure 1 displays the formulas used for calculating ES (Morris & DeShon 2002). If articles provided insufficient information to be able to calculate ES, the results were analysed on the basis of what was reported. The reporting of ES supported the narrative of the evidence for intervention efficacy. Due to the diversity of studies, intervention type, designs, and rigour, a meta-analysis of the results was not conducted (CRD, 2009).
Results

The review process and the number of identified and screened articles are detailed in Figure 2. The database search yielded a total of 1084 potentially suitable records. An additional 35 records were added from other sources identified through scoping searches, resulting in a total of 1119 records. After removing duplicates (n=400), 719 articles were screened against the pre-defined PICOS criteria. Articles were excluded following title and abstract screening, leaving 36 records. The remaining full-text studies were assessed for eligibility, of which 12 were included in the review. The extracted information relating to the PICOS criteria, outlined review questions, and critical appraisal is summarised in Table 3 below.

Figure 1. The formulas used for calculating ES (Hedges $g$) for included studies.

The formula below was employed for ES calculation in single group pre- and post-intervention research designs:

- $ES = (M_{post, exp} - M_{pre, exp}) / SD_{pre, exp}$

The formula below was employed for ES calculation in independent group pre- and post-intervention research designs:

- $ES = \frac{(M_{post, exp} - M_{pre, exp})}{SD_{pre, exp}} - \frac{((M_{post, com} - M_{pre, com})}{SD_{pre, com}}$

The formula below was employed for ES calculation in independent group post-intervention designs:

- $ES = (M_{post, exp} - M_{post, com}) / SD_{post, pooled}$

In these formulas, $M$ is the mean, $exp$ is the experimental group, $com$ is the comparison group, $pre$ is the pre-intervention score, $post$ is the post-intervention score, $SD$ is the standard deviation, and $*$ is weighted.
Figure 2. Results of search strategy and screening process for systematic review using PRISMA flow diagram.
Table 3

**Summary of Studies Included for Analysis in Alphabetical Order**

<table>
<thead>
<tr>
<th>No., Authors, and Country</th>
<th>Design</th>
<th>Participants (Pts.)</th>
<th>Intervention Summary</th>
<th>Outcome Measures</th>
<th>Main Findings and Conclusion</th>
<th>Critical Appraisal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Brands, Bouwens, Gregório, Stapert, &amp; van Heugten (2013). The Netherlands.</td>
<td>Prospective cohort study. Data collected pre (T0), post-intervention (T1), and 6-month follow-up (T2).</td>
<td>ABI (n=26) (44.6 years) ABI aetiologies: Stroke (n=9) TBI (n=10) Haemorrhage (n=4) Tumour (n=1) Infection (n=1) Hypoxia (n=1) Severity not reported. Relatives (n=23) (50.1 years).</td>
<td>A process-oriented neuropsychological rehabilitation group aimed to promote adjustment and meaningful living post-ABI. Group and individual sessions guided by individual goals. Emphasis on group dynamics and process. Relative group focused on psycho-education, emotional adjustment, and expectations. Length of group varied according to individual needs. Mean duration of 8 months, range 2 to 19.5 months. Sessions ran weekly for 1 hr 45 min.</td>
<td>Participation CIQ HRQoL SA-SIP</td>
<td>There were no significant differences on outcomes between T0 and T1 for pts with ABI. T0 to T1: CIQ (p = 1) SA-SIP (p = 1) No significant differences were identified at 6-month follow-up on both measures (T1 to T2). Participation in the programme did not increase levels of participation or QoL for pts with ABI. The group did have positive effects on the attainment of individual goals across group and individual sessions.</td>
<td>Strengths: Representative sample. Use of validated measures. ABI determined by medical documentation. Intervention described in detail. Inclusion of relatives to support insight and environmental aspects of QoL. Intervention tailored for individual everyday needs. Inclusion of follow-up measures to assess if effects were maintained. Weaknesses: Lack of control group. Effect sizes not provided. Variation in intervention duration and dosage complicates data interpretation.</td>
</tr>
</tbody>
</table>

United States of America.

RCT.

Data collected at pre (T0), post-intervention (T1), and 3-month follow-up (T2).

TBI (n=74) (43 years)

Pts were randomised into two conditions: (1) intervention (n=37); and (2) waiting list (n=37).

Injury severity:
PTA mean 148.81 days (control) and 146.91 days (intervention).

A 12-week group health and wellness intervention to improve health promoting behaviours. 12 sessions in total, lasting for 1.5 hours.

The structure of each session was to: (1) enhance learning and take advantage of the group process; (2) review concepts and homework; (3) introduce a new health and wellness-related topic; (4) solve problems regarding barriers; and (5) enhance self-efficacy for health promotion behaviours.

Pts in the control group did not receive a treatment for 6-months.

Participation
PART-O

QoL
Diener SWL Scale

HRQoL
SF-12

A significant time-by-treatment interaction was evident on measures of social participation ($p < .001$) and satisfaction with life ($p = 0.22$). These were attributed to estimates across time, not treatment.

No significant treatment effects were apparent on measures of QoL, HRQoL, and participation.

Insufficient information to calculate ES.

Efficacy of group health-promotion intervention on outcomes of participation and QoL was not supported.

Quality rating: Moderate (63%)

Strengths: Representative sample. Inclusion of control group. Intention to treat analysis. Use of validated measures. TBI determined by medical documentation. Sample at least 6-months post injury.

Weaknesses: Unequal groups pre-intervention. Means and SD not reported for outcomes. Effect sizes not included. Assessors not blind to conditions. Follow-up data not reported.

Quality rating: Moderate (74%)

Strengths: Use of manualised intervention. Use of validated measures. Sample at least 6-months post injury.
The programme was offered on a one-to-one basis, and involved 10 weekly 2-hour sessions. As well as the individual sessions, pts were asked to engage in six periods of leisure activities by themselves.

Leisure satisfaction improved for all three pts at T1 and T2. Frequency in leisure participation improved for P1. P2 and P3 level of leisure participation had returned to baseline at T2.

P1 reported improvement on the MPAI-4 and SIP at T1 and T2. P2 showed improvement on the SIP at T1, and all measures at T2. P3 showed small improvements on the SIP and MPAI-4 at T1 and T2.

Qualitative benefits outlined for pts, such as change in family role, improved leisure confidence and QoL, and development of friendship.

Leisure is important for adults with TBI and provides a basis for further research in this area.

**Weaknesses:**
- Small sample size.
- Opportunity sample.
- Information of how TBI was determined not included.
- Lack of control group.
- Statistical analysis not conducted.
- Short follow-up period.

**Quality rating:** Low (41%)

---

**4. Cicerone, Mott, Azulay, & Friel (2004).**

**United States of America.**

<table>
<thead>
<tr>
<th>Non-randomised controlled intervention trial.</th>
<th>TBI (n=56)</th>
<th>Intensive cognitive rehabilitation programme (ICRP) and standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data collected pre (T0) and post-intervention (T1).</td>
<td>Moderate to severe injury (89% of pts).</td>
<td>ICRP pts received an intensive highly structured cognitive and psychosocial intervention programme. The programme lasted for 16 weeks and was provided in small groups of 5 to 8 pts.</td>
</tr>
<tr>
<td></td>
<td>GCS/PTA data not reported.</td>
<td>The ICRP focused on group and individual cognitive remediation and interpersonal communication skills, as well as group psychotherapy. Interpersonal group process was emphasised.</td>
</tr>
</tbody>
</table>

**Participation**

**CIQ**

**HRQoL**

QCIQ & satisfaction with cognitive functioning (QCOQ Scale).

A significant main effect of time on total CIQ scores was identified (p < .001), with both ICRP and SRP groups improving post-intervention.

Pts in the ICRP showed greater improvements on the CIQ from T0 to T1 when compared with SRP pts (p = .021; g = .69; M).

ICRP CIQ T0 to T1 (g = 1.13; L). SRP CIQ T0 to T1 (g = .44; S).

**Strengths:**
- TBI determined by medical documentation.
- Representative sample.
- Intervention described in detail.
- Use of validated measures.
- Effect sizes provided.

**Weaknesses:**
- Some SRP pts less than 6-months post-injury.
The ICRP was conducted for 4 days per week, for 5 hours per day. ICRP participants received 15 hours of group and individual therapies per week and 1 day per week for community participation. SRP pts received less intense standard neurorehabilitation with support of multiple therapeutic disciplines. Treatment content and duration was determined by individual needs. SRP pts engaged in 15 hours per week of treatment.

SRP pts expressed greater satisfaction with community functioning ($p = .03, g = -.57; M$) and cognitive functioning (non-significant) at T1 than ICRP pts. This was attributed to time after injury differences between ICRP (mean 33.9 months) and SRP (mean 4.8 months) pts and level of awareness.

Outcomes on the QCOQ scale were significantly related to post-intervention total on overall CIQ ($r_s = .42, p = .001$), home integration ($r_s = .41, p = .002$), and social integration ($r_s = .36, p = .007$). This relationship was particularly evident in the ICRP group ($r_s = .55, p = .005$) compared with SRP participants ($r_s = .36, p = .051$). Authors suggested the role of self-efficacy (satisfaction with functioning) for social participation.

The ICRP indicated significant clinical benefits in social participation for pts with TBI. QoL was not related to social participation, but satisfaction with cognitive functioning was (improved by ICRP). Self-efficacy may play an important role in rehabilitation post-TBI.

RCT. Data collected pre (T0) and post-intervention (T1), and at 6-month follow-up (T2).

TBI (n=68) Pts were randomised into two conditions: Intensive cognitive rehabilitation programme (ICRP) and standard neurorehabilitation programme (STD).

ICRP (n=34) (38.7 years)
Injury severity:
Mild (n=2)
Moderate (n=6)
Severe (n=23)
Unknown (n=2)

STD (n=34) (34.5 years).
Injury severity:
Mild (n=6)
Moderate (n=10)
Severe (n=17)
Unknown (n=1)

GCS/PTA data not reported.

Same intervention as Cicerone et al. (2004), with additional modules to support cognitive and emotional self-efficacy (supporting interpersonal relationships).

The two treatments provided 15 hours per week of therapy for 16 weeks. Pts in the ICRP condition initiated treatment simultaneously in small groups of 5 to 8.

The ICRP focused on holistic neurorehabilitation, integrative interventions for cognitive, behavioural, emotional, and interpersonal difficulties. Specific self-evaluation and social problem-solving sessions included. Sessions ended with reflection of group process.

Additional modules for cognitive and emotional self-efficacy (supporting interpersonal relationships).

Pts in the ICRP condition reported valuing peer support and cohesion, fostered through group participation.

There was a significant time by treatment (ICRP vs STD) interaction for overall CIQ (p = .42, g = .60; M), particularly on the social aspects of the CIQ (p = .011, g = .46; S), attributed to the gains made by ICRP pts.

There was a significant time by treatment interaction on the PQOL (p = .49, g = .30; S), caused by significant improvements by the ICRP condition T0 to T1 (p = .004, g = .36; S). The ICRP condition maintained gains from T1 to T2.

T2 functioning for ICRP pts remained significantly different from T0 for the CIQ (p = .018, g = .59; M) and PQOL (p = .023, g = .33; S), identified through paired sample t tests.

Pts in the STD showed significant improvement on the CIQ between T1 and T2 (p = .044, g = .27; S), attributed to significant improvements made on the productivity sub-scale (p = .016, g = .40; S).

There were no significant changes on PQOL in STD pts from T1 to T2.

Strengths:
TBI determined by medical documentation. Representative sample. Use of control sample. Intervention described in detail. Assessors blind to conditions. Use of validated measures. Effect sizes provided. Intention to treat analysis. Evidence of intervention generalisability (vocational activity). Inclusion of follow-up measures to assess if effects were maintained.

Limitations:
Some pts less than 6-months post injury. Lack of blinding for pts and therapists. Both interventions were comprehensive and complex, affecting interpretation of ICRP intervention efficacy.

Quality rating: High (93%)
The results supported the efficacy of an intensive holistic rehabilitation on outcomes of social participation and QoL for people with TBI.

Strengths:
- TBI determined by medical documentation.
- Use of validated outcome measure for participation.
- Qualitative experiences provided by pts.

Weaknesses:
- Inclusion/exclusion criteria not reported.
- Volunteer sample.
- Small sample size.
- Intervention not described in detail.
- Dosage of activities not reported.
- Categorisation of pts post-intervention resulting in sample bias.
- Lack of control group.
- QoL measure not validated.
- Effect sizes not reported.
- No longer term follow-up.

Quality rating: Low (44%)

**The Netherlands.**

**Prospective cohort study.**

Data collected at pre (T0), post-intervention (T1), and 12 month follow-up (T2).

<table>
<thead>
<tr>
<th>ABI (n=24) (28.5 years, range 17-51 years)</th>
<th>The Brain Injury Programme (BIP) aimed to improve community integration through treatment using three modules: (1) independent living (e.g., executing tasks in domestic life), 100 hours per-person; (2) social-emotional (e.g., psychoeducation and social skills to maintain social relationships), 110 hours per-person; and (3) vocational (e.g., work and leisure tasks), 44 hours per-person. Pts received a combination of small group and individual sessions.</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABI aetiologies: TBI (n=18) Stroke (n=3) Tumour (n=2) Infection (n=1)</td>
<td>The intervention aimed to support pts to achieve balance in daily life across family, work, leisure, and social domains.</td>
</tr>
<tr>
<td>TBI pts injury severity: GCS mean 5.9 (range 3-8).</td>
<td>The mean duration of the BIP was 198.9 days (range 112 to 382 days).</td>
</tr>
</tbody>
</table>

**Participation**

<table>
<thead>
<tr>
<th>CIQ</th>
</tr>
</thead>
</table>

**HRQoL**

<table>
<thead>
<tr>
<th>EQ-5D</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>EuroQoL Health</th>
</tr>
</thead>
</table>

**Significant time effects (T0 to T2) were evident for CIQ (p < .001) and EQ-5D (p < .001), but not EuroQoL Health (p = .183).**

<table>
<thead>
<tr>
<th>T0 to T1: CIQ (p = .001, g = .82; L) EQ-5D (p &lt; .001, g = -1; L) EuroQoL Health (p = .013, g = .83; L). These were maintained at 12-month follow-up.</th>
</tr>
</thead>
<tbody>
<tr>
<td>T1 to T2: CIQ (p = 1, g = -.08; S) EQ-5D (p = 1, g = .06; S) EuroQoL Health (p = 1, g = .15; S)</td>
</tr>
</tbody>
</table>

Although a control group was not used, results provided support for the efficacy of a residential community reintegration programme on outcomes of social participation and QoL in adults with ABI.

**Strengths:**

Representative sample. ABI determined through medical documentation. Use of validated outcome measures. Intervention described in detail.

Inclusion of follow-up measures to assess if effects were maintained. Evidence of intervention generalisability (vocation and independent living).

**Weaknesses:**

Small sample size. Lack of control group. Sub-domains of CIQ not presented.

**Quality rating:**

Moderate (66%)

---


**The Netherlands.**

A prospective cohort study with a 3-month waiting list control and 12-month follow-up.

Data collected at inclusion (T0), pre-intervention 3

<table>
<thead>
<tr>
<th>ABI (n=70) (25.1 years)</th>
<th>The Brain Integration Programme (BIP). See intervention description for study seven above (Geurtsen et al., 2008).</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABI aetiologies: TBI (n=47) Stroke (n=7) Tumour (n=10) Infection (n=4) Hypoxia (n=2)</td>
<td>Total intervention time was 254 hours per person.</td>
</tr>
<tr>
<td>TBI pts injury severity:</td>
<td>Mean intervention duration was 196.2 days (range 44 to 357 days).</td>
</tr>
</tbody>
</table>

**Participation**

<table>
<thead>
<tr>
<th>CIQ</th>
</tr>
</thead>
</table>

**HRQoL**

<table>
<thead>
<tr>
<th>EQ-5D</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>EuroQoL Health</th>
</tr>
</thead>
</table>

Data were available for 67 of the pts at T3. No significant differences were identified during the waiting list control period.

A significant overall effect of time was identified (p < .001) for all outcome measures together. A significant effect of time (T0 – T3) was identified for each outcome measure.

**Strengths:**

months later (T1), post-intervention (T2) and at 12 month follow-up (T3).

<table>
<thead>
<tr>
<th></th>
<th>GCS mean 7.5 (range 3-15).</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th></th>
<th>T0 to T3:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CIQ ($p &lt; .001, g = .95; L$)</td>
</tr>
<tr>
<td></td>
<td>EQ-5D ($p &lt; .001, g = -.36; S$)</td>
</tr>
<tr>
<td></td>
<td>EuroQoL Health ($p &lt; .001, g = .58; M$)</td>
</tr>
<tr>
<td></td>
<td>WHOQOL-BREF overall ($p &lt; .001, g = .80; L$)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>T1 to T2:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CIQ ($p &lt; .001, g = .58; M$)</td>
</tr>
<tr>
<td></td>
<td>EQ-5D ($p = .008, g = -.61; M$)</td>
</tr>
<tr>
<td></td>
<td>EuroQoL Health ($p &lt; .001, g = .55; M$)</td>
</tr>
<tr>
<td></td>
<td>WHOQOL-BREF overall ($p = .008, g = .52; M$). All significant changes were maintained at follow-up (T3).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>T2 to T3:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CIQ ($p = 1, g = .09; S$)</td>
</tr>
<tr>
<td></td>
<td>EQ-5D ($p = .85, g = .30; S$)</td>
</tr>
<tr>
<td></td>
<td>EuroQoL Health ($p = .85, g = -.43; S$)</td>
</tr>
<tr>
<td></td>
<td>WHOQOL-BREF overall ($p = .97, g = -.23; S$)</td>
</tr>
</tbody>
</table>

The intervention was efficacious for improvements in QoL and social participation for adults with ABI.

Inclusion of follow-up measures to assess if effects were maintained. Evidence of intervention generalisability (vocation and independent living).

**Weaknesses:**
- Lack of control group.
- Sub-domains of CIQ not presented.

**Quality rating:**
- Moderate (70%)
9. **Hanks, Rapport, Wertheimer, & Koviak (2012).**

**RCT**

- **TBI (n=96):** Final data collected 12-months post-intervention. (38.46 years)
- **Significant others (n=62):** (40.9 years).

**TBI**

- **Treatment:** Mentored TBI (n=47)
  - Injury severity: GCS mean 9.39
- **Control TBI (n=49):**
  - Injury severity: GCS mean 9.80

Pts were randomly allocated to peer mentor or control. As significant others (SO) were included, there were 4 possible groups:

1. TBI mentor and SO mentor
2. TBI mentor and SO no mentor
3. TBI no mentor and SO mentor
4. TBI no mentor and SO no mentor.

The mentors and mentees were requested to meet/talk at least weekly for the first month, bi-weekly for the next 2 or 3 months, and then monthly for the remainder of the year.

The control group was discharged to the community and received the usual socialisation following discharge.

Final data collection occurred 12 months after mentoring was completed (24 months from baseline).

**Participation**

- **CIM**

**HRQoL**

- **SF-12**

There were no statistically significant differences between TBI groups on measures of participation following the intervention ($p = .35, g = .19; S$), identified through $t$ test.

There was a significant difference on a measure of HRQoL between TBI groups following the intervention ($p = .04, g = .42; S$), identified through $t$ test.

TBI mentees reported better emotional coping, physical functioning, and less somatic symptoms and less chaotic life styles when compared to controls post-intervention.

TBI Mentees qualitatively reported feeling less alone through the support of their mentors. Mentors supported mentees with helpful management of emotions.

The programme was reported to be helpful for individuals with TBI for HRQoL when compared to controls. Efficacy cannot be established due to lack of pre and post-intervention data (not collected).

**Strengths:**
- Representative sample.
- Use of control sample.
- Use of validated outcome measures.
- Assessors blind to treatment conditions.
- Intervention described in detail.
- Mentors had to complete a curriculum of training.
- Qualitative experiences provided by pts.
- Effect sizes reported.

**Weaknesses:**
- Pre and post-intervention data not reported, complicating interpretation of efficacy.
- Time since injury for pts not reported.
- Limited intervention dosage.
- Characteristics of mentors not included.
- Analysis not suitable to determine efficacy.
- Poor randomisation process.

**Quality rating:** Moderate (74%)

| Prospective design. | ABI (n=12) (36 years). | A week long, residential, intensive, leisure education programme called “Pushing the Boundaries”.

The intervention programme aimed to provide leisure activities through groups and provided participants with the opportunity to trial a range of sporting and recreational activities to increase leisure satisfaction within their own communities. Intervention also included sessions on social communication skills.

Intervention objectives were: (1) for participants to trial a range of recreational activities with support so that they might participate in some similar activities within their own community; and (2) for participants to improve their communication skills to enable them to meet new people and build friendships in their own community. |

| Data collected pre (T0) and post (T1) intervention, and 3-month follow-up (T2). | ABI aetiologies: TBI (n=10) Non-TBI (n=2) | |

| Medium to severe ABI (GCS/PTA data not reported). | | |

| Participation | Insufficient information to calculate ES. |

| LSS | WHOQOL-BREF |

| Statistically significant improvements on measures of participation and QoL from T0 to T1. |

| T0 to T1: LSS (p = .02) WHOQOL-BREF environment (p = .03) |

| Statistically significant improvements on measure of participation and QoL from T0 to T2. |

| T0 to T2: LSS (p = .002) WHOQOL-BREF (all domains): Physical (p = .008) Psychological (p = .02) Social relationships (p = .02) Environment (p = .01) |

Four pts reported that they were participating in leisure activities at home that were more meaningful to them than their original goals.

Participation in the programme resulted in statistically significantly improvements in social participation and QoL 3-months post-intervention. |

| Strengths: |

| Intervention described in detail. Use of validated outcome measures. Intervention included individual goal planning. Qualitative experiences provided by pts. |

| Weaknesses: |

| Effect sizes not reported. Means and SD not reported. Lack of control group. Small sample size. Volunteer sample. Information of how ABI was determined not included. Short follow-up period. |

| Quality rating: Low (48%) |
Findings supported the concept that social participation is important in the lives of adults with ABI.

| 11. | Rasquin, Bouwers, Dijcks, Winkens, Bakx, & van Heugten (2010). The Netherlands. | A prospective cohort study conducted with repeated measures. Data collected pre (T0) and post-intervention (T1), and 6-month follow-up (T2). | ABI (n=27) Relatives (n=25) (49.5 years total) | Group outpatient cognitive rehabilitation programme. Groups had a maximum of 7 pts. Programme lasted for 2.5 hours and ran for 15 weeks. Programme aimed to help pts gain insight into the consequences of brain injury, offer cognitive strategies for daily life, support the learning of social skills, learn how to control emotional reactions, and to enhance self-efficacy. | Participation: CIQ HRQoL SA-SIP | No significant effects were identified for QoL at T1 (p = 1) or at T2. No significant differences identified using the CIQ at T1 or at T2. Insufficient information to calculate ES. Although participants attained individual goals, this did not result in higher participation levels or better QoL. | Strengths: Representative sample. Inclusion of follow-up measures to assess if effects were maintained. ABI determined through medical documentation. Use of validated outcome measures. Weaknesses: Data for secondary outcome measures not reported. Effect sizes not reported. Lack of control group. Some pts less than 6-months post-injury. Quality rating: Moderate (56%) |
| 12. | Struchen, Davis, Bogaards, Hudler-Hull, Clark, Mazzei, Sander, & Caroselli (2011). | Pilot RCT. Data collected pre (T0) and post-intervention (T1). | TBI (n=41) (31.7 years) Three pts groups: (1) Social peer mentors (SPMs; n=11) (2) peer partners (PPs), treatment group (n=12) | Peer-mentor intervention. SPMs were assessed for mentor suitability and completed extensive training around intervention content. Mentees were randomly assigned into PPs (treatment) or WLPPs (control). SPMs were matched with PPs to facilitate skill-building in the planning of social activities, participate jointly in social events | Participation: CHART-SF SAI QoL Diener SWL scale | No statistically significant interaction effects were found for social participation between T0 and T1 (p = .16). Social participation for PPs moved towards significance at T1. No statistically significant interaction or main effects of time and/or group were noted on measures of social network size. | Strengths: Representative sample. Use of control sample. Appropriate randomisation of pts. Use of validated outcome measures. Mentors had to complete a curriculum of training. Qualitative experiences provided by pts. |
within the community, build social networks for PPs, and develop social communication skills through regular contact through face to face meetings or telephone. Mentors were expected to meet with PPs face-to-face, twice per month, over a 3-month period. Social activity level, or satisfaction with social life.

PPs did show non-significant improvements regarding satisfaction with social activities and perceived social support at T1 when compared with WLPPs.

PPs reported higher perceived levels of social support than WLPPs at T1 ($p < .05$, $g = .60$; M).

No significant main or interaction effects were observed with satisfaction with life ($p = .81$).

87% of PPs felt that mentors had been helpful for social participation and decreasing loneliness.

Pts reported qualitative benefits for social participation following the peer-mentoring intervention, though not statistically supported.

**Weaknesses**

Small sample size. Some pts less than 6-months post-injury. Limited intervention dosage. Effect sizes not reported. Follow-up data not collected. Pts were not blinded to condition.

