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# Development of an Intervention to Identify and Address Long-Term Participation and Well-being Needs of Children and Young People with Acquired Brain Injuries and their Families: A Mixed Methods Study

Thesis submitted to the University of Nottingham  
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*'Start by doing what's necessary; then do what's possible; and suddenly you are doing the impossible.'*

*St Francis of Assisi*

## Abstract

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**Background:** Acquired Brain Injury (ABI) is recognised as a significant public health issue, being the global leading cause of mortality and morbidity across all age groups. Approximately 40,000 UK children and young people (CYP) sustain an ABI every year from traumatic and non-traumatic causes. The physical, cognitive, emotional, and behavioural sequelae of ABI may continue to become evident months or years after the event, as childhood development progresses, and education and social demands increase. These can have a significant impact on the participation and well-being of CYP and their families.

**Aim:** To explore the long-term participation and well-being needs of UK CYP with ABI (5-18 years) and their families and develop a theoretically underpinned intervention to identify and address them.

**Methods:** A complex intervention development study was conducted using a theory-driven, evidence-informed approach, combining the Behaviour Change Wheel (COM-B and Theoretical Domains Framework (TDF)) and the Person-Based Approach (PBA). A scoping review of the literature regarding the long-term needs of CYP with ABI and their families was conducted to inform the study design. Study One was a mixed-methods study including a quantitative cross-sectional survey and multi-stakeholder qualitative study, in one geographical region of the UK. The survey included participation and health-related quality of life (HRQoL) outcomes and goals of CYP with ABI and their families. Standardised measures were used: Child and

Adolescent Scale of Participation, Pediatric Quality of Life Inventory 4.0 Generic, Pediatric Quality of Life Inventory – Family Impact Module and Patient Health Questionnaire for Anxiety and Depression.

Interviews were conducted with CYP with ABI and parents, and focus groups with health, education, social care and charity stakeholders.

Findings were analysed using the framework method using the ICF and COM-B/TDF. Study Two included synthesis of the scoping review and mixed methods study findings, a co-design workshop with CYP with ABI, parent, health education, social care and charity stakeholders, and theoretical modelling of the intervention.

**Results:** The scoping review identified four key themes; CYP-related impairment needs, support needs, return to school and long-term aftercare. Survey responses (n=95) demonstrated 72% of CYP had severely impaired participation and 67% had increased risk of impaired HRQoL. Reduced HRQoL and family functioning was reported by 53% of parents and 37% had an increased risk of anxiety/depression. Significant unmet participation and well-being needs were reported in 10 CYP/parent dyad interviews and focus groups with 17 health, education, care, and charity stakeholders. Barriers spanned the COM-B and TDF domains; the greatest being knowledge, skills, social influences, environmental context and resources, social identity, and emotion. Facilitators included increasing awareness and understanding, parent support, long-term access to specialist assessment and rehabilitation, and integrated collaborative pathways. The co-design workshop participants (n=17) identified potential solutions and

intervention ingredients. These included the need for education for families and schools regarding long-term impact of ABI, and longer-term practical and emotional support for families. Findings from the workshop were analysed using the framework method and synthesised with previous findings using the BCW. The BCW and PBA guided the theoretical modelling of the intervention, 'ABI-Participate'. This included identifying guiding principles and key design objectives that were mapped to intervention functions and behaviour change techniques to produce a logic model.

**Conclusion:** This research has provided an in-depth understanding of the substantial unmet participation and well-being needs of CYP with ABI and their families, and the barriers and facilitators they, and stakeholders, face in accessing support and rehabilitation. A systematic intervention development process using a theory-, evidence-, and person-based approach resulted in a logic model for 'ABI-Participate', which aims to address the unmet needs and barriers of CYP with ABI and their families. Further research is now required to refine this multi-faceted intervention, specify the components and develop the care pathway to support its effective implementation prior to feasibility testing,

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**Deleted:** of the intervention and develop the care pathway to support its effective implementation.

## Related Outputs

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### Publications arising from this thesis

- **Keetley, R.**, Manning JC., Kettlewell, J., Williams, J., Bennett, E., Crozier, D., Dean, M., Radford, K. (Submitted) Enabling participation in children and young people with acquired brain injuries and their families - a theory-, evidence-, and person-based approach to intervention development. *Submitted to BMJ Open*
- **Keetley, R.**, Manning JC., Williams, J., Bennett, E., Westlake, M., Radford, K., (2024) Understanding barriers and facilitators to long-term participation needs in children and young people following acquired brain injuries: a qualitative multi-stakeholder study. *Brain Impairment* 25, IB23100.  
<https://doi.org/10.1071/IB23100>
- **Keetley, R.**, Manning, J.C., Williams, J., Stewart, I. and Radford, K., 2024. Child and family health-related quality of life and participation outcomes and goals after acquired brain injury: a cross-sectional survey. *Brain injury*, pp.1-10.  
<https://doi.org/10.1080/02699052.2024.2309244>
- **Keetley, R.**, Radford, K. and Manning, J.C., 2019. A scoping review of the needs of children and young people with acquired brain injuries and their families. *Brain injury*, 33(9), pp.1117-1128. <https://doi.org/10.1080/02699052.2019.1637542>

## Conference Abstracts, Posters and Presentations

- **Keetley R**, Manning JC., Kettlewell J, Williams J, Bennett E, Crozier D, Dean, M, Radford K. 'ABI-Participate' – Using co-design to develop an intervention enabling participation in children and young people with acquired brain injuries and their families. *International Paediatric Brain Injury Society Conference, Glasgow, September 2024. (Oral presentation)*
- **Keetley R**, Manning JC., Williams J, Bennett E, Westlake M, Radford K. Understanding barriers and facilitators to participation and well-being in children and young people following acquired brain injury: a multi-stakeholder interview study. *European Academy of Childhood Disability Conference, Bruges, May 2024. (Oral presentation)*
- **Keetley R.**, Manning JC., Kettlewell, J., Radford K. (2024) Enabling participation in children and young people with acquired brain injuries and their families: a mixed methods study. *British Paediatric Neurology Association - Neurorehabilitation Special Interest Group meeting, March 2024. (Invited Speaker)*
- **Keetley R.**, Manning JC., Williams J, Bennett E, Westlake M, Radford K. (2024) Enabling participation in children and young people (CYP) with acquired brain injuries (ABI) and their families – mixed methods study – preliminary qualitative results. *University of Nottingham Centre for Children and Young People's Health Research (Oral presentation)*

- **Keetley R.**, Crozier D., Dean M. (2023) The BRILL Service (including PhD research overview). *Neptune (Paediatric Major Trauma) Conference. Nottingham, June 2023 (Invited speakers)*
- **Keetley R.**, Manning JC., Williams J., Stewart I., Radford K. (2022) Enabling participation in children and young people (CYP) with acquired brain injuries (ABI) and their families – mixed methods study – preliminary results. *International Paediatric Brain Injury Conference, New York, September 2022 (Oral presentation)*
- **Keetley R.**, Manning JC., Williams J., Stewart I., Radford K. (2022) Enabling participation in children and young people (CYP) with acquired brain injuries (ABI) and their families – mixed methods study – preliminary survey results. *NUH 'Engage, Enthuse, Empower' conference, Nottingham, June 2022 (Oral and poster presentation)*
- **Keetley R.**, Manning JC., Williams J., Stewart I., Radford K. (2022) Enabling participation in children and young people (CYP) with acquired brain injuries (ABI) and their families – mixed methods study – study protocol. *NUH 'Engage, Enthuse, Empower' conference, Nottingham, June 2022 (Poster presentation)*



- **Keetley R.**, Manning JC., Williams J., Stewart I., Radford K.  
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- **Keetley R.**, Manning JC., Williams J., Stewart I., Radford K.  
 (2022) Enabling participation in children and young people (CYP) with acquired brain injuries (ABI) and their families – mixed methods study – preliminary survey results. *University of Nottingham School of Medicine Sue Watson PGR presentations, May 2022 (Oral presentation)*
- **Keetley R.**, Manning JC., Williams J., Stewart I., Radford K.  
 (2022) Enabling participation in children and young people (CYP) with acquired brain injuries (ABI) and their families – mixed methods study – preliminary survey results. *University of Nottingham Centre for Children and Young People's Health Research, March 2022 (Oral presentation)*