**Quality rating: Moderate (63%)**

---

*Note: GCS = Glasgow Coma Scale (Teasdale & Jennett, 1974), PTA = post-traumatic amnesia. ABI severity classifications: Mild (GCS 13-15; PTA <24 hours), moderate (GCS 9-12; PTA 1-7 days), and severe (GCS 3-8; PTA >7 days). Pts = participants, ABI = acquired brain injury, TBI = traumatic brain injury, QoL = quality of life, HRQoL = health-related quality of life, RCT = randomised controlled trial, SD = standard deviation, ES = effect size, $g =$ Hedge's $g$, L = large ES, M = medium ES, S = small ES, CIQ = Community Integration Questionnaire (Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993), SA-SIP = Stroke Adapted Sickness Impact Profile (van Strated et al., 1997), Diener SWL Scale = Diener Satisfaction with Life Scale (Diener, Emmons, Larsen, & Griffin, 1985), SF-12 = The Medical Outcomes Study 12-Item Short-Form Health Survey (Ware, Konsinki, & Keller, 1998), PART-O = The Participation Assessment with Recombined Tools-Objective (Whiteneck et al., 2011), KAS = Katz Adjustment Scale (Katz & Lyerly, 1963), MPAI-4 = Mayo Portland Adaptability Inventory (Malec & Lezak, 2003), LSS = Leisure Satisfaction Scale (Ragheb & Griffith, 1982), SIP = Sickness Impact Profile (Bergner, Bobbitt, Carter, & Gilson, 1981), QCIQ and QCOG = The Quality of Community Integration Questionnaire and satisfaction with cognitive functioning.
(Cicerone, Mott, Azulay, & Friel, 2004), PQOL = Perceived Quality of Life Scale (Patrick, Danis, Southerland, & Hong, 1988), QoL measure = a self-rated QoL measure (Hadorn, Sorenson, & Holte, 1995), EQ-SD = EuroQoL (including health visual analogue scale; Dolan, 1997), WHOQOL-BREF = The World Health Organisation Quality of Life Scale Abbreviated (World Health Organisation, 1996), CIM = The Community Integration Measures (McColl, Davies, Carlson, Johnston, & Minnes, 2001), CHART-SF = The Craig Handicap Evaluation and Reporting Technique - Short Form (Craig Hospital Research Department, 1999), SAI = The Social Activity Interview (Struchen et al., 2011).
Characteristics of Included Studies

The included studies recruited a total of 522 participants with ABI (range 3 – 96) and 112 significant others. The most frequently reported aetiology was TBI (studies 2, 3, 4, 5, 6, 9, & 12). Studies reporting an ABI population (1, 7, 8, 10, & 11) included TBI, stroke, tumour, haemorrhage, infection, hypoxia, epilepsy, and sinus thrombosis aetiologies. All participants were adults with a mean age range of 25 to 49.5 years.

All studies utilised interventions that promoted engagement in activities with others. The delivery of the interventions included groups (studies 1, 2, 4, 5, 6, 7, 8, 10, & 11), one-to-one (study 3), and through peer-mentors (studies 9 & 12). Interventions varied in duration and ranged from one to 78 weeks (19.5 months).

All included studies measured outcomes relating to social participation, QoL and/or HRQoL. The review’s target outcomes were not always the primary outcomes of the included studies. Measures of social participation included outcomes related to community integration, social inclusion, social activity, and leisure satisfaction. The most frequently used measure of participation was the CIQ (seven of 12). QoL and HRQoL measures explored psychological well-being, social relationships, physical abilities, life participation, health status, and life satisfaction.

Of the 12 studies, four (2, 5, 9, & 12) used RCT designs. One study (study 4) used a non-RCT design. Six studies (1, 6, 7, 8, 10, & 11) employed prospective designs with pre and post-intervention measures, one of which used a waiting list control period (study 8). Study 3 utilised a mixed-method design.

One study (5) was deemed to have high methodological quality and was at lower risk of bias due to appropriate random allocation of participants, blinding of outcome assessors, and consideration of confounders at baseline. A moderate quality
rating was given to eight studies (1, 2, 4, 7, 8, 9, 11, & 12). Three studies (3, 6, & 10) were deemed to have a low overall quality and a higher risk of bias.

**Critical Appraisal: Intervention Method and Efficacy on Target Outcomes**

Intervention methods included peer-mentoring (studies 9 and 12), community integration (studies 7 and 8), leisure activities (studies 3, 6, and 10), outpatient holistic neuropsychological rehabilitation (studies 1 and 11), intensive holistic cognitive rehabilitation (studies 4 and 5), and health-promotion (study 2). Seven of the 12 studies (4, 5, 6, 7, 8, 9, and 10) found statistically significant differences on at least one target outcome post-intervention. Four of the 12 found statistically significant improvements on both target outcomes from pre to post-intervention (studies 5, 7, 8, and 10).

**Peer-mentoring.** Studies 9 and 12 utilised peer-mentoring interventions to support social participation and QoL for participants with TBI. A strength of these studies was the use of an RCT design to determine intervention efficacy against a control group. Study 9 identified a significant difference in HRQoL between mentored participants and the control group at 12-months post-intervention. Mentor discussions focused on three areas: (1) emotional well-being; (2) post-TBI QoL; and (3) community integration. Mentees indicated greater physical functioning and emotional coping than controls, and qualitatively reported greater ability to cope and reduced loneliness. However, a significant limitation of study 9 was the omission of pre and post-intervention data, and a time-by-treatment interaction was not investigated to determine intervention efficacy. Thus, identified differences may have already existed between groups pre-intervention. No significant differences in social participation were identified between groups 12-months post-intervention. The intervention dosage (i.e.,
intensity and focus) was reported to be low, with an average of five mentee-mentor sessions and the majority conducted via telephone.

Study 12 did not show efficacy on outcomes of social participation. Reduced intervention dosage was also a limitation of the study, limiting identified efficacy. Half of mentees in study 12 did not achieve the minimum requirement of two in-person mentor sessions per month. Improvements in QoL were not identified post-intervention and mentees reported significantly greater levels of depression. This was attributed to increased self-awareness through mentorship. A similar unintended consequence of mentoring was noted by study 9 in mentored significant others.

**Community integration.** Study 7 and 8 found the Brain Injury Programme (BIP) to be efficacious on outcomes of social participation, QoL, and HRQoL for adults with ABI, with medium and large ES. The BIP was well described in studies and the intervention ‘dosage’ per-person was provided. The ES on target outcomes post-intervention in study 7 were substantial given the small sample size, and the effects were maintained at follow-up. Participants also reported improvements relating to employment and living situation at follow-up, suggesting intervention generalisability. A control sample was not used as a comparator and the validity of intervention efficacy could not be fully determined.

Study 8 assessed the BIP using a larger sample size and a 3-month waiting list control period pre-intervention to account for possible spontaneous recovery bias during the intervention period. Significant improvements on target outcomes were identified from pre to post-intervention, and across time; with medium and large ES. Improvements were maintained at follow-up. A lack of control group remained a limitation of the study.
Leisure activities. Studies 3, 6, and 10 used leisure-based interventions to support participants to engage in leisure and group-based activities within their communities. All three studies were deemed to be of low quality and at a higher risk of bias. A limitation was the use of small, volunteer (studies 6 and 10) and opportunity (study 3) samples, increasing sample bias. Study 6 reported significant improvements with large ES on a measure of social participation post-intervention in one participant sub-groups (sustained activity). As participants were clustered into groups according to levels of sustained activity post-intervention, the reported effect is likely to have been influenced by participant motivation. Information on intervention ‘dosage’, methods, and content was not reported.

Study 10 identified significant improvements on both target outcomes across time for participants with ABI. Participants qualitatively reported benefits from engagement in the residential programme, including increased confidence to build friendships. Although promising, intervention efficacy was interpreted with caution due to the small volunteer sample and lack of control group.

Outpatient holistic neuropsychological rehabilitation. Studies 1 and 11 conducted a weekly outpatient intervention. Though both studies identified significant improvements in individual participant goals, efficacy for the interventions on measures of social participation and QoL was not supported.

Intensive holistic cognitive rehabilitation. Studies 4 and 5 assessed the efficacy of their intensive cognitive rehabilitation programme (ICRP) against a control group receiving standard multidisciplinary neurorehabilitation. A strength of these studies was the inclusion of a control group for comparison of ICRP efficacy. The studies used validated outcome measures and information relating to intervention methods, content, and ‘dosage’ was provided.
Study 4 identified greater improvements in social participation for the ICRP group (with large ES) post-intervention when compared to controls, but not HRQoL; with controls reporting greater satisfaction with functioning. There was a significant difference between groups pre-intervention (time post-TBI) due to lack of randomisation. Consequently, the authors suggested that ICRP participants were less likely to report greater satisfaction due to greater awareness of difficulties than controls. This bias complicated the interpretation of intervention efficacy. Through a rigorous RCT design, study 5 provided high-quality evidence for the efficacy of the ICRP when compared to the control group. Participants in the ICRP made greater significant improvements on outcomes of social participation (medium ES) and QoL (small ES) than controls. These were maintained at 6-month follow-up. The comprehensiveness and complexity of both interventions was suggested by the authors to have affected the accuracy of ICRP efficacy (enhanced treatment as usual).

Health promotion. Study 2 was the only included study to focus on health promotion. The adapted health and wellness group programme did not show efficacy on secondary outcomes relating to participation and QoL for individuals with TBI. Authors recognised that the randomisation process failed to equate group differences pre-intervention.
Discussion

This review aimed to synthesise evidence for the efficacy of interventions that facilitated social participation on outcomes of social participation and QoL in adult survivors of ABI. A total of 12 studies, utilising a variety of intervention methods were included.

**Question One: Efficacy of Interventions on Target Outcomes**

Currently, there is limited evidence (four of 12 studies) to support the efficacy of social participatory interventions on outcomes of social participation and QoL. These studies varied in quality, duration, settings, and intervention method. On the basis of the results provided by the methodologically stronger studies (studies 5, 7, and 8) there is support for the efficacy of multifaceted interventions on both target outcomes in adults with ABI. A feature of these interventions was intensity (i.e., ‘dosage’, duration, and focus). Indeed, the need for neurorehabilitation interventions to be intensive to support efficacy has previously been recognised (Tate et al., 2015). Though intensive, the sample bias in study 10 resulted in caution when interpreting efficacy. Additional studies reporting improvements in social participation post-intervention (4 and 6) were also interpreted cautiously due to risk of bias.

In support of intensity, studies 1 and 11 reported the detriment of their low-intensity interventions on outcomes of social participation and QoL when compared to efficacy of high-intensity interventions (Cicerone et al., 2008). Similarly, studies 9 and 12 recognised the limitations of reduced face-to-face contact and joint outings in their peer-mentoring interventions. The challenging life dynamics (Eames & Wood, 2003), level of motivation, and mobility (Douglas et al., 2006) for individuals post-ABI are recognised barriers for treatment participation that merit further consideration in future
intervention design, alongside wider cultural factors such as social economic status (Ashida et al., 2016) and ethnicity (Tam & Neysmith, 2006) of participants.

The qualitative insights provided by other studies suggested that involvement with others allowed participants to feel less lonely, try new things, and build confidence to develop friendships (studies 6, 9, 10, and 12). Social isolation and loss of friendship is well recognised post-ABI (Bombardier et al., 2010; Flynn et al., 2018), and social-participatory interventions appear to be subjectively beneficial for people with ABI.

**Question Two: Does Increased Social Participation Result in Improved QoL?**

The findings from studies 5, 7, 8, and 10 identified improvements on both target outcomes post-intervention, which were maintained at follow-up. However, the suggestion that increased meaningful social participation improves QoL (McLean et al., 2014) was not directly tested in these studies, possibly because this was not the primary objective of all reviewed interventions. Though this review question cannot be answered by the included studies, it does suggest direction for future research exploring the possible causal relationship. The findings from the stronger studies (5, 7, and 8) provide an opportunity for secondary data-analysis to explore if post-intervention social participation was a predictor for improvements in QoL at follow-up.

The use of subjective measures of social participation may be more appropriate to evaluate causation than objective measures, because these have shown stronger relationships with measures of QoL (McLean et al., 2014). However, the use of subjective measures for both target outcomes requires careful attention as they may assess the same, or overlapping, constructs; particularly the social domains of QoL. Consequently, determining a causal relationship may be difficult. Future intervention studies exploring causality may benefit from multiple data collections in a sufficient
sample size with appropriate measures, and focus on content that is congruent with participant values and goals (Cicerone et al., 2004; Eriksson et al., 2009).

**Question Three: Psychological Processes that Support Social Participation and QoL**

Study 4 proposed that perceived self-efficacy supported improvements in social participation and HRQoL. Findings indicated that higher participation was significantly associated with improved satisfaction with cognitive functioning following the ICRP intervention. Indeed, perceived disability and reduced functioning have previously been associated with reduced participation and QoL (Cubis et al., 2018; Gerber et al., 2016). Study 4 suggested that community functioning (objective) and satisfaction with functioning (subjective) were separate aspects of participant experience that must be considered (Cicerone et al., 2004). This differentiation has been recognised in the wider literature (McLean et al., 2014; Piškur et al., 2014). Furthermore, they suggested objective measures of functional outcomes and QoL to be moderated by the subjective meaning and value assigned by participants, facilitated by perceived self-efficacy and satisfaction with performance.

Self-efficacy has previously been defined as an individual’s beliefs and judgements around perceived abilities and competency to complete a specific task, or attain a level of achievement (Dijkers, 1997). Additional modules to support self-efficacy were added to the ICRP in study 5. Participants significantly improved on measures of social participation and QoL when compared to controls from pre to post-intervention. This offered support to the suggestion made by study 4. QoL may improve alongside social participation if participants feel confident and competent to engage in activities with others. Thus, enhancing subjective experiences (Cicerone et al., 2008).
Study 12 provided insights into the negative emotional consequences of increased awareness through peer-mentoring. Reduced awareness is common post-ABI (Fleming et al., 1996) and may be protective for HRQoL (Cicerone et al., 2004). Increased awareness through peer-mentoring may negatively affect mood, and subsequently QoL. The association between depression and HRQoL post-ABI has previously been recognised (Goverover et al., 2017). Supporting participants in this regard may be pertinent and clinically beneficial.

**Strengths and Limitations of Current Review**

To current knowledge, this is the first systematic review of the efficacy of interventions that facilitate social participation within an exclusively ABI population. ABI is a leading cause of disability (Jolliffe et al., 2018) and a number of survivors are admitted for rehabilitation. Social participation and QoL are key outcomes within rehabilitation (BSRM & RCP, 2003), and the synthesis of the available evidence to improve such outcomes may provide helpful insights for rehabilitation professionals and their clients.

Lee et al. (2019) recommended that interventions should focus on community and social activities beyond leisure. The definition of social participation used in this review (Levasseur et al., 2010) allowed for the inclusion of multiple intervention methods that facilitated activities with others, rather than one similar concept (i.e., community integration or leisure). This allowed for comparisons of efficacy to be made across several evidence-based interventions.

There are limitations of grouping studies together to discuss evidence relating to overall social participation, a term that appeared to be scarcely used within the reviewed studies, yet frequently used in the rehabilitation literature (Goverover et al., 2017; McLean et al., 2014). Consequently, included studies may not have explicitly
aimed to improve social participation, as defined in this review. Similarly, the inclusion of a variety of target outcome measures leaves caution around the validity of the review’s interpretation of reported improvements relating to social participation. Overall improvements on the social domain of the CIQ may have related to elements of community integration without others, such as shopping or individual leisure activities (Willer et al., 1993). Moreover, as studies 7 and 8 only reported overall CIQ scores, and not the separate domains, inferred improvements in social participation may not have been supported. Reported improvements may have related to engaging in more home or productive activities such as employment, a focus of the BIP.

Finally, whilst the chosen appraisal checklist allowed for wider considerations for intervention quality with ABI populations, it does not ask if pre and post-intervention data was collected. Consequently, study 9 may have received a higher quality rating than what other assessment tools may have provided.

**Clinical and Theoretical Implications**

**Rehabilitation.** The results from this review suggest the need for rehabilitation of social participation to be intensive (studies 5, 7, and 8) and meaningful (studies 4 and 5) for individuals with ABI to support improvements in social participation and QoL. Individual goal setting that accounts for personal values is fundamental in rehabilitation (Wilson, 2017). The most suitable intervention method to support outcomes remains unclear due to limited evidence, however, future interventions may benefit from facilitating meaningful activities with others and providing skills to support confidence and continued engagement. Although cautiously interpreted, this might comprise leisure activities (study 10), social skills (studies 7, 8, and 10), modules for self-efficacy (study 5), and ongoing peer-mentoring (studies 9 and 12).
**Outcome measures.** The variety of included outcome measures relating to social participation highlights the need for the development and validation of a more specific measure in future studies. The CIQ is frequently used in intervention studies with ABI populations, however, only a limited number of items relate to friendship, leisure, and social activity. To work towards a measure of objective and subjective experiences of social participation (Levasseur et al., 2010) for those with ABI, a new measure could explore the number of social activities and the value the person perceives from it (Cicerone et al., 2004). Such a measure, the Social Activity Interview (SAI), was developed by Struchen et al. (2011) and included items around social network size, perceived importance of social activities, and satisfaction with social life.

**Self-efficacy.** Although limited, there is some evidence to suggest that perceived self-efficacy may support improvements with social participation and QoL post-ABI (studies 4 and 5). The taxonomy proposed by Levasseur et al. (2010) could provide a useful guide and goal-setting framework for rehabilitation professionals to support clients to build confidence and perceived competence to engage meaningfully in social activities with others that fall within the more active levels (four, five, and six).

**Recommendations for Future Research**

Recommendations are presented in Table 4.

Table 4

*Recommendations for Future Research*

- Future intervention studies investigating efficacy on outcomes of social participation and QoL might benefit from focusing on content and activities that are meaningful for participants, and providing skills to promote continued engagement and satisfaction with performance (multifaceted).
To explore the causal relationship between increased social participation and improved QoL, future studies may want to consider using suitable outcome measures and collecting data across several time points post-intervention.

To develop and validate a specific social participation measure for the ABI population that includes objective and subjective sub-scales (i.e., the SAI).

Future intervention studies assessing intervention efficacy would benefit from using RCT designs with sufficient sample size.

Future interventions should be delivered intensively and over a number of months, consistent with previous recommendations (Tate et al., 2015).

Conclusion

Currently, there is limited evidence for the efficacy of interventions that facilitate social participation on outcomes of social participation and QoL for adults with ABI. The varying objectives, quality, and potential bias of the 12 included studies limits the conclusions that can be drawn. Nevertheless, social participatory interventions appear to have objective and subjective benefits for adults post-ABI. Appropriate intervention methods (delivery and focus) to support outcomes is uncertain from the limited literature included in this review. However, the four studies that identified efficacy on both target outcomes used multifaceted and intensive interventions. The suggestion that increased meaningful social participation improved QoL was not tested in the included studies. Future intervention studies exploring this relationship would benefit from rigorous methodology and the use of carefully chosen subjective measures. Rehabilitation of social participation to support social participation and QoL post-ABI may benefit from supporting participants to develop the skills and self-belief needed to actively participate in social activities that are important to them, however, further evidence is needed.
References


## Appendices

### Appendix A: Quality Appraisal Scores for Included Studies

| Study                     | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | Total |
|---------------------------|---|---|---|---|---|---|---|---|---|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|------|
| Brands et al. (2013)      | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 1 | 0 | 1   | 1   | 1   | 1   | 0   | 1   | 0   | 0   | 1   | 0   | 0   | 0   | 0   | 0   | 0   | 0   | 17/27 |
| Brenner et al. (2012)     | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 0 | 0   | 1   | 1   | 1   | 0   | 0   | 0   | 0   | 1   | 1   | 1   | 0   | 1   | 1   | 1   | 20/27 |
| Carbonneau et al. (2011)  | 1 | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 1   | 1   | 0   | 1   | 0   | 0   | 0   | 0   | 0   | 1   | 0   | 0   | 1   | 0   | 0   | 1   | 11/27 |
| Cicerone et al. (2004)    | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 1 | 0   | 0   | 0   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 0   | 1   | 1   | 0   | 1   | 0   | 1   | 19/27 |
| Cicerone et al. (2008)    | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 0   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 0   | 1   | 1   | 1   | 1   | 1   | 25/27 |
| Douglas et al. (2006)     | 1 | 1 | 0 | 1 | 0 | 1 | 1 | 1 | 0   | 1   | 0   | 0   | 0   | 1   | 1   | 1   | 1   | 0   | 1   | 0   | 0   | 0   | 0   | 0   | 0   | 0   | 0   | 12/27 |
| Geurtsen et al. (2008)    | 1 | 1 | 0 | 1 | 0 | 1 | 1 | 1 | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 0   | 1   | 0   | 1   | 0   | 0   | 1   | 1   | 0   | 1   | 18/27 |
| Geurtsen et al. (2011)    | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 1 | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 0   | 1   | 0   | 0   | 0   | 1   | 0   | 0   | 1   | 19/27 |
| Hanks et al. (2011)       | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 1 | 0   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 0   | 1   | 0   | 0   | 0   | 1   | 0   | 0   | 20/27 |
| Mitchell et al. (2010)    | 1 | 1 | 0 | 0 | 0 | 1 | 1 | 0 | 0   | 1   | 1   | 0   | 1   | 1   | 1   | 1   | 1   | 0   | 0   | 0   | 1   | 0   | 0   | 1   | 13/27 |
| Rasquin et al. (2010)     | 1 | 1 | 0 | 1 | 0 | 1 | 1 | 0 | 0   | 1   | 1   | 0   | 1   | 1   | 1   | 1   | 1   | 0   | 1   | 0   | 0   | 1   | 0   | 0   | 0   | 15/27 |
| Struchen et al. (2011) | 1 0 0 1 0 1 1 1 0 0 0 0 1 1 1 1 1 0 1 0 1 1 1 1 1 0 1 17/27 |
Appendix B: Journal of the International Neuropsychological Society Publication

Guidelines

https://www.cambridge.org/core/journals/journal-of-the-international-neuropsychological-society/information/instructions-contributors
Improving Peer Relationships for Adolescents with Acquired Brain Injury: 
Using Intervention Mapping as a Framework to Identify Targets for Intervention

Trainee Name: Scott Ankrett

Primary Research Supervisor: Professor Anna Adlam
Associate Professor/Clinical Psychologist
Co-Director for Postgraduate Research for Psychology
University of Exeter

Secondary Research Supervisor: Dr Janet Smithson
Senior Lecturer in Psychology
University of Exeter

Target Journal: Neuropsychological Rehabilitation

Word Count: 9636 words (excluding abstract; including tables and figures)

Submitted in partial fulfilment of requirements for the Doctorate Degree in Clinical Psychology, University of Exeter
Abstract

**Background and aims.** Adolescence is a time for significant social development, facilitated by successful peer relationships. Those with reduced social skills are at risk of being rejected or victimised by peers, and can face significant emotional ramifications and implications for quality of life (QoL). Peer relationships for adolescents with acquired brain injury (ABI) have been largely under-recognised in the paediatric neuropsychology literature. Previous interventions aiming to improve social skills (needed for peer relationships) in this population have shown inconsistent efficacy and the targets for intervention are unclear. The intervention mapping (IM) framework offers a systematic and iterative protocol for the co-production of interventions through engagement with key stakeholders. This consists of six steps for intervention design, implementation, and evaluation: (1) creating a logic model of the target problem; (2) stating programme objectives; (3) programme design; (4) programme production; (5) implementation plan; and (6) evaluation plan.

This study aimed to: (a) develop a collaborative understanding of peer relationship difficulties for adolescents with ABI; and (b) seek the views of adolescents and other key stakeholders on what might be required to improve peer relationships post-ABI, and what intervention the goals might be. Qualitative methodology was used to support these aims. The findings of this study can inform the co-development of a meaningful intervention to support peer relationships and QoL in adolescents with ABI using the IM protocol in future research.

**Method.** Consistent with IM protocol, a planning group comprising four ABI clinical-researchers provided consultation at each stage of the study. First, the planning group completed a survey to develop an initial logic model. This is a framework for understanding peer relationship difficulties following ABI, the
IMPROVING PEER RELATIONSHIPS FOR ADOLESCENTS WITH ABI
determinants (or contributing factors) for these, and the long-term impact on QoL for adolescents. Focus groups and semi-structured interviews were then conducted with four stakeholder groups to develop an in-depth understanding of peer relationship difficulties post-ABI, the impact of these, and the determinants contributing to such difficulties, and to further develop the initial logic model: (1) adolescents with ABI (n=4); (2) parents of adolescents with ABI (n=7); (3) adults who sustained an ABI in adolescence (n=2); and (4) specialist practitioners (n=3). Perspectives were also obtained from stakeholders concerning what might need to change to support peer relationships post-ABI and what the targets for intervention might be. Qualitative data from focus groups and interviews were analysed using thematic analysis.

**Results.** The analysis of stakeholder conversations yielded 11 themes, grouped into two domains: (1) understanding peer relationship difficulties (e.g., dropped and excluded, a need to belong, restricted independence); and (2) supporting peer relationships (e.g., building understanding, meaningful social connection). The logic model underwent six iterations following planning group and stakeholder feedback. This was provided by stakeholders in the focus groups and interviews, and by planning group members and stakeholders through further member-checking procedures following the analysis.

**Conclusions.** Adolescents with ABI were reported to experience difficulties with peer relationships. At an important time for social development, peer rejection can increase feelings of isolation, loneliness, shame, and hopelessness. This can have further implications for mental health, peer relationships, and QoL. The individual, psychological, behavioural, and environmental determinants for peer relationship difficulties are broad. A meaningful intervention would need to be multifaceted attempting to build understanding in others, facilitate meaningful social opportunities,
offer early support post-injury, and help manage psychological wellbeing. A primary focus would be to empower adolescents post-ABI. The presented logic model provides a robust understanding of peer relationship difficulties for adolescents with ABI that can be used to guide intervention development in future research.
Introduction

Adolescence represents a time for significant social development (Blakemore, 2008), marking the growth of independence and social identity through peer relationships, group membership, and belonging (Ownsworth, 2014; Tajfel, 1978). Subsequently, adolescents may be more sensitive to peer acceptance and rejection (Steinberg & Morris, 2001).

Successful peer relationships can be protective for mental health and resilience (van Harmelen et al., 2017). Conversely, difficulties with peers can have significant social and emotional ramifications (Anderson et al., 2013), including loneliness, anxiety, and depression (Parker & Asher, 1987). Those with reduced social skills, physical disabilities, and difficulties with mood are at higher risk of peer rejection (King, MacDonald, & Chambers, 2010; Olweus, 1993; Vannatta, Gartstein, Zeller, & Noll, 2009).

Acquired brain injury (ABI) is a leading cause of death and disability worldwide (World Health Organisation, 2006), with an annual incidence rate in England of 400 per 100,000 for children younger than 15 years (Hospital Episode Statistics, 2013). ABI refers to several injury mechanisms that disrupt brain integrity after birth, and can result in persistent physical, cognitive, emotional, social, and behavioural impairments (Anderson, Brown, Newitt, & Hoile, 2011). Common causes of ABI include traumatic brain injury (TBI), caused by falls, assaults, and road traffic accidents; and non-traumatic injuries, caused by stroke, infection, hypoxia, and tumours (Barber et al., 2018).

Children and adolescents with ABI may have difficulties with fatigue, attention (Catroppa, Anderson, Godfrey, & Rosenfeld, 2011), executive functioning (Wade et al., 2010), memory (Mandalis, Kinsella, Ong, & Anderson, 2007), processing speed,
improving peer relationships for adolescents with ABI

intelligence (Anderson, Godfrey, Rosenfeld, & Catroppa, 2012), communication (Turkstra, Politis, & Forsyth, 2014), social functioning (Greenham et al., 2018), behaviour (Cole et al., 2008), and emotion regulation (Vasa et al., 2015). The often ‘hidden’ nature of these difficulties (Simpson, Simons, & McFadyen, 2002) can result in limited support and understanding from educational, social, and family environments (Keetley, Radford, & Manning, 2019). Consequently, children and adolescents with ABI may follow a different developmental trajectory to their peers and face secondary consequences for quality of life (QoL) including difficulties with identity, mood, and relationships; alongside future challenges with education, occupation, and criminal justice (Anderson, Brown, & Newitt, 2009; Arroyos-Jurado, Paulsen, Ehly, & Max, 2006; Sariaslan, Sharp, D’Onofrio, Larsson, & Fazel, 2016; Williams, 2012).

Research into the social outcomes of adolescents with ABI is expanding (Tousignant et al., 2018; Sirois et al., 2019), however, there is a scarcity of research exploring the intricacies of peer dynamics, which remain poorly understood.

To understand the determinants (or factors) that influence peer relationships following ABI, the underlying processes for adequate social functioning must be considered. The Socio-Cognitive Integration of Abilities Model (SOCIAL; Beauchamp & Anderson, 2010; Anderson & Beauchamp, 2012) offers a theoretical biopsychosocial framework to understand the development of the social skills needed to build and maintain peer relationships throughout childhood and adolescence (Figure 1). The model is supported by empirical evidence of social dysfunction (disorders that are social in nature) in three clinical populations; autism spectrum disorder, schizophrenia, and TBI.
Figure 1. A version of the SOCIAL model re-created with the original author’s permission (Beauchamp & Anderson, 2010).

The SOCIAL model assumes that social skills develop in the context of typical brain maturation within a supportive family and social environment. The model outlines the mediators and cognitive determinants (or functions) that can shape and facilitate successful social skills. Difficulties with social skills are suggested to result from disruption in the development or function of these mediators and determinants (Table 1).
Table 1

Mediators and Cognitive Determinants Outlined by the SOCIAL Model

<table>
<thead>
<tr>
<th>Mediators and Cognitive Determinants</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal and external factors</td>
<td>Inclusion of genetics, temperament, personality, values, attributes. External factors relate to environment such as social economic status, social interactions, family environment, culture, and activities.</td>
</tr>
<tr>
<td>Brain development and integrity</td>
<td>The development of the social brain network and brain maturation.</td>
</tr>
<tr>
<td>Attention/ executive function</td>
<td>Sustaining attention to evaluate a situation and consider suitable actions with adequate processing speed. Ability to think flexibly and rationally to perform goal directed behaviour. Ability to self-monitor progress and inhibit responses.</td>
</tr>
<tr>
<td>Social cognition</td>
<td>Understanding social information through theory of mind, perspective taking, moral reasoning, and emotional recognition.</td>
</tr>
<tr>
<td>Communication</td>
<td>Utilisation of gestures, comprehension and production of language. Understanding of non-linguistic signals, such as volume, intonation, pitch (for sarcasm, and humour).</td>
</tr>
</tbody>
</table>

In the model, social skills encompass three social constructs. Social competence refers to the child’s coordination of multiple sensory processes and resources in interactions to meet social demands (Anderson et al., 2013; Yeates et al., 2007), allowing for the development and maintenance of peer relationships over time (Iarocci, Yager, & Elfers, 2007). Social adjustment is defined as the degree to which children can adapt their social behaviour to perform competently (Crick & Dodge, 1994). Finally, social participation encompasses the number and quality of valued activities a child engages in with others in social environments (Fougeyrollas et al., 1998; Wade et al., 2018).

Neural correlates associated with the ‘social brain’ include the anterior cingulate, superior temporal, and ventromedial, orbital, and dorsolateral prefrontal
cortex (Blakemore, 2008; Garrigan, Adlam, & Langdon, 2016). These areas undergo significant development throughout adolescence and are the most vulnerable in brain injury, particularly TBI (Yeates et al., 2007).

Children and adolescents with TBI have been reported to have difficulties with theory of mind (Turkstra, Dixon, & Baker, 2004), empathy (Dennis et al., 2013), and social participation, competence, and adjustment (Anderson et al., 2013; Sirois et al., 2019; Yeates et al., 2014). Yeates et al. (2012) found that children with TBI (8 to 13 years) reported higher peer rejection-victimisation than those with orthopaedic injuries, and were less likely to have mutual friendships. The psychological difficulties associated with peer rejection may be protected against if children and adolescents with ABI have at least one friend (Heverly-Fitt et al., 2014).

There are a limited number of intervention studies aiming to improve social skills in adolescents with ABI. Wade et al. (2018) piloted an app-based peer coaching intervention to help adolescents (14 to 22 years) attain social participation goals. Post-intervention, participants reported higher levels of confidence in their social participation, however, did not rate the programme as very useful overall.

Barrera et al. (2018) conducted an RCT to explore the efficacy of a social skills intervention on outcomes of social competence and QoL in young brain tumour survivors (8 to 16 years). This was an eight week group-based intervention and included topics such as friendship making, managing bullying, conflict resolution, and empathy. Those in the experimental group showed significant improvements in self-rated empathy scores when compared to control participants. However, no intervention effect was observed in parent and teaching ratings of empathy, or on outcomes of QoL.
In a systematic review conducted with a non-ABI population, Andrews, Falkmer, and Girdler (2015) found strong evidence for improving community participation (including peer relationships), self-esteem, and QoL in child and adolescents with neurodevelopmental conditions. The authors recommended that participants should complete interventions with typically developing peers, and that future interventions should facilitate friendships alongside recreational participation and work on both individual (social skills) and environmental (community support) factors to support participation.

In summary, research within paediatric neuropsychology is beginning to investigate the social skills needed for peer relationships post-ABI. Currently, targets for intervention remain unclear and intervention efficacy is inconsistent. Reviewed evidence for improving peer relationships has used non-ABI populations (Andrews et al., 2015). The additional difficulties associated with ABI, such as loss of identity (Ownsworth, 2014), understanding from others (Keetley et al., 2019), and ‘hidden’ difficulties (Simpson et al., 2002), and their impact on peer relationships remain largely unknown.

There is a rationale to work with stakeholders to understand the complexities of peer relationship difficulties for adolescents with ABI, the impact of these, and what might be needed to improve peer relationships. This ‘bottom up’ approach would allow for the co-development of a meaningful intervention to support peer relationships and QoL post-ABI, and can provide insights into the intervention priorities for stakeholders. Indeed, interpersonal relationships have previously been reported to be the highest priority for adolescents with TBI (Sirois, Boucher, & Lepage, 2014).

The Medical Research Council (MRC) recently published guidelines for the development of interventions to promote worthwhile effects (MRC, 2019). In this
process, existing evidence for intervention should be considered and relevant theories identified or developed. Furthermore, to promote meaningfulness and clarity around intervention aims, the development process can involve collaboration with experts, community members, and other key stakeholders to firstly understand the target problem for intervention and its determinants (Fernandez, Ruiter, Markham, & Kok, 2019; Kok et al., 2015).

In line with MRC guidelines, the intervention mapping (IM) framework (Bartholomew-Eldridge et al., 2016) offers a structured and iterative protocol that guides the design of health promotion interventions. This comprises six steps (Table A1; Appendix A) which provide a map for intervention design, supported by theoretical and empirical knowledge (O’Connor, Blewitt, Nolan, & Skouteris, 2018). Steps one to four focus on the development of the intervention. Step five centres on the implementation of the intervention, and step six evaluates the intervention and its implementation (Fernandez et al., 2019).

A logic model is developed in step one, providing a framework to describe and understand the target problem for intervention, its impact on QoL, and its determinants. An environmental approach is used to identify determinants at an individual, community, and social level. This process includes: (1) involving stakeholders; (2) searching empirical literature to identify determinants of behaviour; (3) identifying theories on determinants; and (4) conducting research to explore unanswered questions (Fernandez et al., 2019).

IM employs community-based participation and co-design of interventions through systematic engagement with stakeholders who will benefit from participation, such as service users and practitioners. Stakeholders are engaged in every step to promote equity in decision-making. This ensures that the intervention suits population
need and context (Fernandez et al., 2019). IM has previously been utilised for improving social networks for diabetes management in minority families (Vissenberg et al., 2017), and communication between hospital staff and disabled children (Gumm et al., 2017).

The efficacy of interventions to improve social participation and QoL in adults with ABI has been suggested to be supported by the meaning and value of the intervention attributed by participants (Ankrett, 2020). Qualitative methodology is well suited for the collection and exploration of stakeholder experiences of peer relationship difficulties for adolescents with ABI, and what they think is needed to improve them. This methodology can consider what is meaningful to stakeholders and explore the heterogeneity of experiences. These experiences can inform the gap within the paediatric neuropsychology literature, and provide insights for the development of a logic model (step one) for the future design of a meaningful intervention using the IM protocol. Findings may also provide further insights into the determinants for social skill difficulties outlined by the SOCIAL model. The development of relevant theories for intervention design is recommended by the MRC (2019).

**Aims and Research Questions**

This study aimed to: (a) develop a collaborative understanding of peer relationships for adolescents with ABI; and (b) to seek the views of adolescents and other key stakeholders on what might be needed to improve them, and what the intervention goals might be. Due to financial and time limitations of the Doctorate in Clinical Psychology (DClinPsy), this study’s qualitative methodology was informed by
the IM protocol, rather than prescriptive to it. Accordingly, focus group and interview schedules were developed with guidance from IM and the SOCIAL model.

For this study, peer relationships comprises relationships of varying quality (Heverly-Fitt et al., 2014), including negative (victimisation), neutral, and positive (friendships). Given the potentially ambiguous meaning of peer relationships for stakeholders, ‘friendships’ was encouraged for accessibility. Stakeholders describes participant groups that would benefit from the intervention (i.e., service users and providers). The following research questions (RQs) were proposed:

1) What are peer relationships like for adolescents with ABI, as described by stakeholders?
2) What do stakeholders believe the key determinants for peer relationship difficulties in adolescence to be following ABI?
3) What do stakeholders think needs to change to improve peer relationships for adolescents with ABI?
4) What do stakeholders think the intervention goals should be?

Methodology

Design

Qualitative methodology was employed utilising both focus groups and interviews. Thematic analysis (TA; Braun & Clarke, 2006; 2013) was the chosen method of data analysis as the study endeavoured to identify commonalities within stakeholder experiences and perspectives. Through TA, the researcher systematically identifies the salient themes or patterns of meaning that emerge from data items, alongside researcher reflexivity and judgement, which are then compared across the
data set. Themes are not ‘discovered’ but actively crafted to capture something important within the data that is relevant to the RQs (Braun & Clarke, 2006; 2016; 2019; Joffe, 2012).

Though the methodology seeks to understand the experiences of the adolescent ABI population, there is limited research into the topic area, and the depth, exploration, and interpretation of individual meaning was not required at this stage. Accordingly, TA was chosen over interpretative phenomenological analysis (Smith, Flowers & Larkin, 2009).

Participants

Planning group. In line with IM protocol, a planning group was established comprising four clinical-researchers within the field of neuropsychology who provided consultation at various stages of the study. Members were contacted individually and invited to participate.

Stakeholder groups. Purposive sampling was used to recruit stakeholder participants who had experience of peer relationships for adolescents with ABI. Four stakeholder groups were invited to participate: (1) adolescents with ABI (12-17 years); (2) parents of adolescents with ABI; (3) adults who sustained an ABI in adolescence; and (4) practitioners working with adolescents with ABI. Both focus groups and interviews were employed due to time restrictions and the difficulties encountered when recruiting this population. Interviews allowed for increased breadth of recruitment.

Recruitment strategy. The study was advertised by charity organisations using a recruitment poster which was shared on social media. Potential stakeholders were asked to contact the researcher via email or through the study’s webpage. A consent to contact form (Appendix B), participant information sheet (Appendices C to
H), and consent to participate form (Appendix I) were then sent for completion. A total of 27 potential stakeholders expressed interest in the study, of which 16 consented to participate (Tables 2, 3, & 4). To protect confidentiality, all identifiable information has been removed and all names used are pseudonyms.

Table 2

**Parent and Adolescent Stakeholders**

<table>
<thead>
<tr>
<th>Parent</th>
<th>Adolescent</th>
<th>Adolescent Age (years)</th>
<th>Age at Injury</th>
<th>Type of ABI</th>
<th>Data Collection Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Harriet Martin</td>
<td>Jessica</td>
<td>13</td>
<td>&lt;1 month</td>
<td>Stroke</td>
<td>Focus group</td>
</tr>
<tr>
<td>Charlotte</td>
<td>Sarah</td>
<td>13</td>
<td>4 years</td>
<td>Infection</td>
<td>Focus group</td>
</tr>
<tr>
<td>Carol</td>
<td>Beth</td>
<td>13</td>
<td>10 years</td>
<td>TBI</td>
<td>Focus group</td>
</tr>
<tr>
<td>Lucy</td>
<td>Luke</td>
<td>13</td>
<td>8 years</td>
<td>Haemorrhage</td>
<td>Joint interview</td>
</tr>
<tr>
<td>Kelly</td>
<td>Did not participate</td>
<td>14</td>
<td>12 years</td>
<td>TBI</td>
<td>Interview</td>
</tr>
<tr>
<td>Shirley</td>
<td>Did not participate</td>
<td>15</td>
<td>12 years</td>
<td>TBI</td>
<td>Interview</td>
</tr>
</tbody>
</table>

Table 3

**Adults with ABI Stakeholders**

<table>
<thead>
<tr>
<th>Adult with ABI</th>
<th>Age (years)</th>
<th>Age at Injury (years)</th>
<th>Type of ABI</th>
<th>Data Collection Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Louise</td>
<td>27</td>
<td>13</td>
<td>Stroke</td>
<td>Interview</td>
</tr>
<tr>
<td>Ben</td>
<td>41</td>
<td>16</td>
<td>TBI</td>
<td>Interview</td>
</tr>
</tbody>
</table>
Table 4

Practitioner Stakeholders

<table>
<thead>
<tr>
<th>Practitioner</th>
<th>Occupation</th>
<th>Years of ABI experience</th>
<th>Data Collection Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hannah</td>
<td>ABI Co-ordinator</td>
<td>4.5 years</td>
<td>Interview</td>
</tr>
<tr>
<td>Ella</td>
<td>Educational Psychologist</td>
<td>&gt;5 years</td>
<td>Interview</td>
</tr>
<tr>
<td>Jackie</td>
<td>Occupational Therapist</td>
<td>&gt;17 years</td>
<td>Interview</td>
</tr>
</tbody>
</table>

Ethical Considerations

Ethical approval was granted by the School of Psychology Research Committee at the University of Exeter (Appendix J). Contact was made with potential stakeholder participants upon completion of consent to contact forms. Stakeholders were required to read and sign a consent form prior to their participation. Confidentiality and anonymity procedures were reiterated within the focus groups and interviews. Stakeholders were informed when confidentiality may be broken in the interest of safety.

Procedure and Data Collection

Stage one: Planning group survey. Planning group members were sent a survey to complete comprising open-ended questions seeking perspectives in line with the RQs (Appendix K). Their responses were analysed separately to inform the initial development of the logic model of peer relationship difficulties (Appendix L) for stakeholder feedback. The logic model was created using the multifactorial precede approach. Here, the target problem for intervention, and its impact upon QoL, is understood to be influenced by individual and environmental determinants. In contrast to the traditional use of logic models (i.e., input and output), the logic model used by
IM provides a visual representation of possible influential determinants for the target problem, and the relationships between them. These derive from stakeholder experiences and perspectives, and are used to identify meaningful targets for intervention.

**Stage two: Stakeholder focus groups.** Two focus groups were held at the University of Exeter. Parents and adolescents with ABI participated in separate focus groups to promote homogeneity within each group. These were facilitated by two researchers who moderated group discussions around the topic areas, guided by a focus group schedule (Appendix M). The moderator role was maintained by facilitating group discussions and allowing each stakeholder to speak, rather than asking questions for a direct response (Braun & Clarke, 2013).

The topics for discussion included: (a) experiences of friendships for adolescents with ABI; (b) the difficulties associated with ABI and the impact of these on friendships; (c) educational, social, and community understanding of ABI; (d) psychological changes following ABI and the impact on friendships; (e) behavioural changes following ABI; (f) feedback on the planning group logic model of peer relationship difficulties; (g) what change is needed to improve peer relationships; and (h) perspectives on intervention design, methods, and goals. Additional prompts were included to probe for further discussion, if required. Focus groups lasted between 55 and 90 minutes.

The focus group schedule was piloted with four adolescents without ABI to explore the clarity and meaningfulness of the questions, and to observe how adolescents responded. This supported the amendment of the schedule following feedback and researcher reflections (Appendix N). A question regarding the nature of ABI was removed. This was due to time limitations within the focus groups and the
relevance of the question to the outlined RQs. Additional amendments included the modification of terms (i.e., cognition to thinking, and peer relationships to friendships), and including examples of changes in thinking, mood, and behaviour to support topic discussions. Feedback from the pilot group suggested that the topic areas were understandable and suitable for adolescents.

**Stage two continued: Stakeholder interviews.** Interviews were completed face-to-face or via telephone or Skype, depending on stakeholder preference and location. These were completed by the researcher and guided by an amended version of the focus group schedule to protect consistency of topic conversations. Interviews lasted between 50 and 110 minutes. The schedule was piloted with a psychological practitioner prior to interviews.

**Transcription.** All focus groups and interviews were audio-recorded and transcribed verbatim. Transcription services were required for the three data items, the remaining seven items were transcribed by the researcher. The data set was listened to prior to transcription, supporting researcher immersion. Researcher reflections and notes were made during focus groups, interviews, and data immersion.

**Data Analysis**

It was recognised that the type of data collected from focus groups and interviews differed. Within focus groups, stakeholders engaged in interactional discussions and were able to build on the perspectives of others. This allowed for themes to be built upon by the group, as well as for conflict of opinion to be shared. In contrast, interviews provided a question and response conversation between the researcher and the stakeholder. Due to time limitations and limited focus group data, the data were analysed collectively. This allowed for similar emergent themes from the two data collection methods to be analysed and further explored.
Transcripts were read and re-read (Braun & Clarke, 2006; 2013). Initial thoughts and codes were recorded prior to the analysis. Data were analysed using NVivo qualitative software (QSR International) through inductive TA. This bottom-up approach allowed for codes and themes to emerge from what was communicated in the data. Although questions were guided by theory (IM and SOCIAL), apparent themes within the analysis were data driven and naturalistically occurring (Joffe, 2012). This allowed the researcher to be open to new emerging concepts within the field of research. To ensure fidelity to the methodology, data analysis was completed following detailed guidance (Table 5) outlined by Braun and Clarke (2006; 2013).

Table 5

Steps for Thematic Analysis (Braun & Clarke, 2006)

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Familiarisation with the data</td>
</tr>
<tr>
<td>2.</td>
<td>Generating initial codes</td>
</tr>
<tr>
<td>3.</td>
<td>Searching for themes</td>
</tr>
<tr>
<td>4.</td>
<td>Reviewing themes</td>
</tr>
<tr>
<td>5.</td>
<td>Naming and defining themes</td>
</tr>
<tr>
<td>6.</td>
<td>Producing the report</td>
</tr>
</tbody>
</table>
Transcripts were systematically and iteratively coded to identify prominent themes which were relevant to the RQs. A complete coding process was utilised and all relevant data were coded (Braun & Clarke, 2013). This was completed by systematically working through whole data items. Codes were then examined and reviewed to inform key themes. This was a continuous process until no new codes or themes were identified.

The data analysed from stakeholder focus groups and interviews informed the first revision of the logic model of peer relationship difficulties, consistent with IM methodology. In this process, the data from communicated stakeholder experiences (i.e., codes) were organised by the categories within the logic model (i.e., determinants, target problem, and impact on QoL). These categories were consistent with some of the pre-determined topics for discussion within the focus groups and interviews to support the outlined RQs. Organising the data according to the logic model categories provided a visual representation of the possible relationships between different parts of the data. This supported the development of themes to explore and interpret stakeholder experiences and perspectives, and how they connected to other themes.

**Credibility Checks**

To ensure that the analysis was trustworthy (Nowell, Norris, White, & Moules, 2017), a number of credibility checks were utilised. There was prolonged engagement with the data, including multiple rounds of analysis and several researcher transcriptions. A reflective journal was used to note down thoughts and assumptions, which were regularly reviewed during the research process to support researcher reflexivity. Analytic processes were discussed amongst peers and codes were
reviewed by two independent researchers through the sharing and critical discussion of two coded transcripts.

Member checking procedures were used to gain feedback on emerging themes to encourage trustworthiness of the interpretations (Braun & Clarke, 2013). A summary of themes (Appendix O) and the revised logic model of peer relationship difficulties were sent to stakeholders with a request to send their feedback to the researcher via email. Stakeholders were asked to comment and reflect on the ‘fit’ between the interpretations made and their discussed experiences, and the relevance of the logic model to their own experiences. These were also shared at a local ABI parent group for feedback on accessibility of information and relevance of the logic model of peer relationship difficulties. Feedback from the stakeholders that were able to provide feedback was enthusiastic, with parents reporting a feeling of relief that their child’s complex experiences had been captured, understood, and presented within the themes and logic model. No inappropriate interpretations were reported by stakeholders and the decision was made to cease member checking procedures.

**Epistemology and Researcher Reflexivity**

To promote credibility, qualitative research requires a disclosure from the researcher around epistemological perspective, experience, assumptions, and biases that may influence analytic conclusions (Braun & Clarke, 2013; Joffe, 2012; Yardley, 2000). This study adopted a social constructionist position. Here, it was assumed that knowledge about the experience of peer relationship difficulties for adolescents with ABI is subjective and socially constructed by those who experience these, as well as by those who aim to understand these difficulties (Schwandt, 2003). From this position, knowledge was accessed and constructed through personal accounts and perspectives, described through language, and influenced by social contexts (Braun
& Clarke, 2013). Thus, the knowledge and experiences of peer relationship difficulties described in this study were constructed by the stakeholders and the researcher throughout the research process.

Reflexivity refers to the researcher’s critical self-evaluation of their role and position within the research process and the creation of knowledge (Bradbury-Jones, 2007). Accordingly, it was important to consider the role of myself, the researcher, in the construction of data. Here, I acknowledge a number of factors that influenced the analysis. These became apparent through the research process, supported by discussions with my supervisors and peer researchers regarding my motivations for the research.