- **Keetley R.**, Manning JC., Radford K. (2021) Enabling participation in children and young people (CYP) with acquired brain injuries (ABI) and their families – mixed methods study – study protocol. *Eastern Child Head Injury Network, November 2021 (Online oral presentation)*
- **Keetley R.** (2021) Journey to PhD (including PhD study protocol. *ARC-EM Partners Board, November 2021 (Online oral presentation)*
- **Keetley, R.**, Radford, K., Manning, JC. A scoping review of the needs of children and young people with acquired brain injuries and their families. *Society of Research in Rehabilitation. Nottingham. February 2019 (poster presentation)*

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## **Abbreviations**

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ABI – Acquired Brain Injury

ABI-P – ‘ABI-Participate’

AHPN – Allied Health Professionals and Neuropsychologists

BCT – Behaviour Change Technique

BCW – Behaviour Change Wheel

BSRM – British Society of Rehabilitation Medicine

CASP – Child and Adolescent Scale of Participation

COM-B – Capability, Opportunity, Motivation and Behaviour

CNS – Central Nervous System

CYP – Children and Young People

CYP-ABI – Children and Young People with Acquired Brain Injury

DALYs – Disability Adjusted Life Years

ED – Emergency Department

EPS – Educational Professionals and Support Staff

FMHS – Faculty of Medicine and Health Sciences

fPRC – Family of Participation-Related Constructs

GCS – Glasgow Coma Scale

GP – General Practitioner

HRA – Health Research Authority

HRQoL – Health-Related Quality of Life

ICB – Integrated Care Board

ICD-10 – International Classification of Diseases – 10<sup>th</sup> version

ICF – International Classification of Functioning, Disability and Health

ICF-CY – ICF–Children and Youth version

ICS – Integrated Care System

IMD – Index of Multiple Deprivation

IQR – Interquartile Range

JBI – Joanna Briggs Institute

KOSCHI – Kings Outcome Scale of Childhood Head Injury

MRC – Medical Research Council

NHS – National Health Service

NSPCC – National Society for the Prevention of Cruelty to Children

NTBI – Non-Traumatic Brain Injury

PBA – Person-Based Approach

PedsQL™ – Pediatric Quality of Life Inventory

PedsQL™-FIM – Pediatric Quality of Life Inventory – Family Impact  
Module

PHQ-4 – Patient Health Questionnaire – 4

PICO – Population, Intervention, Comparison and Outcome

PIS – Patient Information Sheet

PPI – Patient and Public Involvement

PRISMA – Preferred Reporting Items for Systematic Reviews and  
Meta-analyses

QoL – Quality of Life

RCPCH – Royal College of Paediatrics and Child Health

REC – Research Ethics Committee

SCP – Social Care and Charity Professionals

TBI – Traumatic Brain Injury

TDF – Theoretical Domains Framework

UK – United Kingdom

WHO – World Health Organisation

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# 1 Introduction

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## 1.1 Chapter Overview

This chapter introduces the thesis, and the concepts and context it is situated within. It introduces Acquired Brain Injury (ABI) in children and young people (CYP), including the aetiology and epidemiology. The biopsychosocial model used to describe the impact of a health condition on a person and its use within rehabilitation and children's neuro-disability is introduced and used to consider the neurological sequelae of an ABI, the long-term consequences and impact on CYP and the family. The concepts central to this thesis - participation, quality of life, health-related quality of life and well-being - are discussed.

'Rehabilitation' is defined and discussed, specifically the national neuro-rehabilitation context for CYP in the UK. Gaps in the evidence base regarding the long-term needs of CYP with ABI and their families are described. The theoretical frameworks employed in this thesis to support the intervention development are introduced.

## 1.2 Introduction to the thesis

This thesis is presented as a PhD by publication and includes four papers:

- Chapter 1 presents an introduction to the area of research.
- Chapter 2 presents a published scoping review of the literature. I am the lead author and responsible for conceptualisation, methodology, project administration, investigation, data curation, formal analysis, validation, visualisation, writing – original draft, reviewing and editing.
- Chapter 3 presents the methodology for a mixed-methods study and a co-design intervention development study.
- Chapter 4 presents a published paper reporting the results of the first part of the mixed-methods study - a cross-sectional survey. I am the lead author and responsible for conceptualisation, methodology, project administration, resources, investigation, data curation, formal analysis, validation, visualisation, writing – original draft, reviewing and editing.
- Chapter 5 presents a published paper reporting the findings of the second part of the mixed methods study – a multi-stakeholder qualitative study. I am the lead author and responsible for conceptualisation, methodology, project administration, resources, investigation, data curation, formal analysis, validation, visualisation, writing – original draft, reviewing and editing.



- Chapter 6 presents a paper submitted for publication detailing a co-design intervention development study. I am the lead author and responsible for conceptualisation, methodology, project administration, resources, investigation, data curation, formal analysis, validation, visualisation, writing – original draft, reviewing and editing.
- Chapter 7 includes an overall discussion of the thesis, recommendations for practice and policy, strengths and limitations, research impact and future research.

### **1.3 Aetiology and Epidemiology of Acquired Brain Injury**

Acquired brain injury (ABI) is defined as a non-degenerative injury to the brain that has occurred since birth <sup>1</sup>. ABI is a leading cause of death and disability and is categorised as a traumatic brain injury (TBI), as a result of external factors such as a fall or road-traffic collision, or a non-traumatic brain injury (NTBI), as a result of internal factors such as a stroke, encephalitis, infection, hypoxia, or brain tumour <sup>2,3</sup>.

Global incidence rates are reported as 180-825 per 100,000 for TBI and 82.5 per 100,000 for NTBI <sup>4</sup>. The World Health Organization (WHO) recognises ABI as a significant public health issue, contributing to the more than three billion people worldwide now living with a neurological condition <sup>5,6</sup>. The Global Burden of Disease Study 2021 showed an increase of 18% in the overall amount of disability, illness, and premature death (disability-adjusted-life-years (DALYs)) as a result of neurological conditions since 1990 <sup>6</sup>. Both the authors of this study and WHO have called for urgent action in developing interventions to support access to care, treatment, and rehabilitation for the increasing number of people living with neurological conditions across the world<sup>5,6</sup>.

In the UK approximately 40,000 CYP, under the age of 16 years, sustain an ABI every year. NHS (National Health Service) England <sup>7</sup> incidence rates report 35,000 new cases of TBI annually, with 2000 classified as severe, 3000 as moderate and 30,000 as mild. NTBI accounts for 4000 new cases, associated with severe to moderate encephalopathy caused by infection, inflammation, or lack of oxygen.

Central nervous system (CNS) tumours, benign or malignant, account for 500 new cases each year, presenting significant risk of neurological impairment because of the tumour growth, surgery, or treatment <sup>7-9</sup>. Whilst childhood stroke is uncommon compared to adults, it has a similar incidence rate to that of CNS tumours in CYP, with 50% of survivors experiencing ongoing neurological disability <sup>10</sup>. Advances in acute medical treatment and management have improved survival rates for childhood ABI, albeit with varying degrees of neurological sequelae and increased rehabilitation needs <sup>11-13</sup>.

The severity of the ABI is commonly classified using the 15-point standardised Glasgow Coma Score (GCS) as mild (GCS 13-15), moderate (GCS 9-12) and severe (GCS 3-8) <sup>14</sup>. GCS is one of the most established predictors of outcome, with moderate and severe scores being associated with poorer outcomes, particularly across cognitive, behavioural, mental health and social functioning domains <sup>15</sup>. Other predictive factors of outcomes are also used, such as duration of coma and presence of prolonged disorder of consciousness and length of stay in intensive care and in rehabilitation. However, considerable individual variability makes recovery difficult to predict <sup>13,15</sup>. The heterogeneity of ABI means every injury is unique and will affect a CYP differently and at different times. Multiple factors impact recovery, such as age at onset, severity, mechanism of injury, pre-injury ability, pre-existing neurodiversity or disability, family, environmental and psychosocial factors, and variability in rehabilitation provision <sup>13-21</sup>. This heterogeneity makes it challenging to quantify universal impact, design

universal rehabilitation services and research outcomes with this population.

#### **1.4 The Impact of an ABI**

In considering the impact of an ABI and the resultant needs of CYP and their families, it is necessary to define needs. This is complex and challenging as an individual's perceived need reflects their individual, cultural and societal values <sup>22</sup>. Within this thesis, the following definition of need is adopted:

*'a problem that significantly interferes with daily life'* <sup>23</sup> (p502).