I am a white male completing a DClinPsy thesis study. My personal reasons for conducting this research came from a multitude of personal and clinical experiences. I have personal experiences of peer relationship difficulties in the context of a physical health condition. Furthermore, during adolescence, I witnessed a friend’s involvement in a road traffic accident, and subsequently had experience of being a supportive peer to an adolescent with an ABI. Finally, I have worked therapeutically with children, adolescents, adults, and families following ABI, many of whom experienced peer relationship difficulties post-injury. Accordingly, I hold multiple perspectives in relation to this study; as an adolescent with a health condition, as a friend of an adolescent with an ABI, and as a clinician. I have continuously considered these throughout the analysis, alongside the potential biases that are unique to me.

Discussions with peer researchers and research supervisors, alongside the keeping of a reflective journal, surfaced my assumptions when approaching the analysis. These included the assumptions that adolescents with ABI want to be treated as normal, peers find it difficult to understand ABI, and that successful peer
relationships are a priority for adolescents. I regularly reviewed my reflections during the analysis and discussed these with peer researchers and supervisors, and the impact of these upon the analysis. For example, it was important for me to be mindful of not just attending to stakeholder experiences that matched my own. Similarly, there was a need for me to notice and manage my own position within the interpretations of the themes, and to consider if research themes and ideas were supported by the data set. The awareness of my preconceptions helped me to manage my subjectivity in the research process through an awareness of my own position. This also supported me to attend openly to stakeholder experiences (Starks & Trinidad, 2007) and for new themes to emerge.

Results

Themes

The analysis from stakeholder accounts yielded 11 themes (Table 6) organised into two domains: (1) understanding peer relationships difficulties (RQ one and two); and (2) improving peer relationships (RQ three and four). Some presented data excerpts have been modified to remove superfluous information that did not affect the overall meaning (Braun & Clarke, 2013; Sandelowski, 1994b). For the purpose of the results, adolescents refers to those with ABI, and peers and friends is used for non-injured adolescents.
1.0 Understanding Peer Relationship Difficulties

The following themes capture stakeholder understandings of peer relationship difficulties for adolescents and the key determinants that contribute to these.

1.1 Dropped and Excluded

A pervasive sense of loss was portrayed by all stakeholders when describing friendships for adolescents. Parents and practitioners spoke particularly of the hardships adolescents experienced when attempting to maintain or re-integrate into friendship groups post-injury. Beth described these losses as feeling “dropped” by peers, depicting a powerful and emotive image associated with this loss.
“I have only got three friends because all the friends I seem to make keep on dropping me and being horrible.” (Beth, adolescent)

“I could deal with the fact that I had a brain injury. It was losing all the friends that I couldn’t deal with.” (Louise, adult)

A common determinant for this loss emerged where adolescents ‘drifted’ from friends whilst recovering from injury. Consequently, adolescents felt left behind by peers, as they continued in their social development outside of school.

“You’re sick all the time which means you’re off sick even more than you already were, so things go on and people develop friendships in school, and you’re missing it all. I had a best friend when I fell ill and I came back after not being sick and she’d made a new best friend.” (Louise, adult)

Parents and practitioners emphasised the rejection and exclusion that adolescents can experience from peers. This appeared to result from peer frustration towards acquired cognitive and behavioural difficulties, such as impulsivity and forgetfulness. Being perceived as weird appeared frequently within the data, capturing the negative label that adolescents can attract when returning to school whilst navigating acquired difficulties. For example, difficulties interpreting social cues (social cognition) may result in inappropriate responses or behaviours. Peers may find this difficult to comprehend due to the often ‘hidden’ nature of ABI, and consequently find adolescents undesirable to be around at a time of increased sensitivity to peer acceptance.
“…they don’t want to be the one who hangs out with the one who’s just a bit weird.” (Hannah, practitioner)

“When I am trying to be sarcastic, my voice doesn’t sound it at all so people just think I am being really weird. I sometimes take people seriously and then they will be like, ‘It was a joke,’” (Beth, adolescent)

1.2 Isolated and Alone

Isolation for adolescents was felt to be a significant consequence of exclusion or victimisation from peers. Parents spoke of their children subsequently becoming dependent on the family or withdrawing onto online platforms. This perpetuated feelings of isolation. Kelly spoke of her son’s world becoming increasingly “insular and narrow”, and other parents shared their concerns for their children’s futures.

“…they do become so socially isolated they look more and more to the family, they spend more time by themselves or with adults, they lose their ability to act with age appropriate peers, the peers move on with everything” (Lucy, parent).

1.3 A Need to Belong

The importance of connection and belonging in adolescence was acknowledged by adult-aged stakeholders, recognising this to be a basic human need. Sarah spoke of a best friend being there for emotional support. Without this, adolescence was reported to be an extremely difficult time to be alone.
“You need to have a community in which you feel you belong, other than your family, other than mum and dad.” (Charlotte, parent)

“Somebody who is nice to you, supports you if you are upset, makes you feel happy.” (Sarah, adolescent)

Successful peer relationships were felt to be important for psychological wellbeing by some stakeholders. Louise powerfully shared a strong preference for successful peer relationships over academic performance. Parents suggested that this need was overlooked by educational environments primarily focusing on academic achievement.

“I wouldn’t have cared if I got my GCSE’s as long as I still had my friends at school. I would rather I had peer interventions from psychologists at school than I had for educational stuff. I would rather I left school with no GCSE’s and didn’t get bullied.” (Louise, adult)

Parents, practitioners, and adults described a sense of desperation for adolescents to not be perceived as different by their peers. Charlotte, a parent, described how adolescents want to fit in and be accepted by their friends.

“…all they desperately want is to fit in and be, not super popular, but have a little crew. No, just a have normal crew of kids that are the same as them, and that are accepting of them.” (Charlotte, parent)
Considering this, parents spoke of the differences in their treatment priorities compared to their children’s. Shirley, a parent, shared her desire for her daughter to receive support for her cognitive difficulties in school, yet spoke of her daughter’s reluctance through fear of appearing different. Other parents echoed this.

“Kids want to be normal as a teenager. They don’t want to stand out, and by having some form of injury […] you want to be as normal as possible and I think that’s quite hard.” (Carol, parent)

Through wanting to be part of something, parents spoke of how adolescents adjusted their friendship preferences post-ABI. Kelly and Lucy described how their children began to connect with peers who had similar educational and social challenges. Though this strategy supported social competence, it felt as though adolescents had limited choice in this adaptation. This appeared to subsequently impact upon social status, with practitioners describing adolescents as being placed into the “special educational needs group” in the minds of their peers and resulting in further exclusion.

“…some of his friends are with him because they are the ones who find the playground stressful as well.” (Lucy, parent)

It emerged that a desire to belong can increase vulnerability from others. Adolescents were reported to become susceptible to undesirable social influences in an attempt to connect with others. Vulnerabilities can be further compounded by difficulties with social cognition and understanding the intentions of others. Shirley
shared concerns for her daughter’s safety in this regard. Adolescents may also undertake a new role of being comical, entertaining, or useful to a new group of peers, increasing risk of exploitation from peers encouraging the provocation of teachers or engagement in criminal behaviour.

“Her trust in people and just believing everything everybody says. She doesn’t seem to have that little thing inside to say, “Hang on a minute, that’s not quite right”, she doesn’t have that.” (Shirley, parent)

“…they’re very keen to be part of something. So, they might get drawn into activities that are inadvisable or down-right dangerous, just in an attempt to be part of the group.” (Jackie, practitioner).

1.4 No One Understands

A powerful theme for peer difficulties surfaced from stakeholder accounts surrounding the lack of understanding about ABI, and the associated assumptions and stigma. All stakeholder groups felt that others misunderstood ABI and its implications. This included peers, but also parents of peers, teachers, and the wider community. This incomprehension was recognised to be influenced by the ‘hidden’ difficulties associated with ABI in contrast to a physical injury or disability, and adolescents talked about a lack of support at school.

“They don’t tell kids that this person has a brain injury or stop bullying them. They don’t say anything about me, like how to treat me. It is horrible.” (Sarah, adolescent)
“I came back looking the exact same, so it was like nothing had happened.”

(Louise, adult)

Parents spoke of the assumptions and stigma their children experienced. There was frequent reference to peers perceiving difficulties as non-existent, or used as a mechanism to miss school or receive special attention. Parents described often ‘battling’ with schools and other parents in an effort to ‘prove’ their children’s difficulties. This reflected the challenges within the adolescent’s educational and social environment that impacted upon relationships with peers. Some stakeholders, however, reported positive experiences with friends despite a lack of understanding.

“…we’ve got parents who are very much like, “Oh, she’s just making a drama,” or “Just pull yourself together,” or “Is she really dizzy?” and “Does she just not want to be at school?” (Charlotte, parent)

“My few good friends that I have got are really understanding. I don’t think they fully understand what is happening, but they are really supportive and they will help me.” (Beth, adolescent)

1.5 Restricted Independence at a Time for Growth

Parents, practitioners, and adults with ABI suggested that adolescents are restricted in their opportunities for typical peer interaction, contributing to difficulties with peer relationships. This was particularly apparent for adolescents who sustained severe injuries, requiring specialist educational environments.
“…they’ve gone from what was their typical trajectory to being completely taken out of their cohort of peers. So they don’t, certainly in their school hours, they don’t have access to those peers anymore. I doubt how much access they have outside of school.” (Ella, practitioner).

Adolescents who remained in their educational environment were reported to experience over-protection from family members and teaching staff, adding further restrictions for peer relationships. Stakeholders spoke of how having a teaching assistant could lead to further isolation from peers. Having an adult by one’s side can be a signal of difference for peers, inviting curiosity and possible rejection. Jackie shared how peers can exclude adolescents through a reluctance to socialise with an ever-present adult.

“…no one is going to come and tell you a secret or include you in on something if there’s an adult sitting there. So, no one’s going to come over and give you all the gossip and dish the dirt if you’ve got an adult there, so you miss all that.” (Jackie, practitioner)

Opportunities for peer interactions were further affected by physical and cognitive difficulties. Parents, practitioners, and adults highlighted the impact of physical fatigue on meeting peers outside of school. Similarly, difficulties with memory and planning abilities restricted adolescent’s capacities to independently meet up with friends. Consequently, there appeared to be a reliance on parents to
facilitate social activities. If parents were unavailable, opportunities for peer interaction were missed.

“…you had to be accompanied everywhere, because if I forgot what I was doing or where I was then I was going to be like a deer in the headlights, not knowing what to do.” (Louise, adult).

1.6 Loss of Past Self

A commonality surfaced around the grief adolescents and parents can experience following injury, grieving for what could have been. Changes in identity appeared to be frequent for adolescents following a loss of sports, academic abilities, peer groups, and family roles. Adolescents were reported to find this difficult to adjust to, and felt hopeless and uncertain about the future, affecting QoL. Ben shared experiences of referring to the “old” and “new” version of himself. Kelly spoke of her son using a new name entirely. The impact of this resonated more if adolescents were able to remember their abilities before injury and finding themselves in conflict with the new sense-of-self.

“Very lonely, very depressed, you don’t have that sense of achievement anymore, you’ve completely lost your identity, and, it just, it can lead to very downward spiral.” (Louise, adult)

“…if they were younger than you, you were like the ‘big brother’, the younger person over takes you and they’re allowed to go out at night or walk home from school and you’re still not.” (Jackie, practitioner)
1.7 Challenges with Acquired Status

A number of determinants for peer relationship difficulties presented within cognitive, emotional, and behavioural domains. Parents and practitioners spoke about the lability that adolescents can present with, rapidly switching between intense emotions which peers can respond negatively towards.

“…their mood and anxiety and not being able to keep on top of their emotions and having outbursts in school, which obviously leads to them being picked on even more and becoming even more socially isolated.” (Hannah, practitioner)

The emotional sequela of ABI appeared to be significant for adolescents in stakeholder accounts. Anxiety and uncertainty towards new situations increased avoidance and withdrawal, further restricting social participation. Consequently, adolescents were reported to spend more time with the family or alone. Similarly, a loss of hope and confidence was noticed that presented as further barriers for motivation for being with friends. Ben and Louise, both adults with ABI, spoke about the denial and shame that they experienced towards their physical and psychological status post-ABI.

“…she’s lost loads of confidence, so that makes it really hard to make friends when you’re really, really inward.” (Charlotte, parent)

“I knew there was something wrong with me, it kind of brought a shame on you. So you didn’t want people to know because they looked at you as if you were an attention seeker.” (Louise, adult)
2.0 Improving Peer Relationships

The following themes comprise stakeholder perspectives on what might need to change to improve peer relationships for adolescents, and what the goals of an intervention might be.

2.1 Building Understanding

There was a strong commonality shared around the need to increase understanding about ABI in others around adolescents. Parents, practitioner, and adults spoke of the benefit of teachers and peers receiving education around the impact of ABI and what the adolescent might be experiencing. This was hoped to reduce the assumptions and stigma shown by others that negatively impact upon peer relationships. This education and understanding may promote acceptance from others and facilitate compassion within the system around the adolescent, supporting social inclusion.

“…because it’s not talked about, I would love for them to do a massive assembly in the school and say, “This is what goes on,” […] so that it’s not such a taboo thing and so children aren’t so frightened about it…” (Charlotte, parent)

2.2 Meaningful Social Connection

When considering the limited opportunities for peer interactions, parents advocated for meaningful social activities. Here, stakeholders reflected on being with others with ABI and participating in activities with non-injured friends. Ben recognised the benefit of being with others with ABI, promoting a sense of commonality and normalisation. However, some parents and practitioners felt it to be more important to
facilitate fun activities with peers. Louise reflected on her experience in adolescence, subsequently stating that solely socialising with others with disabilities would have furthered peer exclusion.

“I didn’t really like the whole pushing me to surround myself with other people with brain injury. Didn’t like that because [...] I wanted to be normal.” (Louise, adult)

Stakeholder perspectives suggested that adolescents would benefit from having a space to talk openly about their emotions. Parents felt that having someone of a similar age to talk to was important for adolescents, recognising that professionals involved post-injury were mostly middle-aged.

“Somebody that understands the mood that you are feeling.” (Beth, adolescent)

2.3 Support for the Journey

Parents and adults reported feeling lost post-discharge, with many unanswered questions and concerns for the future. It was recognised that professional support fell away and parental help-seeking relied on family resources. Subsequently, early support, assessment, and education for the family about ABI was advocated for to support school re-integration and care planning.

“…you’re not informed on who you are now or what struggles you might deal with, which means then your peers aren’t informed of who you are now and
what struggles you might be having to deal with. You don’t even know, how are they meant to know?” (Louise, adult).

2.4 Empowerment

Parents, practitioners, and adults felt a need to support adolescents to change their relationship with ABI. They suggested that adolescents can feel powerless and hopeless in the context of injury. Kelly recognised the persistent negative messages that adolescents can experience from those around them that perpetuated feelings of hopelessness and shame.

“…all they’re hearing in messages is “You’re making it up” “You’re skiving” they’re being rejected by their peer groups, they’re finding it really hard to interact with their peer groups, and they’re worrying about future relationships…” (Kelly, parent).

Subsequently, it was suggested that an intervention needed to support and build on the strengths of adolescents, fostering confidence despite ABI. Jackie reflected on her experiences of empowering adolescents to become experts in themselves.

“You’re empowering them to say to a teacher “I’m not being lazy, I’ve got an initiation problem”, it just changes the whole world.” (Jackie, practitioner)
**Logic Model of Peer Relationship Difficulties**

The logic model of peer relationship difficulties presented in Figure 2 offers a framework to understand stakeholder experiences of peer relationship difficulties for adolescents with ABI, its determinants, and the impact upon QoL. The planning group’s responses on the survey informed the initial logic model (Appendix L). This was then discussed and reflected on by stakeholders. Data analysed from stakeholder focus groups and interviews informed the first revision of the initial logic model of peer relationship difficulties. The revised model was discussed in research supervision, and was then shared with the planning group for feedback and reflection around the organisation and interaction of the data (i.e., suitable determinant categorisation). This resulted in four more revisions, until no further feedback was provided and a consensus was reached by the planning group. The fifth iteration of the logic model was then shared with stakeholders for feedback around the credibility of what was presented in the logic model and their communicated experiences. This resulted in a sixth and final revision (Figure 2) after improving the accessibility of terminology. No further feedback was provided by stakeholders and no further revisions to the model were made.

The logic model of peer relationship difficulties (Figure 2) shows the variety of peer relationship difficulties that adolescents can experience and the long-term impact on QoL, as described by stakeholders. As presented, these difficulties were perceived as being influenced by the interactions between the outlined determinants. These may maintain peer relationship difficulties, or be further influenced by these difficulties, as represented by the bi-directional arrow. For example, being excluded from social activities (peer relationships difficulties post-ABI) may be influenced by emotional lability and withdrawal (behavioural determinants), time away from peers during
recovery, and the attitudes and assumption of others (environmental determinants). Being excluded from social activities may further influence mental health and mood (psychological determinants), and a reliance on parents (environmental determinants). Adolescents may experience a loss of friendship group over time (peer relationships difficulties post-ABI) and reduced QoL, influenced by isolation and feelings of loneliness.

Supporting these determinants may be the focus of future meaningful interventions to improve the outcomes of adolescents, such as through emotional support, education for others, supporting contact with peers during recovery, and facilitating activities with others; as suggested by stakeholders.
Figure 2. Logic Model of Peer Relationship Difficulties for Adolescents with ABI (6th Revision).
Discussion

This study aimed to collaborate with key stakeholders to: (a) understand peer relationship difficulties for adolescents with ABI (adolescents); and (b) seek their perspectives on what might be needed to improve them and what the intervention goals might be, to inform the development of a meaningful intervention.

The complexities of peer relationship difficulties for adolescents have largely been under-recognised, and the qualitative insights provided in this study inform this gap within the paediatric neuropsychology literature. The analysis, alongside planning group responses, informed the development of the logic model, outlining the difficulties adolescents can experience with peer relationships (target problem for intervention), its impact upon QoL, and its determinants. This offers a robust framework to guide future intervention design using the IM protocol (Bartholomew-Eldridge et al., 2016; Fernandez et al., 2019).

Stakeholders supported that adolescents face difficulties in maintaining peer relationships (Anderson et al., 2013; Ryan et al., 2013; Turkstra et al., 2004; Yeates et al., 2007), which are represented in the logic model. Peer rejection and exclusion was also recognised, consistent with Yeates et al. (2012). Stakeholder insights suggested this to result from peer separation during recovery, restricted peer interactions, and the negative assumptions associated with the ‘hidden’ difficulties associated ABI (Simpson et al., 2002).

Stakeholder conversations and planning group perspectives indicated the determinants for peer relationship difficulties (shown in the logic model) to be broad. Consistent with previous research, difficulties with cognition (Anderson et al., 2012), social cognition (Tousignant et al., 2018), misunderstanding (Keetley et al., 2019), emotional lability (Vasa et al., 2015), and perceived changes in identity (Ownsworth,
2014) were identified to negatively influence peer relationships. Stakeholders reported the lack of understanding about ABI to be an important determinant for peer difficulties. Some adolescents may return to school appearing unscathed, yet can present as very different to peers due to acquired cognitive, socio-cognitive, and emotional difficulties (Simpson et al., 2002). This may invite negative assumptions from peers towards the ‘realness’ of difficulties, resulting in further rejection or peer frustration. Similarly, the emotional consequences associated with ABI (Sariaslan et al., 2016) and a change in identity (Ownsworth, 2014) reduced motivation for social participation, perpetuating feelings of loneliness (Parker & Asher, 1987) and dependency on the family. These, and further implications for QoL are represented in the logic model, including future academic and vocational concerns (Sariaslan et al., 2016), reduced confidence, and risk of early contact with the criminal justice system (Williams et al., 2012), as reported by stakeholders.

The notion that adolescence is a time for belonging (Blakemore, 2008), peer emotional support (van Harmelen et al., 2017), and social identity (Tajfel, 1978) was supported. This was a recognised difficulty for adolescents within the themes and logic model. Successful peer relationships were a priority for some stakeholders over academic achievement, a priority previously reported by Sirois et al. (2014). To support belonging and peer acceptance, adolescents have an apparent priority to appear ‘normal’, and may adjust friendship preferences to perform competently (Anderson & Beauchamp, 2012). This may also increase vulnerability for exploitation from others, compounded by socio-cognitive difficulties and understanding intentions of others (a determinant in the logic model). Difficulties with theory of mind have previously been recognised post-ABI (Turkstra et al., 2004).
The themes and logic model provided in this study offer guidance for the development of a future intervention, and stakeholders offered their perspectives on what is needed to support the needs of adolescents. Their participation in intervention planning supports understanding the context for intervention and population needs to promote intervention efficacy (Fernandez et al., 2019; MRC, 2019). Stakeholder accounts suggested a preference for intervening within the adolescent’s educational, community, and social environment. Individual interventions may be unappealing due to the threat of appearing different and subsequent peer rejection. An intervention may need to be multifaceted to support adolescents at an individual (emotional support) and environmental level (building understanding), consistent with recommendations made by Andrews et al. (2015). This could include providing education and resources about ABI to peers and schools, facilitating meaningful social activities with friends, offering emotional support, and early assessment and signposting post-injury. Empowering adolescents post-ABI was identified to be an important intervention goal.

**Theoretical Implications**

Within the SOCIAL model, social skills and functioning (i.e., competence, adjustment, and participation) are recognised to be fundamental for successful peer relationships (Beauchamp & Anderson, 2010). The model assumes that social skills are mediated by typical brain development within a supportive environment, and that the presence and integrity of social skills are facilitated by cognitive determinants (i.e., attention/ executive functioning, social cognition, and communication). The determinants spoken about by stakeholders in this study offer support for the mediators and cognitive determinants identified by the SOCIAL model. For example, challenges within an adolescent’s external environment (i.e., peer rejection, misunderstanding, and stigma), and difficulties with cognitive and socio-cognitive
abilities were described by stakeholders as key influential determinants for peer relationship difficulties for adolescents with ABI within the themes and logic model. The presented interactions between these determinants are consistent interactions proposed within the SOCIAL model.

Emotional difficulties (i.e., anxiety, hopelessness, shame, and lability) were also described by stakeholders to be influential determinants for peer relationship difficulties within the themes and logic model, impacting upon social competence and motivation for social participation. Emotional determinants appear to be omitted from the SOCIAL model. It could be argued that the presence and integrity of social skills and functioning, in the context of typical brain development and a supportive environment, may also be influenced by emotional determinants (i.e., regulation, mood, and mental health). These determinants may have an important reciprocal role for facilitating successful peer relationships, which in turn, could support emotional difficulties for adolescents. Indeed, successful peer relationships in adolescence can be protective for mental health and resilience (van Harmelen et al., 2017).

The suggested interactions between the mediators and determinants in the SOCIAL model are supported by empirical evidence from TBI, autism spectrum disorder, and schizophrenia populations. The findings from this study may provide the foundation for further research exploring the relationship between social skills and mood in ABI populations. With further evidence, future revisions of the SOCIAL model may consider the inclusion of emotional determinants. As suggested by stakeholders, reduced social skills may invite stigma from the external environment and restrict participation. This may further reduce mood and influence social adjustment and participation.
Clinical Implications

The findings suggested that adolescents can experience difficulties with peer relationships and mental health, though they may not volunteer these difficulties through fear of appearing different. Consequently, their needs could be overlooked. Practitioners can hold this in mind and routinely enquire about an adolescent’s mental health, alongside being curious about their support network beyond the family.

The risks and vulnerabilities associated with ABI and a need to belong were identified. This awareness can support clinicians to formulate risk and intervene appropriately. This awareness could also be shared with commissioners to seek funding for additional community resources to support social belonging for children and adolescents, such as youth clubs. Indeed, those with ABI are at higher risk of early contact with the criminal justice system (Williams, 2012).

Stakeholders suggested that peers should be involved and educated in the post-acute phase of rehabilitation to prevent adolescents ‘drifting’ from friends. This may maintain peer relationships and promote social inclusion throughout rehabilitation, absence from school, and educational re-integration. Social media platforms could support peer communication.

Some stakeholders shared their priority for successful peer relationships over academic achievements. This understanding may inform rehabilitation goal planning and educational learning plans to support adolescents to engage and participate meaningfully with friends, subsequently supporting QoL.

The importance of building understanding about ABI for those around the adolescent (i.e., peers, teachers) was identified as a key part of a meaningful intervention. Understanding could be supported through the creation of online resources or videos made by adolescent stakeholders with ABI. Social media could
facilitate an adolescent-led project to disseminate informative videos. This may simultaneously empower adolescents to become the experts.

The National Acquired Brain Injury in Learning and Education Syndicate was set up in 2018 to ensure that children and adolescents get the educational support they need. One strategic aim is to raise awareness of the educational difficulties associated with ABI amongst policy makers. The findings from this study can support this aim.

**Strengths and Limitations**

The methodology of this study promoted collaboration with planning group members and key stakeholders to co-produce the logic model of the target problem for intervention through a rigorous process. Utilising member-checking procedures throughout the study promoted the credibility of the findings and interpretations made. An additional strength included piloting the focus groups and interview schedules, allowing for the observation of responses and suitability to support the research aims.