Needs can be further categorised into 'met need' (services received), 'unmet need' (perceived need but not receiving services) and 'unrecognised need' (not used or needed a service but reported impairments/limitations) <sup>24,25</sup>. This definition and categorisation enables the identification and description of the needs of CYP and their families utilising a biopsychosocial model.

##### **1.4.1 International Classification of Functioning, Disability and Health**

The International Classification of Functioning, Disability and Health (ICF) provides a universal biopsychosocial model for describing health outcomes for a person, whilst also considering the multidimensional influences on their functioning, disability, and life experience <sup>26</sup> (Figure 1-1).

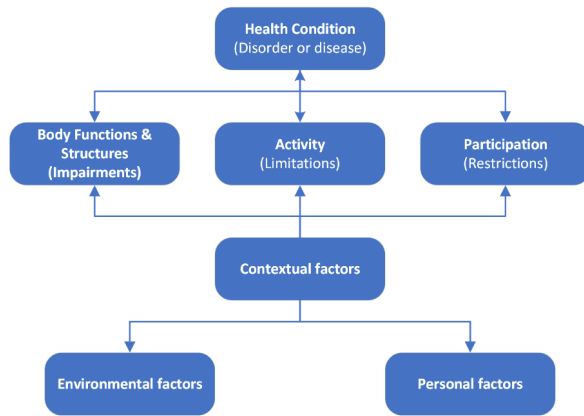


Figure 1-1: WHO International Classification of Functioning, Health and Disability <sup>26</sup>

The ICF encompasses individual, social, and environmental factors and the dynamic relationships between these, within the domains of body functions and structures, activity, participation, contextual environment, and personal factors <sup>27,28</sup>.

With its focus on function, the ICF is *aetiology-neutral*; disability is not differentiated by health condition. It can therefore be applied to heterogeneous populations served by single rehabilitation teams, which facilitates health condition comparison and service evaluation <sup>29</sup>. In 2012 the Child-Youth Version (ICF-CY) was merged into the ICF, ensuring a lifespan approach that includes recognition of the distinct circumstances of a child's development and transition to adulthood <sup>30,31</sup>. The ICF is used as the underpinning framework of many adult and CYP rehabilitation outcome measures and provides a common language for all health professionals which encourages interdisciplinary collaboration

to describe the focus and goals of rehabilitation and identify long-term needs<sup>16,20,30</sup>. The ICF can therefore be used to describe the impact of an ABI for a CYP and their needs (met, unmet, unrecognised), also considering the impact on childhood development and their family<sup>4,19,32,33</sup>.

Whilst the above are some of the strengths of the ICF, it does have its limitations and there is concern regarding the lack of clarity regarding some of the domains. In particular, there is a lack of descriptors within the personal factors domain, combined descriptors for the activity and participation domains and well-being and quality of life are not included<sup>34</sup>. As a result, there has been research seeking to build upon the ICF and provide clarity, which will be discussed in the following sections. Using the ICF domains, the potential impacts of an ABI on a CYP will now be described.

## **1.4.2 Body Structures and Functions**

### ***1.4.2.1 Neurological sequelae of an ABI***

ABI's can lead to an array of complex physical, cognitive, social, emotional, and behavioural impairments which map to the ICF body structures and functions domain and can result in lifelong disability (Table 1-1).

Table 1-1: Common effects/impairments after an ABI

<b>Physical</b>	<b>Cognitive</b>	<b>Emotional and Behavioural</b>
Movement	Amnesia	Frustration
Balance	Memory	Agitation
Coordination	Attention	Aggression
Motor planning	Speech	Anger and Irritability
Headaches	Communication	Depression
Incontinence	Lack of insight and self-	Anxiety
Seizures/epilepsy	awareness	Overactivity
Fatigue	Visual-perceptual	Impulsivity
Hormones	Concentration	Distractable
Sensory difficulties	Motivation	Disinhibited behaviour
Sleep disturbance	Reasoning	Obsessiveness
Speech difficulties	Processing speed	Mood swings

For some CYP, an ABI can result in a severe physical impairment impacting on multiple body structures and functions. These CYP can require prolonged periods of rehabilitation as inpatients in hospital, or rehabilitation units and ongoingly in the community. Hayes et al.<sup>35</sup> used ABI relevant International Classification of Diseases 10<sup>th</sup> version (ICD-10) diagnostic codes and a prolonged inpatient stay of more than 28 days to identify CYP with severe ABI requiring rehabilitation in the UK, estimating an annual rate of 350 admissions.

The impact of an ABI is often represented as an iceberg, with many CYP showing a good visible recovery, but with many more 'hidden' or 'invisible' effects persisting, such as cognitive, emotional, behavioural, social and higher-level physical impairments<sup>36</sup>. These impairments are

difficult to quantify as they may not be immediately obvious resulting in them being more difficult to recognise or attribute to the ABI. This often results in unmet needs due to a lack of understanding and awareness or access to assessment of needs <sup>37,38</sup>.

Cognitive impairments can be hugely impactful on a CYP's ability to participate in activities at home, school and in the community. Anderson et al <sup>12</sup> studied the ten-year outcomes for 76 CYP with TBI, assessing their cognitive and adaptive abilities, executive function, and social skills at initial assessment and ten years later. They found rates of impairment (25%) were higher than expected for the general population (16%), even in the mild TBI group, with survivors' functional abilities falling within the low average to average range regardless of injury severity. However, this was a small sample and therefore generalisability is limited.

ABI should therefore be conceptualised as a chronic condition, with functional changes occurring over a decade after injury <sup>39</sup>. Furthermore, there is evidence of increased risks of long-term poor health and social outcomes in adulthood which present the need for long-term rehabilitation and support <sup>3,40-42</sup>. However, predicting outcomes and monitoring the long-term consequences is a challenge for clinicians as development and recovery of function is complex and unique to each CYP <sup>43</sup>. Additionally, a lack of access to ongoing assessment and follow up for CYP with ABI results in many of these needs going unrecognised and unmet, increasing the risk of poor health and well-being outcomes and well-being <sup>38</sup>.



### 1.4.2.2 ABI and childhood development

Sustaining an ABI as a CYP adds complexity to recovery and the monitoring of impact. Adopting a life-course approach (Figure 1-2) is essential when considering the impact of an ABI on CYP, given they are still developing, gaining functional skills and have their whole life ahead of them<sup>44</sup>. Any injury to the brain during this developmental period can impact on a CYP's intrinsic capacity and functional ability and therefore health and life outcomes in adulthood.

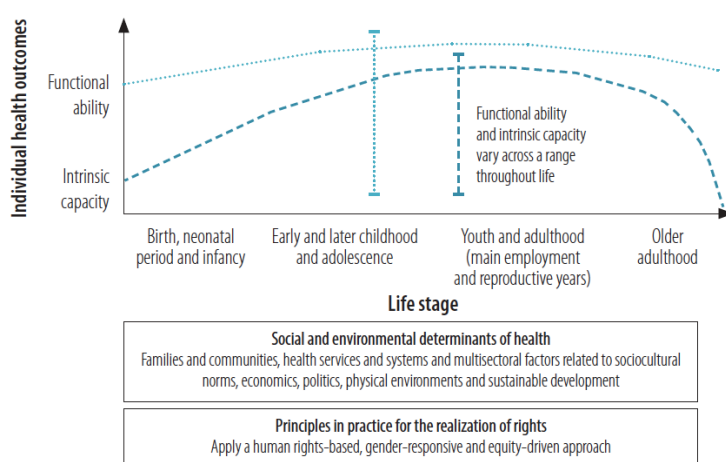


Figure 1-2: WHO conceptual framework of the life course<sup>44</sup>

A CYP's developing brain may contribute to the neuroplasticity and recovery after ABI, however, there is good evidence that the immaturity of a young brain increases vulnerability, with an ABI sustained early in childhood potentially affecting ongoing brain development<sup>12,45,46</sup>. The developing brain has been shown to be vulnerable to drugs and

seizures and to apoptosis (programmed cell death) from trauma and hypoxic ischaemic encephalopathy, resulting in greater impairment following an ABI <sup>16,45,47</sup>. Research has found poorer functional and cognitive outcomes following TBI sustained early in childhood, which could be due to an injury during development affecting developmental progress <sup>43,48</sup>.

An ABI during childhood can also disrupt future development and put a CYP at risk of a 'neurocognitive stall' (Figure 1-3).