A limitation includes the use of focus groups and interviews due to time restrictions and the difficulties encountered when attempting to recruit from the paediatric ABI population. Though focus groups and interviews were of a similar length, stakeholders who were interviewed had increased opportunity to contribute findings. Conversely, the richness of the data collected in interviews was limited due to question and response nature of the conversation. Stakeholders in the focus groups were able to construct opinions, share and build on each other’s experiences, and discuss topics beyond scheduled topics that provided further insights. Future research exploring commonalities in adolescent and parent experiences of ABI may benefit from solely using focus group methodology. This methodology promotes connectivity and peer support to an often isolated population. It may encourage social interaction
and the sharing of social pressures amongst adolescents with ABI. Furthermore, it may allow parents and adolescents with ABI to feel less isolated in their experiences. The normalisation and commonalities discussed amongst participants could promote the disclosure and sharing of experiences beyond an interview setting. In addition, the analysis of focus group data will allow for exploration of how emergent themes are built upon by other stakeholders, and allow for further analysis of differences in opinion.

The parent and adolescent sample used within this study consisted of sample bias. All adolescents were aged 13 years and originated from a white middle-class background. This would have influenced adolescent and parental experiences following ABI, such as resources, access to services, and educational environments. This may contrast with experiences from stakeholders originating from BME or working-class backgrounds. Thus, findings from this study may not be generalisable to all adolescents with ABI. Future research should consider recruiting stakeholder participants from diverse backgrounds. This may be achieved through close working between the researcher and statutory services to seek support for recruitment, such as social care (i.e., youth services), the National Health Service, and the Department for Education. This could support recruitment from a wider and more diverse population, beyond those who are supported by charity organisations. Barriers to participation in research may be considered and supported, particularly for hard to reach communities. Outreach to potential participants could build trust (i.e., building a rapport and managing expectations from the outcome of the research) and provide opportunities to discuss the potential risks of participation (i.e., anonymity, discrimination, and social status).
Adolescent stakeholders had limited representation due to the small sample size and their apparent reservations in conversation. Consequently, their perspectives may not have emerged as strongly in the analysis when compared to other stakeholder groups. Future research should consider using a larger sample of adolescents with ABI.

**Conclusion**

Adolescents with ABI were reported to experience difficulties with peer relationships. At an important time for social development, peer rejection can increase feelings of isolation, loneliness, shame, and hopelessness. This can have further implications for mental health, peer relationships, and QoL. The individual, psychological, behavioural, and environmental determinants for peer relationship difficulties are broad. Reported stakeholder experiences offer new clinical and theoretical insights for the paediatric neuropsychology literature. A meaningful intervention would need to be multifaceted attempting to build understanding in others, facilitate opportunities for meaningful social connection, offer early support post-injury, and help manage psychological wellbeing. A primary focus would be to empower adolescents post-ABI. The presented logic model provides a robust understanding of peer relationship difficulties for adolescents with ABI that can be used to guide intervention development in future research.
References


IMPROVING PEER RELATIONSHIPS FOR ADOLESCENTS WITH ABI


domains in a healthy community cohort. Psychological Medicine, 47, 2312-2322. doi:10.1017/S0033291717000836.


Appendices

Appendix A: Steps of Intervention Mapping

Table A1. *Intervention Mapping Steps (O’Connor, Blewitt, Nolan, & Skouteris, 2018)*

<table>
<thead>
<tr>
<th>Step</th>
<th>Tasks</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Logic model of the problem</td>
<td>• Establish and work with a planning group</td>
</tr>
<tr>
<td></td>
<td>• Conduct a needs assessment to create a logic model of the problem</td>
</tr>
<tr>
<td></td>
<td>• Describe context of intervention (population and setting)</td>
</tr>
<tr>
<td></td>
<td>• State programme goals</td>
</tr>
<tr>
<td>2. Programme outcomes and objectives – logic model for change</td>
<td>• State expected outcomes</td>
</tr>
<tr>
<td></td>
<td>• Specify performance objectives for behavioural and environmental outcomes</td>
</tr>
<tr>
<td></td>
<td>• Construct matrices of change objectives</td>
</tr>
<tr>
<td></td>
<td>• Create a logic model of change</td>
</tr>
<tr>
<td>3. Programme design</td>
<td>• Generate programme themes, components, and scope</td>
</tr>
<tr>
<td></td>
<td>• Choose theory – and evidence-based change methods</td>
</tr>
<tr>
<td></td>
<td>• Select practical applications to deliver change methods</td>
</tr>
<tr>
<td>4. Programme production</td>
<td>• Refine programme structure</td>
</tr>
<tr>
<td></td>
<td>• Prepare plans for programme materials</td>
</tr>
<tr>
<td></td>
<td>• Draft messages and materials</td>
</tr>
<tr>
<td></td>
<td>• Pre-test, refine, and produce materials</td>
</tr>
<tr>
<td>5. Programme Implementation Plan</td>
<td>• Identify potential programme users</td>
</tr>
<tr>
<td></td>
<td>• State outcomes and performance objective for programme use</td>
</tr>
<tr>
<td></td>
<td>• Design implementation interventions</td>
</tr>
<tr>
<td>6. Evaluation plan</td>
<td>• Write effect and process evaluation questions</td>
</tr>
<tr>
<td></td>
<td>• Develop indicators and measures for assessment</td>
</tr>
<tr>
<td></td>
<td>• Specify the evaluation design</td>
</tr>
<tr>
<td></td>
<td>• Complete the evaluation plan</td>
</tr>
</tbody>
</table>
Appendix B: Consent to Contact Forms

**Participant Consent Form**

**CONSENT TO BE CONTACTED**

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K.
Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

Consent to be contacted for more information about participation in the above study.

I consent to be contact by the researchers involved in this study about the opportunity to take part and ask any questions that I might have about the research process and what is expected of me.

I understand that being contacted does not mean that I am obliged to take part in the research and that I am free to change my mind at any time.

I am happy for the researchers above, at the University of Exeter, to securely store the contact details that I provide for the purposes of informing me about the research study.

*Only researchers from the University of Exeter will have access to your contact details, which will be kept for 5 years before being destroyed. All personal information will be kept securely on a password protected university server.*

You will receive a copy of this signed documents for your records.

Name of Person: ……………………………………………………………………………………

Signature Person: …………………………………………………………………………………

Date: ……………………………………………………………
Signature of Researcher Obtaining Consent/ Assent to be contacted

........................................................................................................... Date: ......................

PROVIDED CONTACT DETAILS

Preferred means of contact (phone/ text/ email/ post):

..............................................................................................................

Preferred times of day for contact (if by telephone):

..............................................................................................................

Telephone Number:

..............................................................................................................

Email Address:

..............................................................................................................

Postal Address:

..............................................................................................................

..............................................................................................................

..............................................................................................................
Participant Consent Form

YOUNG PERSON CONSENT TO BE CONTACTED

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K.
Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

Consent to be contacted for more information about participation in the above study.

I consent to be contact by the researchers involved in this study about the opportunity to take part and ask any questions that I might have about the research process and what is expected of me.

I understand that being contacted does not mean that I am obliged to take part in the research and that I am free to change my mind at any time.

I am happy for the researchers above, at the University of Exeter, to securely store the contact details that I provide for the purposes of informing me about the research study.

*Only researchers from the University of Exeter will have access to your contact details, which will be kept for 5 years before being destroyed. All personal information will be kept securely on a password protected university server.*

You will receive a copy of this signed documents for your records.

Name of Young Person: ........................................................................................................

Signature of Young Person: ............................................................................................
Indicating Assent (under 16 years) / Consent (16 years and older) – delete as appropriate.

Date: ..............................................................

Signature of Parent or Guardian .................................................................
Date: ……………………………………………………………………………………

Signature of Researcher Obtaining Consent/ Assent to be contacted

………………………………………………………………………………… Date: ……………………

Provided contact details

Preferred means of contact (phone/ text/ email/ post):

…………………………………………………………………………………………

Preferred times of day for contact (if by telephone):

…………………………………………………………………………………………

Telephone Number:

…………………………………………………………………………………………

Email Address:

…………………………………………………………………………………………

Postal Address:

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………
Appendix C: Adult Stakeholder Participant Information Sheet (Focus Groups)

Participant Information Sheet

STAKEHOLDER PARTICIPATION

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K.
Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

Dear Sir \ Madam

Purpose of the research

Acquired brain injury (ABI) in children and young people is a leading cause of disability worldwide. ABI can alter a child’s developmental trajectory when compared to their peers, with developmental ‘gaps’ becoming increasingly apparent with age. This can cause a number of psychosocial impairments including mood, educational attainment, and friendships. Little is known about the social outcomes in adolescents with ABI. Even less is known about how social impairments can be improved.

Peer relationships are extremely important during childhood. They allow for continual social development, the sharing of experiences, and simple companionship. Those with social impairments are at risk of peer rejection, making it difficult to establish a supportive peer group. As a consequence, those with ABI can experience isolation, loneliness, inappropriate behaviour, anxiety, and aggression.

The aim of this study is to use an intervention mapping approach to address the gap in the literature and to design a suitable intervention aimed at improving peer relationships. The chosen methodology supports the co-design of an intervention with the involvement of various ‘stakeholders’ who have experienced ABI in adolescence. This includes adolescents with ABI, parents, peers, practitioners, and researchers. The study is interested in hearing about the social experiences of those impacted by ABI, and use their consultation to help design a treatment programme.

What type of data is being collected?

The study will be collecting data using questionnaires, surveys, and focus group discussions. The questionnaires are used to collect a number of characterisation and demographic data; this includes social skills, quality of life, social economic status, type of injury, and injury severity. Each questionnaire will come with a set of instructions on how to complete them. A focus group is a group discussion around a particular ‘focus’ topic.

What will participation in focus groups involve?
There will be around six to eight people in each focus group with one facilitator. You will be asked to have a group conversation to express your views and form opinions. The group will be audio recorded and all information is kept confidential. The group will last for approximately 1 to 1.5 hours. For this study, we are interested in hearing your views about the social experiences of adolescents with ABI and to use your experiences to help us design an intervention programme which will aim to improve relationships with peers. There are no right or wrong answers to the questions we will ask you. The questions will aim to explore your experiences and views towards the research topic.

**When will the focus group be?**

It can be really difficult to arrange a time, date, and location for everyone to get together at the same time. We will propose a date in the near future and ask that you contact the researcher as soon as possible to confirm your attendance. If you cannot attend for any reason, please let us know as soon as possible. We ask that you arrive promptly to allow adequate time for the focus group. Refreshments will be provided on the day.

**What will happen on the day?**

You will be welcomed on arrival and offered refreshments whilst we are waiting for everyone to arrive. We will ask you to bring with you the questionnaires we will send to you 2 weeks prior to the focus group. You will then be asked to sign a consent form to state that you are happy to continue with the focus group. You will be unable to participate without this. The facilitator will ensure that everyone is seated and explain the group rules; these include not speaking over others, and to maintain confidentiality following the session. You will then be given the opportunity to ask questions. Once everyone is happy, the audio recording will begin and the group will commence. Following the group, you will be provided with a debrief sheet which will contain further information about support if you require it.

**What are the benefits of taking part?**

This study offers an innovative approach which values the participation of ‘experts by experience’. Your perspectives and consultation will allow for the development of an intervention programme to improve peer relationships for others experiencing ABI. You will have the opportunity to meet others in a similar situation to you and share experiences. As a thank you for sharing your time, we will give you a £10 Amazon voucher.

**Are there any risks?**

The questions are likely to talk about sensitive topics which may be difficult to share. If you become upset by the information spoken about within the focus group, there will be information provided about services where you could access support. You are able to withdraw from the study at any time with no consequence.

**Will my information be kept private?**
Due to recent regulatory changes in the way that data are processed (General Data Protection Regulations 2018 and the Data Protection Act, 2018), the University of Exeter’s lawful basis to process personal data for the purposes of carrying out research is termed as ‘task in the public interest’. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University’s processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University’s Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection. If you have any concerns about how the data are controlled and managed for this study then you can also contact the Sponsor Representation, Pam Baxter, Senior Research Governance Officer (e: p.r.baxter2@exeter.ac.uk).

Making sure that your information remains private is important to us. We will do the following to protect your privacy in this research study:

- All personal and research related information about you will be stored on a secure password protected university server and marked with a unique ID code. No identifiable information will leave university premises.

- Only researchers at the University of Exeter will have access to your personal information (contact details, consent forms). This will be kept securely for 5 years before being destroyed.

- All audio recordings collected as part of the research will be stored on a secure password protected university server for transcription and will be deleted after 1 year.

- Only the researchers at the university involved in this study will have access to audio recordings for transcription purposes. Some audio recordings may be sent to transcription services known to the university who are bound by their own data protection policies.

- All transcriptions of audio recordings will be anonymised and all identifiable information removed. There will be no identifiable information published as part of this study.

- All questionnaires and transcriptions used in the study will be marked with your unique ID code. All participant ID codes and associated personal information will be stored electronically on a password protected database, stored on a secure password protected university server.

- All signed paper consent forms will be scanned onto the university system and securely stored on a server. All paper forms will then be physically destroyed.

- All completed consent to contact forms will be stored on a secure server. All paper versions will be scanned onto the server and then destroyed.
• If you would like your data to be removed once you have taken part in the study, please request this in writing to the chief investigator (sa675@exeter.ac.uk) within 1 year following your participation. All information related to your participation in this study can then be removed using your unique ID code.

• This outlined information will be given to you again on the day of your participation.

Risk and Confidentiality

The only time we would break confidentiality was if we felt that you, or someone else, was at risk of harm. In such cases, we would talk to you about this first and risk procedures will be followed. We may also make contact with appropriate local services for support. You will be reminded of this on the day of participation.

Further information

If you have any further questions about this research study, please contact the lead researcher via email: sa675@exeter.ac.uk

University of Exeter, College of Life and Environmental Sciences, Psychology, Exeter, EX4 4QG.

Tel: 01392 72 2209.

To contact the Chair of Psychology Ethics, please contact Dr Nick Moberly (e: n.j.moberly@exeter.ac.uk t: 01392 724656)

Ethical approval number: eCLESPsy000805
Appendix D: Young Person Participation Information Sheet (Focus Group)

Participant Information Sheet

CHILD AND YOUNG PERSON (Aged 12-17 years)

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K.
Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

We would like to ask you to take part in our research study. It is really important that we give you all the information you need before you say 'yes' or 'no'. Please could you read the information on this page carefully about what you will be asked to do. If it is easier, you can ask someone else to read it with you, like your parents. You can always ask us for more information at any time. The contact details can be seen below.

What is the study about?

Sometimes, teenagers who have had a brain injury can find it hard 'connect' with their friends. This may be for a number of reasons, ranging from difficulties with memories to feeling that friends do not understand you. We would like to hear more about your experiences with friends and think about how we could help. We also want to hear about what’s important to you.

Why am I being asked to take part?

We would like you to be in the study because you are the experts. We are asking both girls and boys between the ages of 12 and 17 years who have had a brain injury, or know a friend who has had a brain injury to take part.

Do I have to?

No, you do not have to take part if you do not want to. It's up to you and your parents. You can say yes or no.

What will happen in the study if I say yes?
If you say yes, we will give you and your parents more information on the study. If you are happy to continue, we will invite you to come to the University of Exeter one day and meet other teenagers with brain injuries. We will ask you to have a group discussion in response to some questions that we will ask the group, there are no right or wrong answers. The group will last for around one hour and refreshments will be provided.

In the group, we will ask you to tell us about the difficulties some teenagers with brain injuries may face with friendships, and the other difficulties with this. We also want to ask you for your advice about what would help.

What’s good about taking part?

You are the ‘experts’ in social experiences following brain injury. You will be helping us to understand what it is like for teenagers and what problems they might have. You can talk to us about what is meaningful and important to teenagers. We can think together about how we might be able to help teenagers who have difficulties with their friends. You will be able to meet other people your age and share experiences. You will also get a £10 Amazon voucher as a thank you for coming along.

What’s bad about taking part?

One possible bad thing about taking part is that some of the discussions may be upsetting. If at any time you feel that you might be upset, you can stop. If you want to, there will be people there who you can talk to and further information about support will be provided. If you want to leave the group at any point, you are more than welcome to.

Will my information be kept private?

Due to recent regulatory changes in the way that data are processed (General Data Protection Regulations 2018 and the Data Protection Act, 2018), the University of Exeter's lawful basis to process personal data for the purposes of carrying out research is termed as a ‘task in the public interest’. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University’s processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University’s Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection. If you have any concerns about how the data are controlled and managed for this study then you can also contact the Sponsor Representation, Pam Baxter, Senior Research Governance Officer (e: p.r.baxter2@exeter.ac.uk).

Making sure that your information remains private is important to us. We will do the following to protect your privacy in this research study:
All personal and research related information about you will be stored on a secure password protected university server and marked with a unique ID code. No identifiable information will leave university premises.

Only researchers at the University of Exeter will have access to your personal information (contact details, consent forms). This will be kept securely for 5 years before being destroyed.

All audio recordings collected as part of the research will be stored on a secure password protected university server for transcription and will be deleted after 1 year.

Only the researchers at the university involved in this study will have access to audio recordings for transcription purposes. Some audio recordings may be sent to transcription services known to the university who are bound by their own data protection policies.

All transcriptions of audio recordings will be anonymised and all identifiable information removed. There will be no identifiable information published as part of this study.

All questionnaires and transcriptions used in the study will be marked with your unique ID code. All participant ID codes and associated personal information will be stored electronically on a password protected database, stored on a secure password protected university server.

All signed paper consent forms will be scanned onto the university system and securely stored on a server. All paper forms will then be physically destroyed.

All completed consent to contact forms will be stored on a secure server. All paper versions will be scanned onto the server and then destroyed.

If you would like your data to be removed once you have taken part in the study, please request this in writing to the chief investigator (sa675@exeter.ac.uk) within 1 year following your participation. All information related to your participation in this study can then be removed using your unique ID code.

This outlined information will be given to you again on the day of your participation.

Risk and Confidentiality

We may have to break confidentiality if you say something that worries us. We will follow risk procedures and might have to tell someone else, such as your parents, what you have said to keep you safe. If we do this, we will talk to you first and provide you with support around accessing local services. You will be reminded of this on the day of participation.
Thank you for reading!

Further Information

If you have any further questions about this research study, please contact the lead researcher via email: sa675@exeter.ac.uk

University of Exeter, College of Life and Environmental Sciences, Psychology, Exeter, EX4 4QG.

Tel: 01392 72 2209.

To contact the Chair of Psychology Ethics, please contact Dr Nick Moberly (e: nj.moberly@exeter.ac.uk t: 01392 724656)

Ethical approval number: eCLESPsy000805
Appendix E: Parent Participant Information Sheet (Focus Group)

Information Sheet for Parents of Potential Participants

CHILD AND YOUNG PERSON (Aged 12-17 years)

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K.
Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

Dear Sir / Madam

Purpose of the research

Acquired brain injury (ABI) in children and young people is a leading cause of disability worldwide. ABI can alter a child’s developmental trajectory when compared to their peers, with developmental ‘gaps’ becoming increasingly apparent with age. This can cause a number of psychosocial impairments including mood, educational attainment, and friendships. Little is known about the social outcomes in adolescents with ABI. Even less is known about how social impairments can be improved.

Peer relationships are extremely important during childhood. They allow for continual social development, the sharing of experiences, and simple companionship. Those with social impairments are at risk of peer rejection, making it difficult to establish a supportive peer group. As a consequence, those with ABI can experience isolation, loneliness, inappropriate behaviour, anxiety, and aggression.

The aim of this study is to use an intervention mapping approach to address the gap in the literature and to design a suitable intervention aimed at improving peer relationships. The chosen methodology supports the co-design of an intervention with the involvement of various ‘stakeholders’ who have in some way experienced ABI in adolescence. This includes adolescents with ABI, parents, peers, practitioners, and researchers. The study is interested in hearing about the social experiences of those impacted by ABI, and use their consultation to help design a treatment programme.

We would like to ask your child to take part in the research study. It is really important that we give you all the information about what your child is expected to do before you provide consent for them to participate. You can always ask us for more information at any time. The contact details can be seen below.

Why is my child being asked to take part?

We would like your child to be in the study because they are the ‘experts’ we would like to hear from in the development of this intervention. We are asking both girls and boys between the ages of 12 and 17 years who have had a brain injury, or know a friend who has to take part and offer their expertise.
What type of data is being collected and how?

The study will be collecting data using questionnaires, surveys, and focus group discussions. The questionnaires are used to collect a number of characterisation and demographic data; this includes social skills, quality of life, social economic status, type of injury, and injury severity (children with brain injury only). Each questionnaire will come with a set of instructions on how to complete them.

A focus group is a group discussion around a particular ‘focus’ topic. Your child will be asked to attend a focus group at the University of Exeter to meet with others their age and with similar experiences (date to be confirmed). There will be between 3 and 6 people in their focus group with one group facilitator. They will be asked to have group conversations in response to some questions, there are no right or wrong answers. For this study, we are interested to hear about experiences of children with brain injury regarding their friendships with others, what needs to improve, and how teenagers would like it to be done so that is meaningful for them. This information can then help design an intervention. The group will be audio recorded and all information is kept confidential. The group will last for approximately 1 hour, refreshments will be included.

What will happen on the day?

You and your child will be welcomed on arrival and offered refreshments whilst we are waiting for everyone to arrive. We will ask you to bring with you the questionnaires we will send to you 2 weeks prior to the focus group (children with brain injury only). You will then be asked to sign a consent form to state that you are happy for your child to continue with the focus group. They will be unable to participate without this. The facilitator will ensure that everyone is seated and then explain the group rules; these include not speaking over others, and to maintain confidentiality following the session. Following the group, you and your child will be provided with a debrief sheet which will contain further information about support if you require it.

Do they have to?

No, they do not have to take part, it is completely up to you and your child. If you choose not to participate, that's okay. This will not impact your child's care.

What's good about taking part?

Your child is the ‘expert’ in social experiences following brain injury. They will be helping us to understand what it is like for teenagers and what problems they might have. They can talk to us about what is meaningful and important to teenagers when thinking about friendships. We can think together about how we might be able to help teenagers who have difficulties with their friends. Your child will be able to meet others their age and share experiences. They will also get a £10 Amazon voucher as a thank you for coming along.
What's bad about taking part?

One possible bad thing about taking part is that some of the discussions may be upsetting. If at any time your child feels that they are becoming upset, they can stop. If they want to, there will be people there who they can talk to and further information about support will be provided. If they want to leave the group at any point, they are more than welcome to, no problem.

Will information be confidential?

Due to recent regulatory changes in the way that data are processed (General Data Protection Regulations 2018 and the Data Protection Act, 2018), the University of Exeter’s lawful basis to process personal data for the purposes of carrying out research is termed as a ‘task in the public interest’. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University’s processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University’s Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection. If you have any concerns about how the data are controlled and managed for this study then you can also contact the Sponsor Representation, Pam Baxter, Senior Research Governance Officer (e: p.r.baxter2@exeter.ac.uk).

Making sure that your child’s information remains private is important to us. We will do the following to protect their privacy in this research study:

- All personal and research related information about your child will be stored on a secure password protected university server. No identifiable information will leave university premises.

- Only researchers at the University of Exeter will have access to your child’s personal information (contact details, consent forms). This will be kept securely for 5 years before being destroyed.

- All audio recordings collected as part of the research will be stored on a secure password protected university server for transcription and will be deleted after 1 year.

- Only the researchers at the university involved in this study will have access to audio recordings for transcription purposes. Some audio recordings may be sent to transcription services known to the university who are bound by their own data protection policies.

- All transcriptions of audio recordings will be anonymised and all identifiable information removed. There will be no identifiable information published as part of this study.

- All questionnaires and transcriptions used in the study will be coded with a unique participant identification code. All participant identification codes will be
stored electronically on a password protected database, stored on a secure password protected university server.

• All signed paper consent forms will be scanned onto the university system and securely stored on a server. All paper forms will then be physically destroyed.

• All completed consent to contact forms will be stored on a secure server. All paper versions will be scanned onto the server and then destroyed.

• If you would like your child’s data to be removed once they have taken part in the study, please request this in writing to the chief investigator (sa675@exeter.ac.uk) within 1 year following their participation.

• This outlined information will be given to your child again on the day of their participation.

Risk and Confidentiality

The only time we would break confidentiality was if we felt that your child, or someone else, was at risk of harm. In such cases, risk procedures will be followed and we might have to tell you or someone else about what they have said in the interest of safety. We may also support you to make contact with appropriate local services for support. You will be reminded of this on the day of participation.

Thank you for reading!

Further Information

If you have any further questions about this research study, please contact the lead researcher via email: sa675@exeter.ac.uk

University of Exeter, College of Life and Environmental Sciences, Psychology, Exeter, EX4 4QG.

Tel: 01392 72 2209.

To contact the Chair of Psychology Ethics, please contact Dr Nick Moberly (e: nj.moberly@exeter.ac.uk t: 01392 724656)

Ethical approval number: eCLESPsy000805
Appendix F: Adult Stakeholder Participant Information Sheet (Interviews)

**Participant Information Sheet**

**STAKEHOLDER PARTICIPATION**

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K.
Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

Dear Sir / Madam

**Purpose of the research**

Acquired brain injury (ABI) in children and young people is a leading cause of disability worldwide. ABI can alter a child’s developmental trajectory when compared to their peers, with developmental ‘gaps’ becoming increasingly apparent with age. This can cause a number of psychosocial impairments including mood, educational attainment, and friendships. Little is known about the social outcomes in adolescents with ABI. Even less is known about how social impairments can be improved.

Peer relationships are extremely important during childhood. They allow for continual social development, the sharing of experiences, and simple companionship. Those with social impairments are at risk of peer rejection, making it difficult to establish a supportive peer group. As a consequence, those with ABI can experience isolation, loneliness, inappropriate behaviour, anxiety, and aggression.

The aim of this study is to use an intervention mapping approach to address the gap in the literature and to design a suitable intervention aimed at improving peer relationships. The chosen methodology supports the co-design of an intervention with the involvement of various ‘stakeholders’ who have experienced ABI in adolescence. This includes adolescents with ABI, parents, peers, practitioners, and researchers. The study is interested in hearing about the social experiences of those impacted by ABI, and use their consultation to help design a treatment programme.

**What type of data is being collected?**

The study will be collecting data using questionnaires, surveys, focus group discussions and individual interviews. The questionnaires are used to collect a number of characterisation and demographic data; this includes social skills, quality of life, social economic status, type of injury, and injury severity. Each questionnaire will come with a set of instructions on how to complete them.

**What will participation in interviews involve?**
Interviews will be conducted face to face at the University or via technology (Skype or telephone), dependent on demographic locations. Interviews will last for approximately 1 to 1.5 hours and will be conducted one to one with the chief investigator. You will be asked to express your views and share experiences in response to the interview schedule. The questions will aim to explore your experiences and views towards the research topic. There are no right or wrong answers, we are just interested in hearing about your experiences. For this study, we are interested in hearing your views about the social experiences of adolescents with ABI and to use your experiences to help us design an intervention programme which will aim to improve relationships with peers. The interview will be audio recorded and all information is kept confidential.

When will the interview be?

If you are interested in taking part and have provided consent to be contacted, you will be contacted individually by the chief investigator to arrange a suitable time for your interview. If you cannot attend on the day, please let us know as soon as possible and we can rearrange.

What will happen on the day?

Face to face interviews

If you are attending in person at the university, you will be welcomed by the chief investigator at the time specified on your individual interview invitation. Refreshments will be provided for you. You will be asked to bring with you the questionnaires that will be sent to you prior to the day. There will be an opportunity to ask further questions, and if you are happy, you will be asked to sign a consent form to continue with the interview. You will not be able to take part without this. The interview will last for approximately 1 to 1.5 hours and you will be asked a number of open ended questions to hear about your experiences and opinions. These interviews will be audio recorded and all information will be confidential. Please see below regarding how your data will be securely managed. Once the interview has finished, there will be an opportunity to debrief and you will be provided with a £10 Amazon voucher as a thank you for your time.

Interviews via technology

If you are attending the interview via Skype or telephone, you will be contacted at the time of your interview, specified on the interview invitation. Once you have provided consent to contact for the study, the chief investigator will ask you which form of technology you find most preferable and support will be given to use the technology if required. You will be asked to return the questionnaires sent to you either by post or scanner. On the day, there will be an opportunity to ask questions, and if you are happy you will be asked to complete a ‘consent to take part’ form electronically via the study’s online webpage (link below) or via email. You will not be able to take part without this. The interview will last for approximately 1 to 1.5 hours and you will be asked a number of open ended questions to hear about your experiences and opinions. These interviews will be audio recorded and all information will be
confidential. Please see below regarding how your data will be securely managed. Once the interview has finished, there will be an opportunity to debrief and you will be sent (via email) a £10 Amazon voucher as a thank you for your time.

Link for online consent form: http://psychology.exeter.ac.uk/research/centres/ccnr/getinvolved/clinical/brain-injury/

What are the benefits of taking part?

This study offers an innovative approach which values the participation of 'experts by experience'. Your perspectives and consultation will allow for the development of an intervention programme to improve peer relationships for others experiencing ABI. You will have the opportunity to meet others in a similar situation to you and share experiences. As a thank you for sharing your time, we will give you a £10 Amazon voucher.

Are there any risks?

The questions are likely to talk about sensitive topics which may be difficult to share. If you become upset by the information spoken about within the interview, there will be information provided about services where you could access support. You are able to withdraw from the study at any time with no consequence.

Will my information be kept private?

Due to recent regulatory changes in the way that data are processed (General Data Protection Regulations 2018 and the Data Protection Act, 2018), the University of Exeter’s lawful basis to process personal data for the purposes of carrying out research is termed as a ‘task in the public interest’. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University’s processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University’s Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection. If you have any concerns about how the data are controlled and managed for this study then you can also contact the Sponsor Representation, Pam Baxter, Senior Research Governance Officer (e: p.r.baxter2@exeter.ac.uk).

Making sure that your information remains private is important to us. We will do the following to protect your privacy in this research study:

- All personal and research related information about you will be stored on a secure password protected university server and marked with a unique ID code. No identifiable information will leave university premises.
- Only researchers at the University of Exeter will have access to your personal information (contact details, consent forms). This will be kept securely for 5 years before being destroyed.
• All audio recordings collected as part of the research will be stored on a secure password protected university server for transcription and will be deleted after 1 year.

• Only the researchers at the university involved in this study will have access to audio recordings for transcription purposes. Some audio recordings may be sent to transcription services known to the university who are bound by their own data protection policies.

• All transcriptions of audio recordings will be anonymised and all identifiable information removed. There will be no identifiable information published as part of this study.

• All questionnaires and transcriptions used in the study will be marked with your unique ID code. All participant ID codes and associated personal information will be stored electronically on a password protected database, stored on a secure password protected university server.

• All signed paper consent forms will be scanned onto the university system and securely stored on a server. All paper forms will then be physically destroyed.

• All completed consent to contact forms will be stored on a secure server. All paper versions will be scanned onto the server and then destroyed.

• If you would like your data to be removed once you have taken part in the study, please request this in writing to the chief investigator (sa675@exeter.ac.uk) within 1 year following your participation. All information related to your participation in this study can then be removed using your unique ID code.

• This outlined information will be given to you again on the day of your participation.

Risk and Confidentiality

The only time we would break confidentiality was if we felt that you, or someone else, was at risk of harm. In such cases, we would talk to you about this first and risk procedures will be followed. We may also make contact with appropriate local services for support. You will be reminded of this on the day of participation.

Further information

If you have any further questions about this research study, please contact the lead researcher via email: sa675@exeter.ac.uk

University of Exeter, College of Life and Environmental Sciences, Psychology, Exeter, EX4 4QG.

Tel: 01392 72 2209.
To contact the Chair of Psychology Ethics, please contact Dr Nick Moberly (e: n.j.moberly@exeter.ac.uk t: 01392 724656)

Ethical approval number: eCLESPsy000805

Appendix G: Young Person Participation Information Sheet (Interviews)

**Participant Information Sheet**

**CHILD AND YOUNG PERSON (Aged 12-17 years)**

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K.
Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.
We would like to ask you to take part in our research study. It is really important that we give you all the information you need before you say ‘yes’ or ‘no’. Please could you read the information on this page carefully about what you will be asked to do. If it is easier, you can ask someone else to read it with you, like your parents. You can always ask us for more information at any time. The contact details can be seen below.

What is the study about?

Sometimes, teenagers who have had a brain injury can find it hard ‘connect’ with their friends. This may be for a number of reasons, ranging from difficulties with memories to feeling that friends do not understand you. We would like to hear more about your experiences with friends and think about how we could help. We also want to hear about what’s important to you.

Why am I being asked to take part?

We would like you to be in the study because you are the experts. We are asking both girls and boys between the ages of 12 and 17 years who have had a brain injury, or know a friend who has had a brain injury to take part.

Do I have to?

No, you do not have to take part if you do not want to. It's up to you and your parents. You can say yes or no.

What will happen in the study if I say yes?

If you say yes, we will give you and your parents more information on the study. If you are happy to continue, we will invite you to come to the University of Exeter one day to sit and have a conversation with the chief investigator about your experiences. If you live far away, this can also be done via telephone or Skype. You will be asked to share your experiences and opinions in response to some questions about peer relationships (friendships) following brain injury. There are no right or wrong answers, we just want to hear about your opinions and what is important to you. The interview will last for around one hour and refreshments will be provided.
We will ask you to tell us about the difficulties some teenagers with brain injuries may face with friendships, and the other difficulties with this. We also want to ask you for your advice about what would help.

What’s good about taking part?

You are the ‘experts’ in social experiences following brain injury. You will be helping us to understand what it is like for teenagers and what problems they might have. You can talk to us about what is meaningful and important to teenagers. We can think together about how we might be able to help teenagers who have difficulties with their friends. You will also get a £10 Amazon voucher as a thank you for coming along.

What’s bad about taking part?

One possible bad thing about taking part is that some of the discussions may be upsetting. If at any time you feel that you might be upset, you can stop. If you want to, we can talk about what might be upsetting you as this can often help. Further information about support will also be provided. If you want to leave the interview at any point, you are more than welcome to.

Will information be kept secret?

Due to recent regulatory changes in the way that data are processed (General Data Protection Regulations 2018 and the Data Protection Act, 2018), the University of Exeter’s lawful basis to process personal data for the purposes of carrying out research is termed as a ‘task in the public interest’. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University’s processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University’s Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection. If you have any concerns about how the data are controlled and managed for this study then you can also contact the Sponsor Representation, Pam Baxter, Senior Research Governance Officer (e: p.r.baxter2@exeter.ac.uk).

Making sure that your information remains private is important to us. We will do the following to protect your privacy in this research study:

- All personal and research related information about you will be stored on a secure password protected university server and marked with a unique ID code. No identifiable information will leave university premises.

- Only researchers at the University of Exeter will have access to your personal information (contact details, consent forms). This will be kept securely for 5 years before being destroyed.

- All audio recordings collected as part of the research will be stored on a secure password protected university server for transcription and will be deleted after 1 year.
• Only the researchers at the university involved in this study will have access to audio recordings for transcription purposes. Some audio recordings may be sent to transcription services known to the university who are bound by their own data protection policies.

• All transcriptions of audio recordings will be anonymised and all identifiable information removed. There will be no identifiable information published as part of this study.

• All questionnaires and transcriptions used in the study will be marked with your unique ID code. All participant ID codes and associated personal information will be stored electronically on a password protected database, stored on a secure password protected university server.

• All signed paper consent forms will be scanned onto the university system and securely stored on a server. All paper forms will then be physically destroyed.

• All completed consent to contact forms will be stored on a secure server. All paper versions will be scanned onto the server and then destroyed.

• If you would like your data to be removed once you have taken part in the study, please request this in writing to the chief investigator (sa675@exeter.ac.uk) within 1 year following your participation. All information related to your participation in this study can then be removed using your unique ID code.

• This outlined information will be given to you again on the day of your participation.

Risk and Confidentiality

We may have to break confidentiality if you say something that worries us. We will follow risk procedures and might have to tell someone else, such as your parents, what you have said to keep you safe. If we do this, we will talk to you first and provide you with support around accessing local services. You will be reminded of this on the day of participation.

Thank you for reading!

Further Information

If you have any further questions about this research study, please contact the lead researcher via email: sa675@exeter.ac.uk
University of Exeter, College of Life and Environmental Sciences, Psychology, Exeter, EX4 4QG.

Tel: 01392 72 2209.

To contact the Chair of Psychology Ethics, please contact Dr Nick Moberly (e: nj.moberly@exeter.ac.uk t: 01392 724656)

Ethical approval number: eCLESPsy000805
Appendix H: Parent Participant Information Sheet

Information Sheet for Parents of Potential Participants

CHILD AND YOUNG PERSON (Aged 12-17 years)

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K.
Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

Dear Sir / Madam

Purpose of the research

Acquired brain injury (ABI) in children and young people is a leading cause of disability worldwide. ABI can alter a child’s developmental trajectory when compared to their peers, with developmental ‘gaps’ becoming increasingly apparent with age. This can cause a number of psychosocial impairments including mood, educational attainment, and friendships. Little is known about the social outcomes in adolescents with ABI. Even less is known about how social impairments can be improved.

Peer relationships are extremely important during childhood. They allow for continual social development, the sharing of experiences, and simple companionship. Those with social impairments are at risk of peer rejection, making it difficult to establish a supportive peer group. As a consequence, those with ABI can experience isolation, loneliness, inappropriate behaviour, anxiety, and aggression.

The aim of this study is to use an intervention mapping approach to address the gap in the literature and to design a suitable intervention aimed at improving peer relationships. The chosen methodology supports the co-design of an intervention with the involvement of various ‘stakeholders’ who have in some way experienced ABI in adolescence. This includes adolescents with ABI, parents, peers, practitioners, and researchers. The study is interested in hearing about the social experiences of those impacted by ABI, and use their consultation to help design a treatment programme.

We would like to ask your child to take part in the research study. It is really important that we give you all the information about what your child is expected to do before you provide consent for them to participate. You can always ask us for more information at any time. The contact details can be seen below.

Why is my child being asked to take part?

We would like your child to be in the study because they are the ‘experts’ we would like to hear from in the development of this intervention. We are asking both girls and boys between the ages of 12 and 17 years who have had a brain injury, or know a friend who has to take part and offer their expertise.
What type of data is being collected and how?

The study will be collecting data using questionnaires, surveys, focus group discussions, and individual interviews. The questionnaires are used to collect a number of characterisation and demographic data; this includes social skills, quality of life, social economic status, type of injury, and injury severity (children with brain injury only). Each questionnaire will come with a set of instructions on how to complete them.

What will participation in interviews involve?

Interviews will be conducted face to face at the University or via technology (Skype or telephone), dependent on demographic locations. Interviews will last for approximately 1 to 1.5 hours and will be conducted one to one with the chief investigator. Your child will be asked to express their views and share experiences in response to the interview schedule. The questions will aim to explore their experiences and views towards the research topic, peer relationships following ABI. There are no right or wrong answers, we are just interested in hearing about your child’s experiences. For this study, we are interested in hearing their views about the social experiences of adolescents with ABI and to use these to help us design an intervention programme which will aim to improve relationships with peers. The interview will be audio recorded and all information is kept confidential.

When will the interview be?

If you are interested in your child taking part and have provided consent to be contacted, you will be contacted individually by the chief investigator to arrange a suitable time for their interview. If they cannot attend on the day, please let us know as soon as possible and we can rearrange.

What will happen on the day?

Face to face interviews

If your child is attending in person at the university, they will be welcomed by the chief investigator at the time specified on your individual interview invitation. Refreshments will be provided. They will be asked to bring with them the questionnaires that will be sent prior to the day. There will be an opportunity to ask further questions, and if they are happy, they will be asked to sign a consent form to continue with the interview. They will not be able to take part without this. The interview will last for approximately 1 to 1.5 hours and they will be asked a number of open ended questions to hear about their experiences and opinions. These interviews will be audio recorded and all information will be confidential. Please see below regarding how their data will be securely managed. Once the interview has finished, there will be an opportunity to debrief and they will be provided with a £10 Amazon voucher as a thank you for their time.

Interviews via technology
If your child is attending the interview via Skype or telephone, they will be contacted at the time of their interview, specified on the interview invitation. Once you both have provided consent to contact for the study, the chief investigator will ask which form of technology your child would find most preferable and support will be given to use the technology if required. You (or your child) will be asked to return the questionnaires sent to them either by post or scanner. On the day, there will be an opportunity to ask questions, and if you are both happy they will be asked to complete a 'consent to take part' form electronically via the study’s online webpage (link below) or via email. They will not be able to take part without this. The interview will last for approximately 1 to 1.5 hours and they will be asked a number of open ended questions to hear about their experiences and opinions. These interviews will be audio recorded and all information will be confidential. Please see below regarding how their data will be securely managed. Once the interview has finished, there will be an opportunity to debrief and they will be sent (via email) a £10 Amazon voucher as a thank you for their time.

Link for online consent form:
http://psychology.exeter.ac.uk/research/centres/ccnr/getinvolved/clinical/brain-injury/

Do they have to?

No, they do not have to take part, it is completely up to you and your child. If you choose not to participate, that’s okay. This will not impact your child’s care.

What’s good about taking part?

Your child is the ‘expert’ in social experiences following brain injury. They will be helping us to understand what it is like for teenagers and what problems they might have. They can talk to us about what is meaningful and important to teenagers when thinking about friendships. We can think together about how we might be able to help teenagers who have difficulties with their friends. They will also get a £10 Amazon voucher as a thank you for coming along.

What’s bad about taking part?

One possible bad thing about taking part is that some of the discussions may be upsetting. If at any time your child feels that they are becoming upset, they can stop. If they want to, they can use some time to discuss how they are feeling and information about support will be provided. If they want to leave the interview at any point, they are more than welcome to, no problem.

Will information be confidential?

Due to recent regulatory changes in the way that data are processed (General Data Protection Regulations 2018 and the Data Protection Act, 2018), the University of Exeter’s lawful basis to process personal data for the purposes of carrying out research is termed as a ‘task in the public interest’. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University’s processing of your personal data that cannot be resolved by the research
team, further information may be obtained from the University’s Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection. If you have any concerns about how the data are controlled and managed for this study then you can also contact the Sponsor Representation, Pam Baxter, Senior Research Governance Officer (e: p.r.baxter2@exeter.ac.uk).

Making sure that your child’s information remains private is important to us. We will do the following to protect their privacy in this research study:

- All personal and research related information about your child will be stored on a secure password protected university server and marked with a unique ID code. No identifiable information will leave university premises.

- Only researchers at the University of Exeter will have access to your child’s personal information (contact details, consent forms). This will be kept securely for 5 years before being destroyed.

- All audio recordings collected as part of the research will be stored on a secure password protected university server for transcription and will be deleted after 1 year.

- Only the researchers at the university involved in this study will have access to audio recordings for transcription purposes. Some audio recordings may be sent to transcription services known to the university who are bound by their own data protection policies.

- All transcriptions of audio recordings will be anonymised and all identifiable information removed. There will be no identifiable information published as part of this study.

- All questionnaires and transcriptions used in the study will be marked with your child’s unique ID code. All participant ID codes and associated personal information will be stored electronically on a password protected database, stored on a secure password protected university server.

- All signed paper consent forms will be scanned onto the university system and securely stored on a server. All paper forms will then be physically destroyed.

- All completed consent to contact forms will be stored on a secure server. All paper versions will be scanned onto the server and then destroyed.

- If you would like your child’s data to be removed once they have taken part in the study, please request this in writing to the chief investigator (sa675@exeter.ac.uk) within 1 year following their participation. All information related to your child’s participation in this study can then be removed using their unique ID code.

- This outlined information will be given to your child again on the day of their participation.
Risk and Confidentiality

The only time we would break confidentiality was if we felt that your child, or someone else, was at risk of harm. In such cases, risk procedures will be followed and we might have to tell you or someone else about what they have said in the interest of safety. We may also support you to make contact with appropriate local services for support. You will be reminded of this on the day of participation.

Thank you for reading!

Further Information

If you have any further questions about this research study, please contact the lead researcher via email: sa675@exeter.ac.uk

University of Exeter, College of Life and Environmental Sciences, Psychology, Exeter, EX4 4QG.

Tel: 01392 72 2209.

To contact the Chair of Psychology Ethics, please contact Dr Nick Moberly (e: n.j.moberly@exeter.ac.uk t: 01392 724656)

Ethical approval number: eCLESPsy000805
Participant Consent Form

STAKEHOLDER INTERVIEW PARTICIPATION

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K.
Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

Please tick as appropriate:

I confirm that I have read the information sheet dated 30/07/19 (version 3) and understand what is expected of me in this study.

I confirm that I have had opportunities to ask questions about this study and that these have been answered sufficiently.

I understand that I am participating on a voluntary basis and that I am free to withdraw at any time without consequence.

I understand that the information about me will be kept confidential and may only be viewed by members of the research team.

I understand that in the interest of safety, if a risk issue is identified by the chief investigator they may have to contact my GP. I understand that they will talk to me about this first.

Name of GP……………………………………..Telephone Number………………

I understand that all collected information about me will be anonymised and that there will be no identifiable information published following this study.

I agree that my contact details can be kept securely for the research team to contact me about the findings of the study.

I give my consent to participate in the interview for this study.

Name: ............................................................................................................
If you have any further questions about this research study, please contact the lead researcher via email: sa675@exeter.ac.uk

University of Exeter, College of Life and Environmental Sciences, Psychology, Exeter, EX4 4QG.

Tel: 01392 72 2209.

*Ethical approval number: eCLESPsy000805*
Parent/ Guardian Consent Form

PARENT/ GUARDIAN

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K.
Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

Please tick as appropriate:

I confirm that I have read the information sheet dated 16/04/2019 (version 2) and understand what is expected of my child in this study.

I confirm that I have had opportunities to ask questions about this study and that these have been answered sufficiently.

I understand that my child is participating on a voluntary basis and is free to withdraw at any time without consequence.

I understand that the information about my child will be kept confidential and may only be viewed by members of the research team.

I understand that all collected information about my child will be anonymised and that there will be no identifiable information published following this study.

I agree that my contact details can be kept securely for the research team to contact me and my child about the findings of the study.

I understand that my child’s GP will be informed of their participation in this study and I agree to this

I give my consent for my child to participate in the focus group for this study.

I agree that my contact details can be kept securely and used by researchers from the University of Exeter to contact me about future research projects.

(please tick or leave blank)

Name of Participant:........................................................................................................
If you have any further questions about this research study, please contact the lead researcher via email: sa675@exeter.ac.uk

University of Exeter, College of Life and Environmental Sciences, Psychology, Exeter, EX4 4QG.

Tel: 01392 72 2209.

Ethical approval number: eCLESPsy000805
Child Assent Form

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K.
Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

I have read or heard the participant information sheet

I have had the opportunity to ask questions about my involvement which have been answered

I understand what I would have to do in the study

I know that all the information about me will be kept secret

I know that I am allowed to leave the study at any time

Would you like to take part in the study?

YES

NO

Name of Participant:…………………………………………………………………...
Name of Parent: ……………………………………………………………………………

(please also complete the attached parental consent form)

Signature: ……………………………………………………………………………………

Date: ………………………………………………………………………………………

Signature of researcher taking assent/ consent: …………………………………………

Signature: ……………………………………………………………………………………

Date: ………………………………………………………………………………………

If you have any further questions about this research study, please contact the lead researcher via email: sa675@exeter.ac.uk

University of Exeter, College of Life and Environmental Sciences, Psychology, Exeter, EX4 4QG.

Tel: 01392 72 2209.

Ethical approval number: eCLESPsy000805
Participant Consent Form
(Young Person aged 16 years+)

Improving Peer Relationships in Adolescents Following Acquired Brain Injury:
Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K.
Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

Please tick as appropriate:

I confirm that I have read the information sheet dated 04/01/2018 (version 1) and understand what is expected of me in this study.

I confirm that I have had opportunities to ask questions about this study and that these have been answered sufficiently.

I understand that I am participating on a voluntary basis and that I am free to withdraw at any time without consequence.

I understand that the information about me will be kept confidential and may only be viewed by members of the research team.

I understand that all collected information about me will be anonymised and that there will be no identifiable information published following this study.

I agree that my contact details can be kept securely for the research team to contact me about the findings of the study.

I understand that my GP will be contacted about my participation in this study and I agree to this.

I give my consent to participate in the focus group for this study.

I agree that my contact details can be kept securely and used by researchers from the University of Exeter to contact me about future research projects. (please tick or leave blank)

Name: ……………………………………………………………………
Dear Scott Ankrett,

Application ID: eCLESPsy000805 v3.3

Title: Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Through Intervention Mapping.

Your e-Ethics application has been reviewed by the CLES Psychology Ethics Committee.

The outcome of the decision is: **Favourable**

**Potential Outcomes**

| **Favourable:** | The application has been granted ethical approval by the Committee. The application will be flagged as Closed in the system. To view it again, please select the tick box: View completed |
| **Favourable, with conditions:** | The application has been granted ethical approval by the Committee **conditional** on certain conditions being met, as detailed below. Unless stated otherwise, please resubmit the requested amendments via the online system before beginning the research. |
| **Provisional:** | You have **not** been granted ethical approval. The application needs to be amended in light of the Committee’s comments and resubmitted for Ethical review. |
| **Unfavourable:** | You have **not** been granted ethical approval. The application has been **rejected** by the Committee. The application needs to be amended in light of the Committee’s comments and resubmitted / or you need to complete a new application. |

Please view your application [here](#) and respond to comments as required. You can download your outcome letter by clicking on the ‘PDF' button on your eEthics Dashboard.

If you have any queries please contact the CLES Psychology Ethics Chair: **Nick Moberly** n.j.moberly@exeter.ac.uk

Kind regards,

CLES Psychology Ethics
Appendix K: Planning Group Survey

Planning Group Survey

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping

Dear Planning Group member,

Thank you for accepting the invitation to provide consultation for the above study, as part of my Doctorate in Clinical Psychology research thesis. As you may recall, you will be asked to provide consultation at various stages of the study (timeline outlined in appendices; Appendix A).