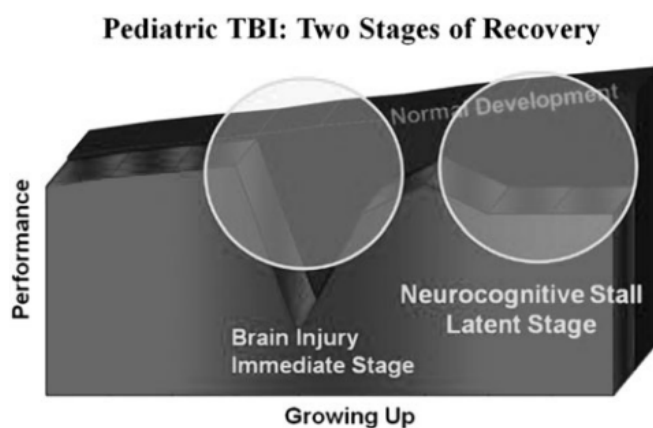


Figure 1-3: Representation of the neurocognitive stall <sup>49</sup>

This is defined by Chapman <sup>49</sup> as:

*'a halting or slowing in later stages of cognition, social, and motor development beyond a year after brain injury.'* (p84)

Neurocognitive stall can result in CYP plateauing in their developmental milestones. As childhood development progresses and educational and social demands increase, there is the potential for delayed or impaired

skill development, and impairments may become more evident with needs emerging and changing, often continuing into adulthood<sup>3,16,19,38</sup>. Therefore, not all needs will be immediately evident after a childhood ABI, or they may be unrecognised or misinterpreted, and rehabilitation interventions must be adaptable to the potentially changing needs of CYP as they continue to grow and develop.

The body structures and functions domain of the ICF enables identification of impairments, the impact of which on activity and participation will now be considered.

#### **1.4.3 Activity and Participation**

The ICF aids the description of the impact of a health condition on a person's function. Impairments can impact on a CYP with ABI functional ability and therefore their ability to participate in activities at home, in school and in the community, which can impact their long-term health and well-being. Whereas there is a strong foundation for understanding the ICF body structures and functions domain, the activity and participation domains are less detailed and therefore the constructs less well understood, making measurement difficult<sup>50-53</sup>.

Activity is defined as *the execution of specific tasks or actions by a person* (functioning at an individual level), and participation as encompassing *involvement in life situations* (functioning as a member of society)<sup>26</sup>. However, both domains share the same descriptors – *learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal*

*interactions and relationships, major life areas and community social and civic life*<sup>54</sup>. Describing the impact of a health condition on a person's activity is generally regarded as assessing the impact on a person's ability to perform functional tasks and participate in activities within their context. This includes activities such as mobility, activities of daily living and communication and participation in education, recreation, and leisure activities, such as sport and physical activity, and social interaction with friends and family<sup>53,55,56</sup>.

#### **1.4.3.1 Education**

Education is the primary occupation of CYP. It is fundamental to their recovery and ongoing development, with educational settings (school/college) being the main context for ongoing rehabilitation for CYP with ABI<sup>57</sup>. Long periods out of education, delays in return to school or college and ineffective support within the setting are all factors known to negatively impact CYP with ABI participation and well-being<sup>17,57-65</sup>.

#### **1.4.3.2 Sport and physical activity**

CYP with ABI may experience difficulties reintegrating back into their sports and activities due to restrictions as a result of their injury (e.g., no contact sports) or impairments impacting on their ability to participate (e.g., balance or cognitive difficulties). This can impact on both their health and well-being. Reduced cardiovascular fitness is a known short and long-term secondary physical impairment of TBI<sup>66</sup>. Additionally, a higher prevalence of obesity (19% compared to 5%) has been found in CYP with ABI compared to typically developing children<sup>67</sup>.

#### **1.4.3.3 Social interaction**

Reduced participation leads to reduced social interaction and increased isolation which is detrimental to health and well-being<sup>68</sup>. Indeed, there is evidence linking perceived social isolation to adverse health consequences such as poor sleep, mental health and cardiovascular function, impaired executive function, accelerated cognitive decline and impaired immunity at every life stage<sup>68</sup>. Social participation, being involved in activities with others, interacting with friends, family and others has been found to be a protective factor against mental ill health<sup>69</sup>. There has been minimal investigation of the impact of an ABI on CYP's mental health. However, a recent study by Hendry et al<sup>70</sup> found a heightened risk of poor mental health following ABI in adolescents, particularly females, and there is evidence of poor mental health in CYP with other neuro-disabilities<sup>69</sup>. Furthermore, CYP with ABI have increased risks of further ABI, being bullied at school, entering the criminal justice system, and becoming homeless, particularly in the presence of social adversity, compared to those without ABI<sup>41,42,71</sup>.

#### **1.4.3.4 Participation as an outcome**

Participation in home, school and community activities is a fundamental right and enhances the well-being of all, including children with disabilities<sup>27,72</sup>. The development of the ICF has led to successful participation in everyday life being seen as the ultimate outcome of healthcare services, which enables a wider view on how to influence long-term well-being<sup>27</sup>. Participation is an essential part of child development, associated with increased quality of life, social

competence, educational success, future life outcomes and well-being of CYP with and without disabilities<sup>58,73-76</sup>. It is seen as a major determinant of healthy living in adulthood, linked to the development of physical, psychological, social emotional skills and competencies and important in shaping identity and a sense of belonging<sup>77</sup>. Research with CYP with a range of disabilities indicates that their conceptions of participation are related to their age, not type of disabilities, and that their focus when defining participation differs from that of their parents, teachers, and health professionals<sup>78</sup>.

To optimise individual participation outcomes and achieve equity there is a need to understand how to support and effectively influence participation outcomes<sup>79</sup>. Whilst there is an increasing commitment within CYP health services internationally to be participation-focused, the literature demonstrates that the concept of participation is still evolving, with several schools of thought on how to define and operationalise it more clearly<sup>9,51,52,77,80</sup>.

Participation is a complex multidimensional construct influenced by multiple factors<sup>26,50,72</sup>. The Family of Participation Related Constructs (fPRC) framework,<sup>50</sup> uses the ICF as a foundation and proposes a more detailed understanding. It defines participation as having two core elements – attendance (physical or virtual presence) and involvement (the experience of participating while attending). It also considers other factors that influence participation which include intrinsic person-related concepts; activity competence, sense of self, preferences, extrinsic

environmental and contextual factors, as well as the transactional processes operating among the factors <sup>50</sup>.

Biomedical models of rehabilitation have traditionally focused on 'fixing' body function and structure impairments rather than enabling a person to participate. Whilst rehabilitation therapists may address physical environmental barriers, there has been less focus on social, attitudinal, and institutional environmental factors that impact on participation <sup>77</sup>. It is essential that these are considered if rehabilitation interventions are to be successful in minimising CYP's impairments, maximising activity performance and optimising participation outcomes <sup>19,27,32</sup>. Building on the work of Imms and colleagues <sup>50</sup>, Anaby et al's <sup>77</sup> Participation-focused Knowledge Translation framework advocates for participation to be at the forefront of rehabilitation, providing a way of gaining skills and being the desired outcome. Developed to support the translation of participation-focused knowledge into clinical practice, the framework includes consideration of contextual factors across every level of society, ensuring a child and family centred approach. However, further evaluation of its effectiveness in practice and validation with stakeholders is required.

Therefore, participation was identified as an important outcome for CYP with ABI and vital to be included within the development of rehabilitation interventions.

#### **1.4.4 Contextual Factors**

Consideration of the impact of contextual factors on a person's function and ability to participate is crucial. Within the ICF, contextual factors are subdivided into personal and environmental factors domains.

One of the limitations of the ICF is that it does not include set descriptors for personal factors. In response to this, Geyh et al.<sup>81</sup> developed a classification structure for this domain which includes:

- Individual socio-demographic factors such as age, gender, ethnicity, cultural background, education or occupational status;
- Subjective experiences such as feelings, thoughts, personal interests, identity, motivations and goals;
- Patterns of experience and behaviours such as patterns of thoughts, feelings, motives and behaviours.

Environmental factors consist of the physical, social, and attitudinal environment in which people live and conduct their lives. For CYP these centre around their family, school and recreation and leisure activities.

These personal and environmental contextual factors play an important role in function and participation, having either a positive or negative impact on an individual and the level of disability they experience<sup>82</sup>.

However, the evidence-base focusing on the impact of these on CYP with ABI is limited and research is needed to more clearly identify contextual factors that are influential on rehabilitation and outcomes<sup>30</sup>.