As part of Phase 1, I would like to ask you to complete this open-ended survey, aiming to gain your perspectives on the multiple possible determinants which influence peer relationships following acquired brain injury (ABI) in young people. Your responses will be collated to inform a logic model.

The logic model is created using the multifactorial precede approach (Green & Kreuter, 1999). Using this approach, the target problem for intervention (peer relationships), and its impact upon quality of life, is understood to be a result of a number of determinants or factors. Determinants include personal, biological, environmental, cultural, and interpersonal factors which may influence peer relationships following ABI.

Please try to answer the questions as openly as possible. Your answers will be transcribed and analysed to inform the initial development of the model. I will then provide feedback to the planning group as a whole. The developed logic model will then be shared with stakeholders in focus group sessions for their feedback and for re-development. Stakeholders will include adolescents with ABI, parents, peers, and practitioners.
Questions

1. How long have you worked within the field of acquired brain injury (ABI)?
   • Has this largely been with adults or young people?
   • Mainly in a research, clinical, or community role?
   • Particular areas of specialty?

2. For this study, ABI will refer to a number of injury mechanisms resulting in disconnection or structural damage within the brain, its neurons, and neuronal pathways after a typical period of development. Causes of ABI within the paediatric population include TBI, infection, stroke, hypoxia, tumour, radiation treatments, non-accidental injury, and secondary swelling.

3. What do you think are common difficulties experienced by young people with ABI?
   e.g., cognitive, social, behavioural, emotional.

4. What challenges can these difficulties cause in everyday life for young people with ABI?

5. What is your perspective on the importance of peer relationships in adolescence in general?

6. How do you think peer relationships are affected following ABI in young people?
   e.g., What might change? How will sequela of ABI influence changes? What will the consequences be?

7. In your experience, what is the impact of peer relationship difficulties on quality of life in young people with ABI.
   e.g., What aspects of their lives will be affected? What are the ongoing psychological implications?

8. Which biological determinants do you think influence peer relationships following ABI in young people?
   e.g., age, sex, brain development, genetics, health difficulties, pain, injury type (mechanism and severity), post-medical interventions (radiotherapy, surgery)?

9. Which personal determinants do you think influence peer relationships following ABI in young people?
   e.g., personality, sense of self, social skills, pre-injury factors?
9. Which psychological determinants do you think influence peer relationships following ABI in young people?
   e.g., cognition (e.g., memory, attention, processing speed, executive functioning, visuospatial, fatigue, awareness), communication, social cognition, mood (PTSD, anxiety, depression), resilience, coping skills?

10. Which environmental factors do you think influence peer relationships following ABI in young people?
   e.g., family functioning, educational support, peer understanding, social relationships, engagement, societal understanding, on-going community support (healthcare and social)?

11. Which behavioural factors do you think would influence peer relationships following ABI in young people?
   e.g., impulsivity, inappropriate behaviour, aggression, social isolation?

12. How do you think young people with ABI can be supported to improve peer relationships?

13. Is there anything else that you think is important to discuss which the questions have not covered?

Thank you.

Further information

If you would like to know more about the study or ask any further questions, please do not hesitate to get in touch with myself (sa675@exeter.ac.uk) or Prof Anna Adlam (a.r.adlam@exeter.ac.uk).

Thank you for taking the time to complete this survey.

Please return your completed version via email using the addresses above.

Warm wishes,

Scott Ankrett
Trainee Clinical Psychologist

University of Exeter
sa675@exeter.ac.uk
Appendices

Appendix A: Outline Timeline of Planning Group Involvement Across Study

1. Forming of the planning group (March 2019)
2. Surveys sent for completion (March/April 2019)
3. Consultation in Phase 1 – feedback on first draft of logic model of the problem (a model which outlines the determinants which influence peer relationships following ABI) developed from planning group responses (May 2019)
4. Consultation in Phase 2 – feedback following stakeholder focus groups and feedback on revised logic model of the problem (re-developed with stakeholder input). (December 2019)
5. Consultation in Phase 3 – feedback on qualitative analysis of the study, providing a completed logic model of the problem, suggested determinants for change, and intervention themes and aims (February 2020)
6. Thesis submission for examination (May 2020)
7. Thesis viva (July 2020)
8. Submit manuscript for publication (by September 2020)
Appendix L: Logic Model of the Problem (1st Draft) for Focus Groups and Interviews

**Determinants**

**Biological Determinants**
- Age of Injury
- Injury characteristics [type, severity, location]
- Gender
- On-going health issues

**Personal Determinants**
- Maturity
- Personality
- Popularity at school
- Social skills [pre-injury]
- Stability in identity [pre-injury]

**Psychological Determinants**
- Cognitive abilities
- Communicative ability
- Mental health and mood
- Resilience
- Social cognition [ability to process and respond to social information]

**Behavioural Determinants**
- Behaviour that challenges
- Fixed thinking
- Emotional control
- Motivation [mood]
- Avoiding social situations [self-isolating]

**Environmental Determinants**
- Family relationships and support
- Peer support and adaptability
- Community support and understanding
- Location and available services
- Family openness to share difficulties
- Parental coping
- Family, school, and peer understanding

**Everyday Difficulties of ABI**
- Vulnerability to social influences [intensions of others, gangs, crime]
- Academic challenges
- Grieving past identity and abilities
- Opportunities to participate in activities
- Feeling misunderstood
- Social skills [multifactorial]

**Peer Relationships and ABI**
- Peer victimisation and rejection
- Seen as ‘different’ [to others and compared to pre-injury]
- Uncertainty from peers on how to interact with teenager with ABI
- Ability of peers to be able to adapt to changes in personality
- Ability to manage stressful social situations
- Cognitive barriers to friendships
- Social communication difficulties
- Quality of interaction and relationship
- Time away from peers and reintegration
- Social avoidance and isolation due to mood

**Quality of Life**
- Difficulty with acceptance [from self and others]
- Change in identity
- Increased dependence on family
- Isolation and reduced social contact
- Mental health difficulties
- Loneliness
- Risk of harm to self

Determinants = factors that can influence everyday difficulties for teenagers with ABI and their friendships.
Appendix M: Focus Group Schedule for Adolescents

Adolescent Focus Group Schedule

Introduction – 5 Minutes

“My name is Scott and this is NAME, and we’re here today to have a conversation and be creative”

“The aim of this group is for us to have a discussion about friendships following brain injury in teenagers. We want to hear about the good things and the bad things”

“As you are the experts, we also want to ask for your help and tell us what would be useful to help you and other young people with brain injuries to build friendships”

“We will work together for around one hour and I will ask the group some questions. I hope that we can have a discussion around these and make some notes together using this big piece of paper and coloured pens. There are no right or wrong answers, we are just here to hear each other’s opinions”

“To help me remember what has been said in the group, I will use this to record the session, but only the research team and transcription services will listen to this. You can talk to your family and friends about what you have said in the group. You can also talk about what others have said but you cannot use their names, as their opinions may be personal to them”

“The only time I will tell someone about what you have said in this group is if you share something that worries us, something which may result in either you or someone else getting hurt, but I will talk to you about this first”

(Some of what we speak about today might make you feel sad or angry, if you find this difficult, please let me know and we can stop and have a break. You
can then either carry on in the group or leave the room. If you feel too sad to carry on, that's okay.”

“Do you have any questions?”

Respond to questions

**Open Question – 10 Minutes**

“Okay let’s get started”

“Let’s talk about friendships, what are these? Why are they important?”

- What are your experiences of these after ABI?

“Thinking about some of the difficulties that young people can experience following brain injury how can these influence friendships?

- “Changes in thinking”
  - (attention, memory, executive functioning, fatigue)
- “Changes in ability to communicate to others”
- “Changes in mood”
  - (sadness, anger, worry, PTSD)
- “Changes in behaviour?”
  - (impulsivity, aggressive, withdrawn)

**Key Questions – 35 Minutes**

**Determinants**

**Social Factors**
“Let’s talk about school…do you think schools, teachers or friends, understand brain injuries?”

“Do you think that schools provides enough support to help other young people in class to understand brain injury”

“What do you think other children think about brain injury, do you think this affects friendships?”

“Does ongoing medical support affect friendships?”

“Do you think there are enough opportunities for teenagers with brain injuries to meet new friends? Or be with their friends?”

Psychological Factors

Cognition

“Changes in thinking are common following brain injury, people may experience changes in their ability to remember things, problem-solve, communicate, or concentrate. Let’s talk about how this can affect friendships”

“What’s your experience of this?”

- Remembering what friends have said?
- Keep up with conversations
- Tiredness - gets in the way of being with friends?

Social Cognition

What about processing and responding to social situations?

- Interacting with friends
• Understanding how friends are feeling
• Understanding jokes
• Upsetting friends without knowing why

**Mood**

“Changes in mood are common for everyone. Following brain injury, people may experience strong feelings of sadness, worry, or anger, which can affect being with friends”

“What’s your experience of this?”

**Behaviour**

“What about behaviour with friends following brain injuries?”

• Isolation?
• Unacceptable behaviours?
• Aggressive behaviours?
• Acting without thinking?

**Quality of Life**

“How do you think all of these difficulties which we have discussed so far affect quality of life for teenagers?”

**BRIEF TASK**

Logic Model of the Problem
“Here is a diagram which has partly been filled in by some people who have worked a lot with young people with brain injuries. Here, we are trying to understand what can influence friendships and how this can affect day to day life.”

Talk through model.

“Does this make sense, are there any questions?”

“Now, although these people have worked a lot with young people with brain injuries, they have not had one themselves. I need your help to see if we need to make changes to this to ensure that this is meaningful for you”

“Do you think that there is anything missing from this?”

Prompts:

- “Do you think that this has included everything we have spoken about so far?”
- “Does anything need re-wording or deleting?”
- “Is there anything that you do not agree with?”

**What Needs to Change?**

“Okay, what needs to change to help build friendships following brain injury? What do you think can help?”

Prompts:

- “What about awareness and understanding?”
- “What about increasing opportunities and practice?”
- “What about learning new skills?”
- “What about help with thinking?”
• “What about help with mood?”
• “What about help with behaviours?”

Meaningful Intervention Design

“If you were being supported with friendships at school or hospital, what would be most important to you?”

Prompts

• “Would this be online or in person?”
• “How long would you like this to be?”
• “Would you like this to be individual or in a group?”
• “Would you like this to be delivered by a teacher, psychologist, or young adult?”
• “What type of goals would you have, or hopes following the support?”

Ending – 5 Minutes

“Okay, thank you, that's all the questions I have. I think we have had a really good discussion and spoken about some really important things (summarise key points).”

“Are there any questions?”

“How is everyone feeling? Does anyone have any concerns?”

“Thank you so much for taking part in the group and helping me with this project”
Provide thank you cards with £10 Amazon voucher.
Provide debrief and additional resources sheet.
15/04/19 **Focus Group Piloting**

Piloted the focus groups schedule (adolescents) with four adolescent females without ABI (2 aged 15, 2 aged 13). The purpose of the piloting was to assess the accessibility of the draft schedule, checking with the participants the meaningfulness of the questions for their age range and to see if how they responded to the questions was suitable for the research questions. The challenge with this is that the schedules were designed for individuals with extensive experience of ABI in adolescence. As such, a significant amount of time was spent attempting to get the participants to consider themselves to have an ABI or to imagine being a character who had an ABI. For this, we created a character called Viveka (see below) and built up her story, allowing the participants to imagine what life would be like if they were Viveka.

The consequence of doing this is that we spent a large amount of time talking around the brain injury in the paediatric population. Similarly, the first questions asked for perspectives on common difficulties following brain injury. This resulted much time being spent on a question which wasn’t related to the research questions. As a result, I amended the focus group to exclude this question. This is with the assumption that those coming to the focus group will have a good understanding of ABI, saving time and relevance for the study.

Other questions on the schedule appeared to be accessible to the piloting group, and they did not report any difficulties understanding the questions. I expect that a significant amount of time may be taken when explaining the logic model within interviews and focus groups. To account for this, I will make a summary sheet of
the logic model and send this to stakeholders prior to their participation. The piloting group presenting with no difficulties in being able to talk about friendships in adolescence and think about how having an ABI might alter peer dynamics. As suggested by the piloting group, no further changes are required on the schedule.

Out of the conversation with the piloting group, some interesting topics arose. Assumptions from peers appeared to be a potential barrier for friendships in young people with ABI. The piloting group said that without understanding, assumptions may be made, such as “she’s sensitive, she’s a drama queen” which may affect the ability to connect with others. Similarly the group offered some helpful suggestion around how an intervention programme should be delivered to people of their age, based on their experiences of what they have found helpful at their school, such as not having an external person come deliver an assembly, opting for more of an in depth teaching and rationale, co-delivered by a teacher and independent person.

Key points from discussion:

- Lack of understanding from staff and students
- Assumptions: taking things personally
- Understanding jokes – hard to lighten mood around brain injury, may be easier to withdraw from peers
- Jealousy from peers 'special treatment' – without communication and understanding as to why.
- Difficulty 'fitting in'
- Family can be over protective
- Social anxiety
- Increased impulsivity for arguments
- Memory problems causing tension
- Friendships are important at school – someone to rely on and share things with, provides understanding
- More likely to get bullied without friends, no one stands up for you
- Feel left out
- Less likely to be motivated at school
- Friends are someone who you can share problems with, moan at, relate to
- Workshop would be better than an assembly (no pointless work sheets)
- Lack of understanding from friends, assumptions:
  - What happened?
  - Lazy, naughty, using it as an excuse
  - Rumours if the child is unpopular
  - Faking illness – bringing a doctor’s note for friends (?)
  - No physical difficulties – invisible injuries.
  - Less likely to be invited to things – “kill joy”, have to be more careful around what you’re saying.
## Appendix O: Theme Summary for Stakeholder Feedback

<table>
<thead>
<tr>
<th>Theme</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DOMAIN ONE: UNDERSTANDING</strong></td>
<td>This domain encompasses an understanding of what peer relationships are like following ABI in adolescence, and what causes difficulties with peer relationships, as described by stakeholders.</td>
</tr>
<tr>
<td>Dropped and Excluded</td>
<td>This theme captures stakeholder experiences of adolescents feeling dropped by friends following brain injury. Stakeholders describe the loss of friendships, influenced by friends moving on whilst the adolescent is away recovering. In addition, when re-integrated back into social contexts, peers can perceive adolescents as weird, or frustrating, influenced by behavioural, cognitive, and social cognitive consequences of ABI. As such, peers are more likely to reject adolescents or exclude them from social activities, as for many teens this is a stage of important social development and sensitivity to social acceptance.</td>
</tr>
<tr>
<td>Isolated and Alone</td>
<td>This theme describes the feelings of isolation and loneliness of adolescents following ABI, resulting from the exclusion by friends.</td>
</tr>
<tr>
<td>A Need to Belong</td>
<td>This is an important theme that follows stakeholders identifying the importance of peer relationships for belonging. Adolescents following ABI have a strong desire to fit in, appear normal, and be accepted in some capacity. As such, adolescents can make adjustment to friendship groups, such as relating to those with similar needs, or becoming vulnerable to undesirable influences.</td>
</tr>
<tr>
<td>No one Understands</td>
<td>Stakeholder accounts suggested that difficulties with peer relationships are compounded by people’s lack of understanding around ABI and how individuals may change, although look the same. This is the difficulty with ABI as they are often termed ‘invisible injuries’ whereby survivors appear the same to others but act differently. Without education and understanding of this, people around adolescents can make assumptions or becoming victimising towards them (stigma).</td>
</tr>
<tr>
<td>Restricted Independence at a Time for Growth</td>
<td>Adolescents following ABI experience significant restrictions on their lives compared to their peers. This is at a time of important social development, as such, adolescents can fall behind when compared to their peers. Such restrictions include over-protection, always having a TA, and reliance on others.</td>
</tr>
<tr>
<td>Loss of Past-Self</td>
<td>Following ABI, adolescents experience significant change in terms of their identity. They may not be able to continue with previous career aspirations, may lose sporting identity, and lose and overall sense of self amongst friends and family. This comes with significant emotional ramifications and adolescents attempt to adapt to their new identities post-injury.</td>
</tr>
<tr>
<td>Challenges with Acquired Status</td>
<td>This themes encompasses the conflicts and difficulties adolescents face following ABI, in terms of mood, emotions, behaviours, and</td>
</tr>
</tbody>
</table>
cognition. There is a sense of loss of previous abilities as well as challenges in their new way of being. This can impact upon peer relationships through responses to behaviours, withdrawal, or cognitive challenges.

**DOMAIN TWO: SUPPORTING**

This domain encompasses themes from stakeholder accounts regarding what needs to change to improve peer relationships and what outcomes the intervention should focus on.

**Building Understanding**

This theme captures the need for increased understanding around ABI within the adolescents educational, social, and community contexts. This may include teaching training, education sessions, online resources, videos, apps, to help build understanding and acceptance.

**Meaningful Social Connection**

Stakeholders identified a need for more opportunities, however, not just an objective amount of opportunities but subjectively meaningful opportunities. These include, being with friends, meeting others, peer mentoring, doing fun activities, having someone to talk to.

**Support for the Journey**

Within this theme, stakeholders felt the need for early support following ABI. Often, stakeholders felt isolated and unsure of the future following discharge from hospital. Furthermore, lack of assessment resulted in lack of understanding within contexts. Within this, it would be important to consider anxiety management, knowledge, and realistic expectations.

**Empowerment**

An intervention needs to empower adolescents in the context of ABI. Often they received negative messages from their contexts which can result in feelings of shame. Empowering adolescents may include validation, normalisation, knowledge, hope, and opportunities for adolescents to become the experts, such as using social media to describe experiences or to teach others about ABI. An increase in confidence may support relationships with peers.
I have only got three friends because all the friends I used to make keep dropping me and being horrible. (FG)

You know when you put on your thing it's usual about getting this … because she really does remember what she was like 1½ years ago to how she is now and what her friendship groups were like, and now she doesn’t see anybody that she was at primary school with. (FG)

The move to secondary school further sometimes because your able friends, although they might have supported you in primary school, when you go to secondary school they move on and meet other people and your further dropped really. (I)

So you’re sick all the time which means you’re off sick even more than you already was, so things go on and people develop friendships in school, and you’re missing it all, like I had a best friend when I fell ill and I came back after not being sick and she’d made a new best friend because she couldn’t go through school every single day without somebody (I)

So that I missed out on that big time and then all of my friends that I went to it with all of these years seems to have all been lost and then I didn’t go to get in then and obviously you grow apart from them because of that. (I)

Well, (right), just because, you know, she seems to have lost everything previous to the accident, you know, all of her friends and she’s lost all of them (I)

Ern, no, I think it’s the whole you’re missing from school for so much then, that’s when everybody plans things, if they’re even doing something after school or they’re doing something that weekend, they plan it while they’re in school and you’re not there for that planning stage, therefore you just don’t get invited, and that’s it. So you’re already missing that peer interaction from school, but you’re also missing any type of interaction outside of school. (I)

I didn’t know them before they had their brain injuries, but for these two who have had a real severe impact, the difference is massive because they’ve gone from what was their typical trajectory to being completely taken out of their cohort of peers, so they don’t currently in their school hours, they don’t have access to these peers anymore, erm, and I think that makes a huge amount of stress for them to have outside of school (I)

They just think she’s a bit odd. (FG)

Their friends, while they don’t necessarily want to isolate people, knows there is something different about them and just wants to kind of get on with everybody and fit in everybody else, and then you actually miss I think there is a lack of things if you’ve got not understanding on their level of what their experiencing. So, of course you’re going to get left out of that. (I)

But if you’re not got empathy into their situation and how it’s devastating for them then how their friends have dropped it, and they don’t want to be the one who hangs out with people with a brain injury because they don’t see that it’s appropriate to do it. (I)

Their friends or the whole level thing will just broken down their friendship and they just don’t want to be around you if you’re not happy. (I)

Yes, I make fun of it. Then they say I am even worse because I am making fun of it. It isn’t something to make fun of, but when I have got nothing else to do about it, it is better to make fun of it than just sat about all the time (FG)

I have got some friends that I thought were my friends, but then they are really nice to me when I am dizzy and stuff. Then they are caring and trying to look after me, but as soon as I am not they don’t hang out with me at all. I question now almost all of my friends. Do you actually like me or do you just feel sorry for me? (FG)

No, she has no filter, [name], sometimes, so she says things that are – inappropriate is probably too strong – but in the wrong context, and so the other kids are like, “Well, that’s a joke,” or something (FG)

She didn’t want it at all so people just think I am being really weird. Sometimes take people seriously and then they will be like, “It was a joke.” (FG)

She’s got new friends now, as I said, she seems to make friends easily, but they don’t last. They’re sort of…quick friendships, there’s nothing to them if you know what I mean? (FG)

...
<table>
<thead>
<tr>
<th>1.2 Isolated and Alone</th>
<th>1.2.1 Feeling isolated</th>
<th>1.2.2 Difficulties meeting up with friends</th>
<th>1.2.3 Mental health/ trauma</th>
<th>1.2.4 Being alone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Their friends, while they don’t purposely want to isolate this person, know there is something different about them and just wants to kind of get on with everybody else and fit in everybody else, so they don’t want to be the one who hangs out with the one who’s just a bit weird. (I)</td>
<td>You’re also not allowed to do the same things that your peers would have been able to do like, like I wasn’t allowed outside for like six months (laughter). You know because I was, it was feared that I got hit in the head, so I didn’t go out and then I wasn’t allowed to play hockey and I was a big sporting person, so I wasn’t allowed to play hockey, I wasn’t allowed to play netball, I wasn’t allowed to play anything in case I got hit on the head. (I)</td>
<td>It sounds, it sounds, really awful but, erm, the, whenever you go to the doctors and go to the doctors and whatever and see them and stuff like this and they say “oh yes, you suffer for post-traumatic stress disorder, because of your brain injury.” I’m like, “no, I didn’t suffer from post-traumatic stress disorder because of my brain injury”, I could deal with that fine. I could deal with the fact that I had a brain injury. It was losing all the friends that I couldn’t deal with. (I)</td>
<td>And then we’ve had to move her schools again because the school that she was in couldn’t really accommodate her so she’s gone to knowing nobody, and really, she really needs a better friendship network and she finds it really hard. Whether she would have always found that hard I don’t know, but she’s certainly lonely, and more lonely probably than she would have been if she hadn’t banged her head and could actually stay in a classroom. (FG)</td>
<td></td>
</tr>
<tr>
<td>I think that’s the issue that people have, is that they just changed so much and they just don’t fit into those friendships groups anymore and then they just end up being really isolated and in so many families and children with adolescence, that was the hardest thing that they found for them, not kind of mourning for the child that they lost but seeing their children being kind of sad and lonely. (I)</td>
<td>Yeah, like I said it’s the hardest thing, it’s not like the loss of the academic ability or even the loss of the physical side of things, it’s that isolation and loneliness that is really hard for the young person themselves to deal with but it’s hard for the families to witness. (I)</td>
<td>Low mood obviously does, is socially isolating because you don’t, it’s a lot of effort isn’t it if you want to keep up a social life and if you, if in your mind it’s been proven that actually no one wants to be with you then why bother? You don’t do it do you? (I) But then because you’re so low mood, when if you’re around people when you feel like you want to be around them, they don’t want to be around you. Like, nobody wants to be around someone that’s not happy, and then also you’re so frustrated that, obviously you’re angry, and your anger shows. (I)</td>
<td>if you are not connecting with people of your own age in an appropriate way, then you can feel very isolated and lonely, and you’re going to be able to achieve anything else, like, you’re not going to be to progress in school if you’re going into school and feeling very socially isolated, and anxious, and depressed. (I)</td>
<td></td>
</tr>
<tr>
<td>Their friends, while they don’t purposely want to isolate this person, know there is something different about them and just wants to kind of get on with everybody else and fit in everybody else, so they don’t want to be the one who hangs out with the one who’s just a bit weird. (I)</td>
<td></td>
<td></td>
<td>He’s not even wanted to have that kind of interaction, it’s almost like my family, my dog, and if you talked to him which hopefully you will, it’s “milly this, milly that, milly everything”, his dog, his brothers, his dog, his swimming, his art, it’s just, his world has narrowed. And it carries on now when I see how narrow it’s got, I was really worried (I)</td>
<td></td>
</tr>
<tr>
<td>Yeah, like I said it’s the hardest thing, it’s not like the loss of the academic ability or even the loss of the physical side of things, it’s that isolation and loneliness that is really hard for the young person themselves to deal with but it’s hard for the families to witness. (I)</td>
<td>But with this, nothing, nothing. It’s the most isolating condition, and we’ve hit a lot of medical conditions within my family and extended family, it’s the most isolating condition I’ve ever come across. (I)</td>
<td></td>
<td>Erm, then, you can get bullied obviously, erm, just become very lonely and then, in my case, you just try to abandon ship and leave (laughter). Erm, it, its crap quality of life. Can you put that in your research paper? (I)</td>
<td></td>
</tr>
</tbody>
</table>
1.3 A Need to Belong

1.3.1 Wanting to be with friends/
belonging

You need to have a community in which you feel you belong, other than your family, other than your home and dad. As you're getting older you need to have something, whether it's just you who play football, somebody else who actually is helping you in some way to move on to becoming an adult. (FG)

They just need to feel like they belong to something, whether it's someone or something or certainly for us it is. She just needs to feel accepted and normal, that's her daily thing. (I)

I think that when you are younger, they don't matter, like friends, you know, you have your friends... with Tommy one day and Delilah the next. It's not, you know they're just who you hang about with but as you get older and you go through different situations, scenarios and backgrounds, you start to have a structure of friends otherwise you'll be isolated. (FG)

So whether the children there, they're just who you hang about with but have friends../ (I)

Yeah, she just wants to be a normal teenager, and get on with doing normal stuff, but there's just that little bit behind it. (I)

1.3.2 Fitting in and being normal

I think that's the issue that people have, is that they just changed so much and they just don't fit into those friendship groups anymore and then they just end up really isolated. (FG)

Yes, do fit in? Yes, exactly. Kids want to be normal as a teenager. They don't want to stand out, and they are having some form of injury - whatever it is, it's, is, disability or anything - you want to be as normal as possible and I think that's really hard. (FG)

Yes, because she's so vulnerable. And they're desperate to be liked - and co-dependent to fit in, and desperate to look cool, whatever that is. And they don't understand what any of this is. (FG)

Because kids don't... it.. do they? That's the thing, and. All they desperately want is to fit in and be - not super-normal... but have a little crew. And not look normal. - crew of kids... that... the same sex, and that are accepting of you? (FG)

The reason you're not sure is because you've bumped your head and you're not as normal as everybody else. (FG)

You're particularly for one of us, because to be part of that group in terms of, erm, it's really hard to put into words, or, use some aspects of normality, like, er, for one of the young girls now, she's still struggling and, when she's around her siblings, she wants to be wearing pants because she knows that that's what they do, so there's that sense of wanting to be "normal". (FG)

You've got this child who, all they want to do is just fit in and they can't. (FG)

They're not really engaging with her because, and this is very important for your study, because he didn't want to appear different. (FG)

And if my peers and my friends who, you would like to think would want to take it in, if it was a week-long I think that they would. I didn't really like the whole pushing me to surround myself with other people with brain injury. Didn't like that because, like CBT didn't and I love CBT and everything, but I wanted to be normal. (FG)

You just kind of want to forget about it. It's weird, because you want them to understand you but also want to be normal. It's a bit conflicting. (FG)

Yeah, she just wants to be a normal teenager, and get on with doing normal stuff, but there's just that little bit behind it. (FG)

1.3.3 Vulnerability

1.3.4 Similar level friends

One day, because he is the only friend that's just chilled, and he's a little bit quieter and a little bit slower, and even though they were friends at school, now, they're really good friends just because they're now on about the same sort of pace. (FG)

And because the girl was French, even though she spoke really good English she was just a little slower at her processing because it was a foreign language, and they just got on brilliantly because she was actually on a par. (FG)

But the girl only stayed for a term. (FG)

And actually I think some of those are the vulnerable kids at school, aren't is in a separate unit and they come to the unit rather than having to face all the kids in the playground. (FG)

So it's his situation has helped him. (FG)

But I said, some of his friends have, because they're the ones who find the playground stressful as well. But it seems to have half the kids who have got - which suits him brilliantly - anxiety, not fitting in at school or whatever. We've never found an activity where he can go and interact with peers who have no brain injury. (FG)

But I knew he was, his, the only friends I would say that he's kept, have been, literally, from age, (FG), a child called (name), that he was friends with his primary school, who's got ADHD, who she also has problem making friends, and they've been able to refresh their friendships over Fortuite on line. (FG)

1.3.5 Moving schools

And then we've what I know her school again because the school that she was in couldn't really accommodate her so she's gone to know nobody, and really, she really needs a better friendship network and she finds it really hard. (FG)

I was going to say to you, think back to what it was really hard to get friends. Because [name], we've got him into a school now where he's made some new friends but for a long time after he went it was a bit hard, wasn't it? (FG)

Well, yes, I've done as much as I can to try and get people to help him. Because I think they understand... So we have specifically chosen the school based on their special needs record and what they can offer. (FG)

So I left school to college, but a lot of people in colleges were coming from secondary schools in which people had classroom assistants and people had learning difficulties so there wasn't a judgment and so no one knew me before so this is who they knew me as, and that was that. (FG)

1.3.6 Friends over grades

One boy, because he's the only friend that's just chilled, and he's a little bit quieter and a little bit slower, and even though they were friends at school, now, they're really good friends just because they're now on about the same sort of pace. (FG)

And because the girl was French, even though she spoke really good English she was just a little slower at her processing because it was a foreign language, and they just got on brilliantly because she was actually on a par. (FG)

But the girl only stayed for a term. (FG)

And actually I think some of those are the vulnerable kids at school, aren't is in a separate unit and they come to the unit rather than having to face all the kids in the playground. So it's his situation has helped him. (FG)

But I said, some of his friends have, because they're the ones who find the playground stressful as well. But it seems to have half the kids who have got - which suits him brilliantly - anxiety, not fitting in at school or whatever. We've never found an activity where he can go and interact with peers who have no brain injury. (FG)

But I knew he was, his, the only friends I would say that he's kept, have been, literally, from age, (FG), a child called (name), that he was friends with his primary school, who's got ADHD, who she also has problem making friends, and they've been able to refresh their friendships over Fortuite on line. (FG)

Yes, my brain would be split off all the other clinical crop and more onto managing now that those peer relationship doesn't break down. (FG)

Our whole experience of the brain injury, the thing that has spent the most as patient was friendships. So we have, so we had his school and most of his educational healthcare plan not on the academic side but the friendships side. So that, for us, was kind of like we don't care if he doesn't come out with any formal qualifications, or low; we want him to have friends. And so for us, that has always been the most important thing. And so that why high school has been working for you; because you have found some friends, but we identified that in the most difficult thing for him. (FG)

I wouldn't have casual if you got my GCSE's as long as I will had my friends at school. I would rather I had made interventions from psychopathology at school that I had for educational stuff. I would rather I left school with no GCSE's and didn't get bullied. (FG)

The peer relationship is more key to an adolescent's happiness at adolescence than their ability to succeed at school or to be better. (FG)
1.4.1 Environmental understanding

1.4.1.1 Impact of the injury

1.4.1.2 Support received

1.4.2 Assumptions and attitudes of others

1.4.3 Invisible injury / Appearing the same

1.4.4 Peer acceptance

1.4 No one understands

My school tells me that at this age. It was sort of Breach because the school was so that I wouldn't have a meeting about my concussion. It was a really weird school so we moved and now the school are really supportive. They have a special area that you can go into and it's really good now. (FG)

And we had a friend, and her daughter – this happened – and her daughter decided she didn't want to, and we said, "Well we could watch from the house so if it's not quite so intense, and we were like, "Oh, but you really want to go down to the field with everybody." So, they're going to do, so [name] stayed on her own. And I was like, "That's pretty creepy friendship," but that's what some of the parents can be like as well, that they just go. "Well, she's just bringing about noticing to join in," and it's, "Well, no. She would love 1.4.5 Support received

My school is actually good at accommodating me because if I am down in the dups or somebody hasn't met me, I can go straight to the quad and they have a lock here who I can tell. (FG)

No, my school doesn't do that. They don't talk like this person has a brain injury or stop bullying them. They don't say anything about me, like how to treat me. It is terrible. (FG)

Well, mine happened at primary school, the injury happened at primary school so I think my primary school suddenly stepped up. I've never looked at it from any other… I've never really thought could do something but I wasn't. And so, she returned in Year 1 and they put an and lot of stuff in place, but only because of what had happened. And there was a local secondary school. They refused to do anything; they wouldn't, even have a meeting (FG)

Yes I mean, I don't know, you're the first people I've met, ever, since she's banged her head in those years (FG)

1.4.4 Peer acceptance

back into these social groups, and it's kind of at that point, when everything else has fallen away from families in terms of support, the child goes back to school and you think it's never going to be the same as it was before and it wasn't, and that's when things become very apparent and very quickly (FG)

Erm, a bit, but a bit, when children go to adolescence, the going support they get is minimal, it depends obviously at what point you had your injury, if they are having lasting adolescence then they will still get a lot of support, but especially here. (FG)

Well, I think that they have the sometimes it's in the hospital, their medical input is really minimal, you don't have any community nurses or anything like that, you just kind of get your once a year appointment with your neuropsychologist and then it's just kind of, get on with it, and here CBT (FG) of support

So, mine didn't say anything about the injury, just sort of… I'm sure I probably thought it was just kind of get on with it. (FG)

Yes, it's crap. The hospital is amazing and it's got a really good programme, but once you get into the community that's it, there is no services, and I don't know what that is like across the others areas, are, but I'm kind of, yeah, get on with it. (FG)

And, then I got like, I was in the adult ward, I got released without support so nobody, so my mom and dad couldn't really as, so and he would you to do this, which is when my mom found CHET and CHET came in, and kind of got the talk to the teachers and I finally got my assessment done by psychologists and memory therapists, or whatever you want to call them and all of my professionals, then they put my statement down. Then my statement was written up when I was 17. as it took 3 years for them to summarise what was actually wrong with me following my brain injury. (FG)

And, I think that this one is… (FG)

IMPROVING PEER RELATIONSHIPS FOR ADOLESCENTS WITH BRAIN INJURIES-185...
1.5 Restricted independence at a time for growth

He would pretty much like me to be around all the time. That’s another thing because we’ve spent an unrationally long time together. As if, when you’re in hospital, we lived together 24 hours a day, didn’t we? And so from our point of view, just having an opportunity to be in a safe environment doing something else with kids his own age would be a great, great thing for us. (I)

during this, so they become so socially isolated they look more and more to the family, err, they spend more time by themselves or more time with adults, they lose their ability to act with age appropriate peers, err, the parents move on with everything (I)

you have to rely on your parents more because they’re obviously a bit stupid (right) cautious about letting you out on its own by yourself or something like that, you know, in case you forget where you are, you just get lost and you can’t find your way back, so you make sure you’re there safely, and you get lost and you know, in case you forget where you are and so forth (I)

So I think it’s been a bit restrictive really. (I)

Do we have any idea of how it is living without normal social interaction, and that kind of stuff, and that’s when it becomes you start worrying about what other people think and how you’re behaving, and not really being able to do things, because you’re just looking at other people and pretending to be like them. (FG)

1.5.4 Restrictions on meeting friends

We’ve probably, around the time when he should have been having a bit more independence, he was actually quite if we then think we’ve been a bit. Well, not just as an advice but from others. We’ve been very conscious of how much he can do on his own (I)

Well, because no one is coming to tell you or tell you a secret or include you in something if there’s an adult sitting there. So, no one is going to come and ever say, you know, give you all the group and this diet if you’ve got an adult there, you just see all that. Err, you miss all the rude jokes and stuff like that, because it’s like “oh, he’s got her with her” or whatever, err. Rem, the naughty bits and all that. (I)

For good reason to begin with but now I think we’ve a bit protective and so we, perhaps, don’t do as much as we would have done in the past. That we’re working on that. (FG)

Well, because no one is coming to tell you or tell you a secret or include you in something if there’s an adult sitting there. So, no one is going to come and ever say, you know, give you all the group and this diet if you’ve got an adult there, you just see all that. Err, you miss all the rude jokes and stuff like that, because it’s like “oh, he’s got her with her” or whatever, err. Rem, the naughty bits and all that. (I)

Well, no one is coming to tell you or tell you a secret or include you in something if there’s an adult sitting there. So, no one is going to come and ever say, you know, give you all the group and this diet if you’ve got an adult there, you just see all that. Err, you miss all the rude jokes and stuff like that, because it’s like “oh, he’s got her with her” or whatever, err. Rem, the naughty bits and all that. (I)

For good reason to begin with but now I think we’ve a bit protective and so we, perhaps, don’t do as much as we would have done in the past. That we’re working on that. (FG)

Well, no one is coming to tell you or tell you a secret or include you in something if there’s an adult sitting there. So, no one is going to come and ever say, you know, give you all the group and this diet if you’ve got an adult there, you just see all that. Err, you miss all the rude jokes and stuff like that, because it’s like “oh, he’s got her with her” or whatever, err. Rem, the naughty bits and all that. (I)
1.6.1 Past self/ loss of identity/ loss of sports

Firstly, it’s just that it’s very similar. Erm, nobody can tell you what’s wrong with you, therefore nobody can explain to the person that you love what’s wrong with you, and therefore how are they meant to understand it? Therefore you get isolated. Very lonely, very depressed, you don’t have that sense of achievement anymore, you’ve completed lost your identity, and, it just, it can lead to you downward spiral. (I)

Then, it was, I used to go to A-levels, go to University and do the normal like adolescent thing, so you’re not well enough to do that. So, then it was then you have to go to college that you were further isolated and that then caused more problems with your mood and then it goes on and on as well, like I can’t work full time. (I)

I know from talking to the kids that siblings actually highlight your demise as well. Because if they were younger than you, you were like the big brother, the younger person over-takes you and they’re allowed to go out at night or walk home from school and you’re sort of not, or they’re allowed to go out and get a girlfriend but you haven’t got one. When that reaches its tipping point, then I would think that that then reduces your quality of life, because you’re thinking “oh god, I used to be a big brother, now I’m not.” (I)

His entire identity was through swimming, he had really close friendships with his swimming mates (I)

He started to call himself, like Frank, erm, he said he wasn’t (name), he kind of had this rating of who he felt, and he like “I’m not (name) anymore, I’m Frank” and then there was another one and I can’t remember the other name that he gave, but it was almost like he was rating himself on, he was so not himself (I)

Then, like, you’re meant to be a high achiever, for example like over anybody else, but like how he should have done this and you have a constant comparison of where you should be, and you’re not there. (I)

You kind of deal with that whole loss of identity and get very depressed because you’re not achieving what you could have achieved maybe a couple of months prior. Erm, then, you can get bullied obliviously, erm, just become very lonely and then, in my case, you just try to abandon ship and leave (laughing). Erm, it’s, its crap quality of life. Can you put that in your research paper? (I)

Very lonely, very depressed, you don’t have that sense of achievement anymore, you’ve completed lost your identity, and, just, it can lead to a very downward spiral. (I)

And so their view of themselves is damaged and they have adjustment issues although they might be on the way after the injury. The move to secondary school brings it all up again. (I)

Yeah, hackney and northall, I had trials for the district teams and the under 16, whatever it was for like his island and everything, and I couldn’t go to them because I wasn’t allowed to play (I)

So then I missed out on that big time and then all of my friends that I went to it with all get on the teams and then I didn’t go to, and, and obviously you grow apart from them because of that. It would be the same if you’re in a certain clique (KELLO), then you’re in a certain clique, like I was in the choir one, if you were in the music one and you weren’t able to go to music because you were too tired, you’re going to lose your music friends. It’s just that way inclined. (I)

1.6.2 Changing after injury

So, she’s not the same. But if she’s better, she’s changed; and she has changed, but has she changed because she’s become a teenager in part of it, but she has changed from the child she was before she banged her head to how she is now? And she’s lost loads of confidence, so that makes it really hard to make friends when you’re really, really isolated. (FG)

And that’s definitely what’s changed, because for me obviously, your kids were a bit younger, but I had an 11 year old who was really, really on and it and there, top of the class, blah blah blah, and literally within six months she can’t remember the alphabet, she can’t count to 10 and she’s got a tutor, and she’s not the cool kid in class that’s selected for all the games because now she throws the ball it doesn’t quite go where it should. So, she’s got a real personal battle. (FG)

Yes, (name) was a completely normal child until she had the ABI, and now she’s not. And they were taping her being as gifted and talented and things and all the rest of it because she was not bright, and now she’s not bright. And so you, we’ve got the before and after – (FG)

You, yes you kind of say that she didn’t remember how she was before. And she doesn’t remember all of it, and I don’t remember about all of it, but then I don’t know what’s the right thing to do, as a parent, or you’re not there. (FG)

...you know, because me before my injury was (name) before my injury, I’ve always explained this to my wife, I said “oh, you know, this is me now, and you know, this is the (name) now”, and I remember the old (name), and I always say to her, “you never knew the old (name)”, and I guess that’s funny to get your head around if you’re not familiar with brain injury (I)

He’s just very, the epilps gone out of him, he’s just very, very pale, he’s not the same child, basically. (name) is just not the same child. (I)

1.6.3 Maturity

Erm, I suppose initially it would be, (name) might think. My first thought might be that the brain injury might affect the level of kind of, cognition and maturity, and that might result in a young person behaving in a way that was less developmentally mature than their peers, and that would have a significant impact. (I)

I think it, sometimes they become much more mature than their peers, and that causes separation. Sometimes their much less mature than their peers, and that causes a separation. (I)

(That’s) been through and they have their ability, certainly was a bright…now we’re sort of thinking, she’s going to sort of, of, those meta-cognitive thoughts, I don’t think, younger teenage boys. Girls might a little bit more, err, but, being a teenager is about being in the moment, and you can’t be in the moment with a brain injury. (I)

Yes, I worry for her, because she really does remember what she was like 2½ years ago to how she is now and what her friendship groups were like, and now she doesn’t really see anybody that she was at primary school with. (FG)

So I think he only point of reference now, although you can remember… I know he can remember what you could do physically, like how you could walk and ride your bike and all that kind of stuff before, but your injury, I think it’s harder for him to see how his speech and processing might have an effect. (FG)

Yes, I think it’s a hard thing for a child to go through really, particularly… I think we well, Penny has always said, the thing about an acquired brain injury is they quite often remember how they were before and so they comment how difficult it was before, to how it is now. (I)

Yeah, I think she used, she’s found stuff, we’ve been clearing out her room and stuff over a couple of days here when she’s been home, and we found all this poetry, she used to write poetry and things like that, she can’t do anything like that now. (I)

She hasn’t been able to sort of think, and her imagination seems to have been affected or something, but she won competitions and everything at school for poetry and things like that, she can’t do anything like that now. (I)

You know when you put on your thing it’s about giving the… because she really does remember what she was like 2½ years ago to how she is now and what her friendship groups were like, and now she doesn’t really see anybody that she was at primary school with. (FG)

So I think he only point of reference now, although you can remember… I know he can remember what you could do physically, like how you could walk and ride your bike and all that kind of stuff before, but your injury, I think it’s harder for him to see how his speech and processing might have an effect. (FG)

Yes, I think it’s a hard thing for a child to go through really, particularly… I think we well, Penny has always said, the thing about an acquired brain injury is they quite often remember how they were before and so they comment how difficult it was before, to how it is now. (I)

Yeah, I think she used, she’s found stuff, we’ve been clearing out her room and stuff over a couple of days here when she’s been home, and we found all this poetry, she used to write poetry and things like that, she can’t do anything like that now. (I)

She hasn’t been able to sort of think, and her imagination seems to have been affected or something, but she won competitions and everything at school for poetry and things like that, she can’t do anything like that now. (I)
1.7 Challenge

1.7.1 Mental health/depression/anger

There’s a bit of a relationship between the two, but there’s also a bit of a difference. The reality is that, if I said, it’s a lot more common knowledge now and people can easily talk about it without feeling ashamed. (I)

You’re not going to be in progress in school if you’re going into school and feeling very socially isolated, and anxious and depressed. You’re not going to be able to kind of, you know worry about going home and talking to your parents about it, because they’re not going to understand, erm, and I think that, it’s just life in it’s, it’s going to have a really massive impact on your mental health and if you’re already, kind of, behind and lagging behind, and then you’ve got all this depression and anxiety and rubbish situation then, that’s just impairs everything. (I)

And I think that’s what kind of takes over, Yes, he did get himself into a couple of pretty hard low mood and what’s the point?, but he’s picked himself up each time. But that’s harder and harder, and I was having this conversation with your mum in another 8 months time, I’d be very worried. (I)

Erm, obviously these days I didn’t use them before the brain injury, erm, but I assume that, that she (говорит), there’s a lot of low mood, erm, and frustration, erm (говорит), kind of occasional episodes of aggression and crying, but those are intriguing really. (I)

And, and mood, you know, I think I’m feeling sad or low or depression, if I say, in a big word for teenagers with ABI, rather than depression, I think they just are depression and I think it’s just a big gap, it’s the subject, it’s an area really, it’s a horrible area for teenagers to understand because you know, ‘will anyone ever marry me, will I get a job, will I be able to drive?’, it’s all those questions going on all the time, and of course their parents are not all those questions either. (I)

Low mood obviously does, is socially isolating because you don’t, it’s not an offener if it’s if you want to keep up a social life and if you’re in a mental health’s been proven that actually once no one, little things, you know, there’s something wrong with you, Erm, but, I don’t see, in that teenager group. I don’t see actually what I would call depression or what’s diagnosis with depression, erm, I think the low mood, and the low energy, and the low motivation, and the low behaviour, they just all thing what the kind of, I’ve seen them in the emergency. (I)

If you say, in one case like me, ‘I can’t play football anymore, what’s the point?’, but that was their background. (I)

Lack of hope is probably the biggest thing. (I)

If anything sad happens, they really don’t show that much emotions and yet, for little things, you know, like getting caught doing something, it’s like, in the extremes, and then her anger, you know, she’s got some sort of anger, but they don’t long it out, long it’s about her, you know, it’s like, it’s not unexpected, you know, I think you’re not to see “why, they don’t understand”, and it will go over the simplest things. But that’s definitely been a big thing, that’s a really different, I think with her friends, but what it’s how much does she know because you’re not like, explained. (I)

I only remember things when somebody speaks really slow. Not quick. (FG)

I think the other thing with her friends with the friends – I don’t know if your girls get it - like when you go a gaggle of girls and they’re doing the three or four-way conversations and they’re all talking, they’re all talking, they’re all talking, I’m not ever speaking to them, over something really, really minute. It’s like over exaggerating to everything. (I)

Whereas, normally people know if someone’s getting angry, whereas a child with a brain injury might be completely fine and then bang, it can change so quickly, and can be hard for other teenagers to understand. (I)

And then also, they’ve got this idea that if anything went wrong, then they’re going to have their friends, and they’re going to talk about it, and they might get into trouble, and they’re going to feel even more anxious and nervous about it, and so as your family, they’re going to go and talk to you. (I)

When she gets tired, he struggles to find the words and then he’s worried that he’ll come across as stupid. (I)

For a long time he was in denial that anything... Well he knew something had happened but he was never wanted to talk about it. It’s only recently that you’ll talk about it, isn’t it? Before he was like, “I don’t want to...” (I)

And that’s view of themselves is damaged and they have adjustment issues although they might be way after the injury. The move to secondary school brings it all up again, I think. (I)

And she’s lost loads of confidence, so that makes it really hard to make friends when you’re really, really introverted. (FG)

It was Norman, but he was so removed from himself, but she didn’t feel like he could talk to teachers, nobody understood, etc, he didn’t like talking to people or anyone around him and said “how are you (name)?”, he would just “I am fine” and that would be it, and he would shut down. (I)

Yeah, and I also feel that you’re very caught up in the emotions and you don’t want to talk about yourself and like, speaking from personal experience, I didn’t want to open up. (FG)

And tell people what was really going on, or how were you feeling. You’re half scared that someone may do something or make you do something and you just don’t want to open up. (FG)

And you’re not going to want to open up. You don’t want to talk about it. (I)

I am like, ‘No, I don’t want to...’ (I)

And she’s lost loads of confidence, so that makes it really hard to make friends when you’re really, really introverted. (FG)

Yeah, and I also feel that you’re very caught up in the emotions and you don’t want to talk about yourself and like, speaking from personal experience, I didn’t want to open up. (FG)

And tell people what was really going on, or how were you feeling. You’re half scared that someone may do something or make you do something and you just don’t want to open up. (FG)

And you’re not going to want to open up. You don’t want to talk about it. (I)

I am like, ‘No, I don’t want to...’ (I)

And she’s lost loads of confidence, so that makes it really hard to make friends when you’re really, really introverted. (FG)

Yeah, and I also feel that you’re very caught up in the emotions and you don’t want to talk about yourself and like, speaking from personal experience, I didn’t want to open up. (FG)

And tell people what was really going on, or how were you feeling. You’re half scared that someone may do something or make you do something and you just don’t want to open up. (FG)

And you’re not going to want to open up. You don’t want to talk about it. (I)

I am like, ‘No, I don’t want to...’ (I)

And she’s lost loads of confidence, so that makes it really hard to make friends when you’re really, really introverted. (FG)

Yeah, and I also feel that you’re very caught up in the emotions and you don’t want to talk about yourself and like, speaking from personal experience, I didn’t want to open up. (FG)

And tell people what was really going on, or how were you feeling. You’re half scared that someone may do something or make you do something and you just don’t want to open up. (FG)

And you’re not going to want to open up. You don’t want to talk about it. (I)

I am like, ‘No, I don’t want to...’ (I)

And she’s lost loads of confidence, so that makes it really hard to make friends when you’re really, really introverted. (FG)

Yeah, and I also feel that you’re very caught up in the emotions and you don’t want to talk about yourself and like, speaking from personal experience, I didn’t want to open up. (FG)

And tell people what was really going on, or how were you feeling. You’re half scared that someone may do something or make you do something and you just don’t want to open up. (FG)

And you’re not going to want to open up. You don’t want to talk about it. (I)

I am like, ‘No, I don’t want to...’ (I)