Limond et al<sup>83</sup> propose, in their model guiding use of neurocognitive interventions in CYP with ABI, that addressing psychosocial and



systemic factors (including family functioning) is a prerequisite to any neurocognitive rehabilitation intervention. This could be supporting health needs or sensory impairments, addressing challenging behaviour, or providing emotional and practical support to parents. Therefore, in considering the impact of an ABI on a CYP and contextual factors, it is essential to consider the impact on their family.

#### **1.4.4.1 Impact on the family**

Family life is busy, with parents needing to manage work and family commitments<sup>84</sup>. The impact of a CYP sustaining an ABI on the family is well documented. The sudden change in roles and way of life for families affected by ABI adds additional challenges and stress for the whole family, impacting on family functioning and well-being<sup>85</sup>. Having one member of a family who has challenges affecting their ability to participate in activities in and out of the home can lead to a loss of social interaction, increasing isolation and marginalisation, which impacts on the participation and well-being of the whole family unit<sup>68,86,87</sup>. There is substantial caregiver burden, emotions and stresses for parents and the wider family, disorganisation, and mental health problems<sup>88-91</sup>. There is evidence of the health disparities of families with a CYP with ABI and the impact of socioeconomic status on outcomes<sup>92,93</sup>. Unmet health and social care needs, the need for information and support are prevalent, as is the need to 'grapple' to get what their child and the family needs<sup>88,94,95</sup>. Whilst there is evidence of the impact on the family, further research is required to better

understand influential factors on family functioning to harness those that support positive outcomes <sup>85</sup>.

An evaluation of a regional paediatric neurorehabilitation service identified several needs for families <sup>18</sup>. Parents reported the need to 'project manage', process reams of information and 'get to grips' with how health, social care and education systems work for children with additional needs. They reported the need for long-term access to information and support to address these needs. Psychological and specialist emotional support for the CYP and wider family was particularly lacking, which families felt was vital, along with the need for peer support with other families affected by ABI. Families also spoke of slow return to school and extra-curricular activities, the impact of this both educationally and socially on the CYP, and the need for support to achieve this <sup>18</sup>.

When a CYP sustains an ABI, parents find themselves having to rapidly learn about their CYP's condition and the impact of this on their CYP and family. There is a clear link between parental health literacy (the ability to understand and interpret health information and navigate the healthcare system), health behaviour and health outcomes for children with chronic disease <sup>96</sup>. Low health literacy is associated with poorer health knowledge and disease management, increased chronic illness, underutilisation of preventative health services and increased hospitalisations. This can affect a parent's self-efficacy (a person's belief or confidence in their ability to produce desired outcomes by their behaviour) in supporting and managing their child's health and recovery

after an ABI<sup>97</sup>. Therefore, there is a need to support parent and family understanding of their CYP's ABI, the rehabilitation process and navigation of systems.

The impact on siblings is also important to recognise, with research showing siblings of CYP with chronic health conditions or disabilities are at higher risk of developing emotional and behavioural problems and experiencing poor well-being than that of their peers, highlighting the need for family support post-injury<sup>98-101</sup>. Families that have a CYP with a disability experience greater barriers to physical activity, potentially impacting on whole family fitness and future health<sup>68,102-104</sup>.

The impact of the COVID-19 pandemic and national lockdowns on families generally, but also in this population, should not be underestimated. The WHO called for increased investment in services to support the well-being of families, recognising the pandemic only added to the emotional and psychological distress of these families<sup>105</sup>. Cross-sectional survey and interview studies investigating the impact of the pandemic on CYP with neurodevelopmental disorders and their families found a wide variety of unmet support needs during periods of lockdown, including a significant negative impact on health and well-being of both CYP and parents<sup>106-109</sup>.

Collectively these factors affecting families need to be recognised to identify and support the most vulnerable families, and reduce the impact of these on the recovery of the CYP with ABI and well-being of the whole family. Family-centred care is seen as gold-standard practice within paediatrics, recognising the importance of family well-being and

influence on a child's functioning and experiences <sup>110</sup>. It includes all members of the family as care recipients and aims to target the needs of whole family holistically <sup>104,111</sup>. Whilst a family-centred approach to care is known to be key in supporting CYP with disabilities, it is an ideal and is not generally a reality in practice, with ambiguity regarding what the term means, ineffective implementation and evaluation impacting widespread adoption <sup>77,110,111</sup>. Therefore, a family-centred approach is integral to the development of interventions to support CYP with ABI and their families.

### **1.5 Well-being, Quality of Life, Health-related quality of life**

A person's health and their ability to function, participate and live their life is inherently linked to their overall well-being <sup>27,112</sup>. Similarly to the concept of participation, the concept of well-being is also constantly evolving, with ongoing debate regarding the difference between quality of life (QoL), health-related quality of life (HRQoL) and well-being <sup>113</sup>.

Quality of life (QoL) is defined by the WHO <sup>114</sup> as:

*'Individuals' perceptions 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.11).

Health-Related Quality of Life (HRQoL) is defined as a multi-dimensional construct that focuses on the impact health status has on

QoL and includes physical, mental, emotional, and social functioning domains <sup>115</sup>. HRQoL is commonly used as a health outcome for CYP clinical services and in research and helps identify health populations with poorer health status <sup>116</sup>.

Well-being is defined in the 2008 Foresight Report <sup>117</sup> as:

*'A dynamic state, in which the individual is able to develop their potential, work productively and creatively, build strong and positive relationships with others, and contribute to their community. It is enhanced when an individual is able to fulfil their personal and social goals and achieve a sense of purpose in society.'* (p.404).

Furthermore, there is an increased focus on health and well-being through the NHS Long Term Plan <sup>118</sup> and the 2022 Health and Care Bill<sup>119</sup>, introduced to parliament in July 2021, which recommend a needs-led and person-centred integrated care system to address the health and well-being of the population.

Within the evidence-base regarding CYP with ABI, the increased awareness of long-term impairments and rates of involvement with the criminal justice system within this population has led to a focus on well-being, resilience, and participation <sup>117</sup>. McCarron and colleagues' <sup>117</sup> study of neuropsychological goals for CYP with ABI demonstrated goals to be widespread across the domains of the ICF, however, over 50% were participation-focused. They advocate the need for further research into participation-focused rehabilitation interventions that are individualised and context-sensitive using a systems approach to

address the well-being of CYP with ABI. Therefore, well-being was also identified as an important outcome to be measured and addressed when exploring the impact of an ABI on CYP and developing rehabilitation interventions.

## **1.6 Rehabilitation**

Rehabilitation following an ABI aims to enable CYP to achieve optimal levels of participation by reducing the impact of difficulties and maximising well-being, activities of daily living, functional ability, and social integration <sup>19,120</sup>. In doing so, rehabilitation aims to improve a person's experience of health, ensuring they can live their life to the fullest <sup>112</sup>.

Efforts have been made to define rehabilitation as a construct, however, with the potential for vast variety in content, process, and delivery setting, this has been difficult <sup>120</sup>. Wade's <sup>120</sup> evidence-based description of effective rehabilitation is adopted in this thesis.

Rehabilitation:

- is of benefit to anyone at any stage of illness or disability.
- delivered in any setting (hospital, rehabilitation unit, outpatient clinics, home).
- involves a multi-disciplinary team (e.g., physiotherapist, occupational therapist, speech and language therapist, psychologist, paediatrician).

- is a problem-solving process that uses a biopsychosocial framework.
- is delivered in a person-centred, or family-centred way.
- is goal-focused.
- includes many different interventions tailored to individual patients.
- collaborative, working across boundaries.
- adaptive to change and monitors effectiveness of specific rehabilitation interventions.

For CYP with ABI, rehabilitation begins during the acute hospital admission and continues beyond discharge home, within the home, school, and community environment. CYP and the family should be actively involved in the goal-setting process to address their needs and goals<sup>4,16</sup>. As discussed above, in recent years participation has become the focus and ultimate goal of rehabilitation and a research priority within paediatric rehabilitation<sup>77,80</sup>.

#### **1.6.1 National Paediatric Neuro-rehabilitation Context**

The introduction of NHS specialist services in 2010 and Major Trauma centres in 2012 led to the designation of eighteen regional paediatric neurosciences specialist centres across England, which deliver acute inpatient care. National service specifications for the provision of paediatric neurorehabilitation for CYP with ABI and other acquired neurological conditions aimed for equitable provision across the country<sup>7</sup>. However, there is widespread variability of service provision and a lack of long-term specialist follow-up of CYP with ABI<sup>35</sup>.

The British Society of Rehabilitation Medicine (BSRM) provide core standards for rehabilitation and a rehabilitation pathway (Figure 1-4) <sup>121</sup>. However these were created for adult services and the same level of provision is not available within paediatric services, for example there is only one level 1 specialist inpatient rehabilitation unit nationally for CYP compared to regional units for adults. Long-term therapy for children with neuro-disabilities is provided by community services. However, globally there is substantial variability in provision and a lack of services for those CYP with ABI with less impactful physical impairments, but higher-level balance and coordination or cognitive needs <sup>3,18,35,122-124</sup>.

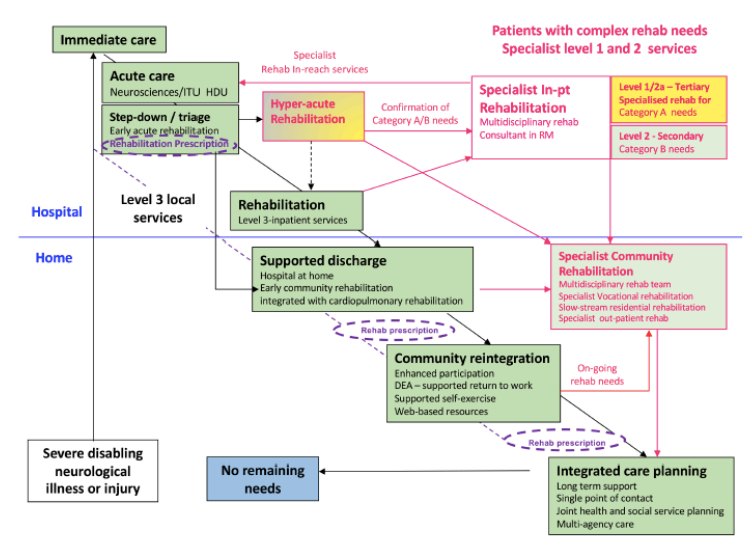


Figure 1-4: UK adult rehabilitation pathway <sup>121</sup>



These gaps and significant variations in the provision of paediatric neuro-rehabilitation services nationally were identified in the Major Trauma Network peer review <sup>125</sup> and the House of Commons Committee of Public Accounts <sup>126</sup>, which also reported no evidence of impact on outcomes for CYP with ABI from the national service specifications. Studies by Hamilton et al. <sup>127</sup> and Hayes et al. <sup>35</sup> highlighted the continued variability in UK service provision, along with the need to identify optimum rehabilitation models. NHS England and the Department of Health remain focused on commissioning equitable specialised services and consider rehabilitation as essential to meet the requirements of the NHS Outcomes Framework, laid out in the Government's Mandate to NHS England for 2016-17 <sup>128,129</sup>.

NHS England's Commissioning Guidance for Rehabilitation <sup>128</sup> states: *"It is increasingly acknowledged that effective rehabilitation delivers better outcomes and improved QoL and has the potential to reduce health inequalities and make significant cost savings across the health and care system"* (p.5).

Research regarding rehabilitation for adults with brain injury has demonstrated cost effectiveness, particularly in more severely impacted patients <sup>130</sup>. However, the economic benefits of paediatric rehabilitation have not been fully investigated and are not completely understood<sup>35,128,130</sup>. Guidelines published by the Royal College of Paediatrics and Child Health (RCPCH) in 2017 for the diagnosis, management, and rehabilitation of stroke in childhood provide comprehensive recommendations for commissioners and clinicians <sup>10</sup>.

These recognise the disparity between adult and CYP acute stroke care and rehabilitation services, as well as the significant variations nationally. They aim to provide standards of care for the entire patient pathway, from presentation to long-term medical management and rehabilitation, with a firm focus on CYP and family-centred care and ICF-based individualised goals <sup>10</sup>.

The resource and financial constraints within the current NHS context present significant barriers to the commissioning and implementation of service specifications and guidelines. There is a real need for robust evidence to support service development initiatives. However, due to the complexity of rehabilitation and variations in service provision already mentioned, measuring, and evaluating outcomes for CYP with ABI is difficult <sup>20,131</sup>.

To date, there is no centralised outcome data collection for CYP with ABI and as a result, identification of influential factors for recovery is limited, impacting on the development of an evidence base for interventions <sup>9,20,132</sup>. Researchers and clinicians agree that a multi-faceted approach to outcome measurement is required. The RCPCH <sup>10</sup> guidelines recommend multi-disciplinary assessment of needs that considers all the ICF domains for a CYP and their family and the use of QoL measures. Other outcome recommendations within the literature include family functioning, school performance, participation and HRQoL <sup>20,132</sup>. However, research is required to identify influential factors and outcomes important to families to inform future work, aimed at improving the quality of out of hospital care and ongoing

rehabilitation, to support CYP with ABI and their families to achieve better outcomes and live healthier lives. This aligns to the NHS Long Term Plan's <sup>118</sup> focus on health and well-being and the aim of improving patient care and experience laid out in the Health and Care Act 2022<sup>119</sup>.

As discussed, there is a complex array of factors to consider in researching rehabilitation and the impact of an ABI on CYP and their families. Therefore, a systematic, theoretical approach is approach is required.

## **1.7 Complex Intervention Research**

Rehabilitation is complex with multiple interacting components and therefore is defined as a complex intervention. This is because of the number of components, range of behaviours targeted, skills and expertise required to deliver, the context in which it is being delivered and the flexibility permitted within the intervention components <sup>133</sup>.

Complex interventions can be multi-faceted, being able to flexibly deliver a range of components, dependent on the need of the recipient <sup>133</sup>.

### **1.7.1 Medical Research Council Guidance**

The Medical Research Council's (MRC) guidance for developing and evaluating complex interventions aims to support researchers to work with stakeholders to develop robust complex interventions, assess the feasibility of delivery, evaluate it, and ensure implementation is successful <sup>133</sup>.

The MRC framework consists of four phases: development or identification of the intervention, feasibility, evaluation, and implementation (Figure 1-5). Core elements are applicable to all four stages and should be considered and revisited throughout the research process. Research can commence within any phase of the framework depending on the research questions regarding the intervention. It incorporates a systems approach to include whole system intervention development and evaluation, as well as the impact interventions have on systems. It places engagement with stakeholders (patients, professionals, policy makers) at the core to ensure factors that can impact on implementation are considered from the start, such as acceptability, practicality, cost-effectiveness, and transferability.

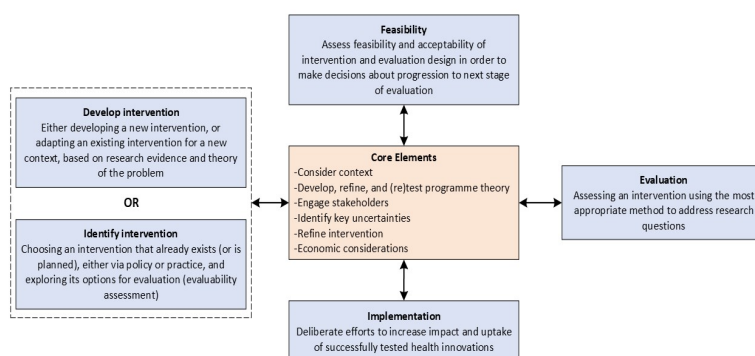


Figure 1-5: MRC framework for developing and evaluating complex interventions <sup>133</sup>

### 1.7.2 Implementation Science Research

Implementation science offers a pragmatic, systematic, theoretical approach to healthcare research that incorporates the use of theories, models and frameworks to guide the process of translating research

into evidence-based practice <sup>134,135</sup>. It draws on a range of theories, such as psychological theories, to help identify and define core components of complex interventions and ensure that the integrity of these is maintained regardless of the context for implementation <sup>133</sup>. Theoretical frameworks, such as the Behaviour Change Wheel (BCW), help us to understand target behaviour(s), barriers and facilitators to behaviour and mechanisms likely to lead to successful implementation of evidence-based behaviour change interventions <sup>134,136</sup>. Additionally, engaging stakeholders using qualitative methods when developing theory-informed interventions ensures the needs, barriers and facilitators to the target behaviour and the real-world context are well understood. This detailed understanding guides intervention development and implementation by ensuring new interventions are acceptable, address the target population's needs, and identify potential implementation barriers and facilitators <sup>136</sup>. Investing in the intervention development process increases the likely success of effectiveness and implementation in practice <sup>137</sup>. This approach has therefore informed the research in this thesis.

## **1.8 Gaps in CYP with ABI Research**

Understanding the needs of the population is essential in developing interventions, delivering pathways of care, and providing effective rehabilitation. Sparse long-term specialist follow-up in the UK means little is known about the longer-term participation and well-being

outcomes and needs of UK CYP with ABI, particularly as childhood development progresses and needs potentially change over time<sup>18,35,127</sup>. Whilst there is evidence that those with childhood-onset disabilities and their families experience restrictions in their participation, greater understanding of the needs of UK CYP with ABI and their families is needed, especially those that have experienced a good physical recovery<sup>27,58,75,76</sup>. Additionally, understanding the impact of the COVID-19 pandemic on CYP with ABI and their families is essential in supporting families, in planning restoration of services and promoting full participation in society<sup>109,138,139</sup>. Further in-depth insight into the participation and well-being needs, barriers and facilitators experienced by CYP with ABI, their parents, the professionals, and services supporting them is required to inform intervention development. Whilst there has been some research conducted to develop rehabilitation interventions for this population, the use of theory would enhance this process and translation into clinical practice<sup>77,140</sup>.

Therefore, this thesis aimed to explore the long-term participation and well-being needs of UK CYP with ABI (5-18 years) and their families, and to develop a theoretically underpinned intervention to identify and address identified needs. Research in this area will inform clinical teams and commissioners as they seek to develop services and identify and commission optimum rehabilitation models. It will inform the national agenda regarding long-term follow-up, care and support of CYP with ABI and their families, in line with the priorities of the NHS Long Term

Plan and Health and Care Act to improve care and outcomes for people  
with long-term conditions <sup>118,119</sup>

## **1.9 Chapter Summary**

This chapter has introduced the thesis and area of research. ABI can have a significant impact on a CYP and their family. The ICF provides a framework to describe the impact of an ABI on a CYP and influential contextual factors. Rehabilitation aims to minimise impairment, maximise function and optimise participation and well-being. Research exploring the long-term needs and outcomes of UK CYP with ABI is required to inform the development of interventions, care pathways and rehabilitation models. The next chapter presents a scoping review of the literature that was conducted to inform this research.



## 2 Scoping Review of the Literature

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### 2.1 Chapter Overview

The previous chapter presented an overview of ABI in CYP and the rehabilitation context, providing a foundation for the thesis. It also included the rationale for the research conducted in this thesis. Chapter 2 presents a scoping review which aimed to identify relevant literature and key themes relating to the nature and extent of needs (met, unmet or unrecognised) of CYP with ABI and their families. [Further detail regarding the methods is added here in addition to the paper.](#)

#### 2.1.1 [Scoping review rationale](#)

Colquhoun <sup>141</sup> defines a scoping review as:

*'a form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence and gaps in research related to a defined area or field by synthesizing existing knowledge'* (p1292-94).

A scoping review was identified as the most appropriate form of literature review. [The aim was to explore and map the extent of the research regarding the needs of CYP with ABI and their families, identify knowledge gaps, clarify concepts and inform the development of the research study](#) <sup>142,143</sup>. [A scoping review can accommodate a diverse range of literature, enabling me to review all the existing literature regarding the needs of this population, ensuring a broad range of research designs and the grey literature were included](#) <sup>143</sup>. [A](#)

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systematic review ~~would not have facilitated this and was therefore~~ not appropriate at this point <sup>143</sup>.

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### **2.1.2 Method**

A scoping review protocol was formulated using the Joanna Briggs Institute (JBI) methodology for scoping reviews <sup>144</sup>. ~~A pragmatic and iterative search strategy was developed, following advice from a university librarian. To identify past, current and planned research, a range of databases were identified, including those containing study protocols and systematic reviews (e.g. Prospero, Cochrane Library). A grey literature search was conducted to identify relevant current news items, clinical guidelines or policies. This was conducted pragmatically, only including documents published within the last ten years, and the first ten pages of Google being reviewed.~~

~~In the preparatory work for the scoping review, a recently published scoping review of the needs of CYP and other family members after a traumatic injury was identified <sup>23</sup>. However, this did not include the needs of CYP with non-traumatic brain injuries (e.g. stroke, infection, tumour) and therefore did not include all the literature relating to the needs of CYP with ABI, meaning completing a further scoping review was warranted.~~

~~Three systematic reviews were also identified during the scoping review. Two focused specifically on the experiences of return to school for parents and clinicians and educators, and one on the long-term psychosocial impact reported by childhood critical illness survivors.~~

including CYP with ABI. None of these covered the breadth of literature required to inform the research question and study but were all included in the scoping review results.

I conducted the initial identification and screening of titles. I and a fellow PhD student independently screened all abstracts to assess eligibility, and I reviewed the full article if it was not clear within the abstract. At the time of conducting the search there was not a PRISMA reporting protocol for scoping reviews, therefore the systematic review protocol was used.

The results were charted using the JBI recommendations using the following headings: author, year of publication, country of origin, aims/purpose, study population and sample size, methodology/methods, findings/outcomes, key findings related to scoping review question. Braun and Clarke's thematic analysis was used to code the key findings, identify and review themes <sup>145</sup>. The findings were also mapped onto the ICF to review the coverage of the domains within the literature. The coding, identification of themes and mapping was iterative, and discussed, verified and validated with the research team.

The scoping review is presented in published format and includes the methods, findings and a discussion of the key themes identified. It was published in *Brain Injury* in 2019.

Keetley, R., Radford, K., Manning, JC. (2019). A scoping review of the needs of children and young people with acquired brain injuries and their families. *Brain Injury*,33(9), 1117-1128.

DOI: [10.1080/02699052.2019.1637542](https://doi.org/10.1080/02699052.2019.1637542)

## **2.2 A scoping review of the needs of children and young people with acquired brain injuries and their families**

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### **2.2.1 Abstract**

Understanding the needs of children and young people (CYP) with acquired brain injuries (ABI) is essential in delivering pathways of care and providing effective rehabilitation.

**Aim:** To identify relevant literature and key themes relating to the nature and extent of needs (met, unmet or unrecognised) of CYP with ABI and their families.

**Method:** Scoping review. Sixteen electronic bibliographic databases were searched using terms relating to children, brain injury and need. Papers were screened against eligibility criteria by two independent reviewers. No date limits were applied. Data was extracted by the lead author regarding the needs of CYP with ABI and their families and thematic analysis conducted to identify the key themes. Methodological quality was not assessed.

**Results:** A total of 28 articles were identified including three systematic reviews, one scoping review, two practice recommendation articles and 22 original research studies. Participants included CYP with ABI, parents, siblings and professionals. Four key themes were identified; CYP-related impairment needs, support needs, return to school and long-term aftercare.

**Conclusion:** CYP with ABI and their families report extensive needs, many of which are often unmet or unrecognised by those supporting the CYP. Needs transcend the health, social care and education domains.

**Keywords:** Acquired brain injury, traumatic brain injury, rehabilitation, education, care, children, young people, adolescents, paediatric, needs.

### **2.2.2 Background**

Acquired brain injury (ABI) in children and young people (CYP) is defined as a traumatic (such as a fall or road-traffic collision) or non-traumatic (such as a stroke, infection, or brain tumour) injury to the brain that has occurred since birth <sup>1</sup>. It is estimated that each year in the UK 40,000 CYP sustain an ABI, with traumatic brain injury (TBI) being the most common cause of death or disability <sup>2,7</sup>.

With advances in critical care, mortality has reduced, however CYP may go on to experience significant neurological impairment and life-long disability <sup>35,91</sup>. The physical, cognitive, emotional, and behavioural sequelae of ABI are well described within the literature, as are factors impacting on recovery such as age at onset, severity, mechanism of injury and family, environmental and psychosocial factors <sup>14,16,17,88</sup>. The long-term impact of these impairments on the quality of life of CYP and their families can be significant <sup>95,146</sup>.

Acute and post-acute neurorehabilitation for CYP with ABI is delivered by 16 regional specialist centres across the UK. National service specifications for paediatric neurorehabilitation aimed for equitable provision across the country, however, there is widespread concern regarding the variability of service provision and a drive towards identifying and commissioning optimum rehabilitation models <sup>7,35,127</sup>. Research regarding rehabilitation for adults with brain injury has demonstrated the benefits and cost effectiveness of comprehensive rehabilitation models, this is yet to be fully investigated in paediatric



rehabilitation or the impact on the life course of the CYP and family

128,147.

Understanding the needs of the population is essential in delivering pathways of care and providing effective rehabilitation. A scoping review of the literature was required in order to map the current relevant literature and synthesize that knowledge as a preliminary step towards conducting a systematic review regarding the needs of the population<sup>141</sup>.

### **2.2.3 Objective**

The objective of this scoping review was to identify relevant literature and key themes relating to the needs of CYP with ABI and their families and the nature and extent of those needs, met, unmet or unrecognised.

### **2.2.4 Inclusion criteria**

A scoping review protocol was formulated using the Joanna Briggs Institute (JBI) methodology for scoping reviews<sup>144</sup>. The following eligibility criteria were set:

#### **2.2.4.1 Inclusion criteria**

- Participants:
  - CYP aged 0-18 with an ABI (traumatic brain injury (TBI) and non-traumatic brain injury (NTBI))
  - Parents/family members of CYP with ABI
  - Education, health or social care professionals involved in the care of CYP with ABI

- Concept:
  - Defining and measuring 'need' is complex and challenging as a person's perceived need reflects their individual, cultural and societal values <sup>22</sup>. As this scoping review was exploratory in nature it was decided that a broad search strategy would be employed to try to capture a breadth of evidence whilst maintaining specificity to the topic area and population. Definitions of need were adopted from the existing literature and therefore defined as a problem that significantly interferes with daily life <sup>23</sup> and further categorised into 'met need' (services received), 'unmet need' (perceived need but not receiving services) and 'unrecognised need' (not used or needed a service but reported impairments/limitations) <sup>24,25</sup>.
- Context
  - CYP in any healthcare or educational setting, worldwide.

#### **2.2.4.2 Exclusion criteria**

- Adults over 18 years
- CYP with birth injuries or congenital disorders
- Studies focusing on experiences, functional or health status related outcomes, interventions or service provision rather than needs.
- Policies and guidelines where need is not explicitly discussed.

### **2.2.5 Types of sources**

A search of PROSPERO International Prospective Register of Systematic Reviews revealed no ongoing reviews in this topic area. Sixteen electronic bibliographic databases (Medline, CINAHL, Embase, Pedro, Web of Science, JBI, Cochrane Library, PROSPERO, UK Clinical trials gateway, NIHR Journal Library, EuropePMC, Clinical trials.gov, ISRCTN registry, NICE Evidence search, PsychINFO) were searched between April and July 2018. Additional grey literature searches were conducted (Google Scholar, James Lind Alliance, NICE guidelines, Kings Fund).

### **2.2.6 Search Strategy**

The search strategy was formulated using the JBI Scoping review methodology and PICO framework (Table 2-1). An initial search of Medline and CINAHL was conducted to identify relevant articles and keywords. The search strategy was adapted to the individual database requirements and terms were deliberately kept broad to ensure all relevant literature was identified. Searches using all identified keywords were then undertaken across all included databases. Grey literature sources and reference lists were reviewed for additional articles. No date limits were imposed; however, only English language articles were included due to lack of funding for translation.

Table 2-1: JBI scoping review search strategy

Search Stage	Search Terms	Databases Searched
Initial search:	PICO framework: - Children and Young People - Acquired Brain Injury - Needs	MEDLINE CINAHL
Search terms, MESH headings, keywords identified and second search completed.	- Children and young people, Child*, adolescen*, youth, paediatric - Acquired brain injury, ABI, traumatic brain injury, TBI, brain injur*, stroke, brain neoplasms - Needs, needs assessment, unmet needs, health needs, health demands	MEDLINE, CINAHL, Embase, Pedro, Web of Science, JBI, Cochrane Library, PROSPERO, UK Clinical trials gateway, NIHR Journal Library, EuropePMC, Clinical trials.gov, ISRCTN registry, NICE Evidence search, PsychINFO
Grey literature search		Google, James Lind Alliance, Kings Fund, NICE guidelines
Reference list search of included articles		

Papers meeting the inclusion criteria were classified according to level of evidence provided by the research design. Table 2-2 shows the classification for each type of question.

Table 2-2: Levels of evidence according to research design <sup>148</sup>

	Range of needs	Prevalence of need	Service availability/use
<b>Level 1</b>	Qualitative syntheses of need/experience	Population/area-based need assessments, or systematic reviews of need prevalence	Population/area-based surveys of service availability, cost, use
<b>Level 2</b>	Qualitative studies collecting data from patients/carers	Longitudinal cohort or matched comparative studies	Intervention studies that include qualitative process/outcome evaluations
<b>Level 3</b>	Multiple case-studies	Correlation/cross-sectional studies, secondary analyses	Satisfaction surveys, audits

### 2.2.7 Data extraction, summary and synthesis

The PRISMA guidelines for preferred reporting items for systematic reviews and meta-analysis and flowchart were used. The initial identification and screening of titles was conducted by the first author (RK). Two reviewers independently screened all abstracts to assess eligibility against the inclusion and exclusion criteria and by the first author from full articles if not clear within the abstract. Any discrepancies were resolved through discussion. Full texts were obtained for all shortlisted articles. The results were charted using the JBI recommendations using the following headings: author, year of publication, country of origin, aims/purpose, study population and sample size, methodology/methods, findings/outcomes, key findings

related to scoping review question. From the results chart, key themes relating to the needs of the population were identified and synthesised. The quality of the articles was not assessed as this is a scoping review to identify relevant evidence <sup>144</sup>.

### **2.2.8 Results**

The searches identified 327 potentially relevant articles which were screened, and 60 full-text articles were assessed for eligibility (Figure 2-1). A total of 28 articles met the inclusion criteria and were examined in-depth with data tabulated. Three qualitative systematic reviews <sup>17,61,91</sup>, one scoping review <sup>23</sup> and two practice recommendation articles <sup>3,149</sup>, (Table 2-3) and 22 original research studies were identified<sup>22,24,25,59,60,62,65,88,94,95,101,146,150-159</sup> (Table 2-4).

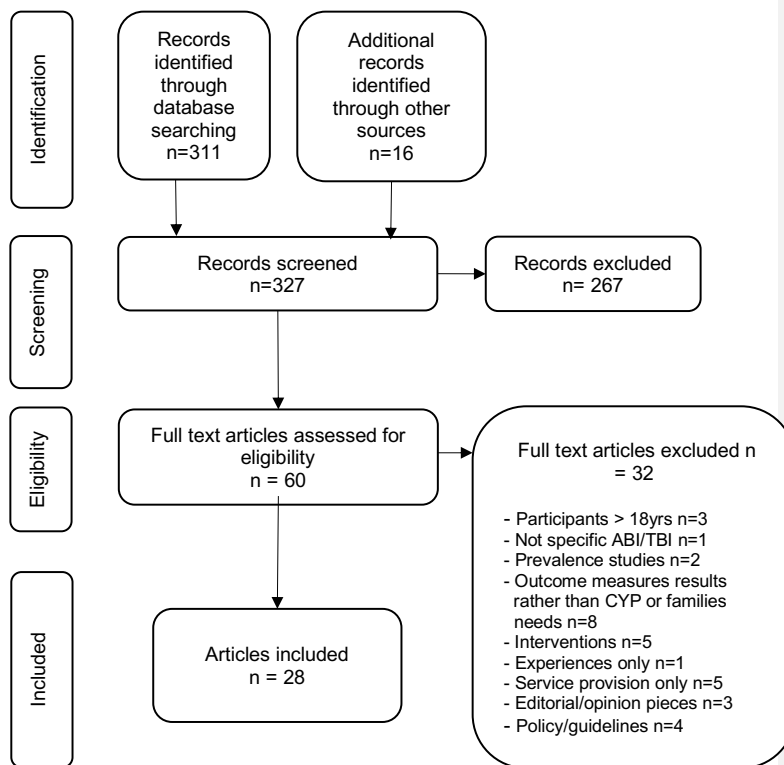


Figure 2-1: PRISMA flow diagram of the scoping review process

Table 2-3: Results – Systematic, scoping reviews and recommendation papers

Authors	Year	Country of origin	Participants			Methods	Level of Evidence	Time since injury/ diagnosis	Needs identified	Theme
			CYP	Parents/ Family	Professionals					
Andersson et al	2016	Australia		Parents of 106 CYP with mild, moderate and severe ABI (2-20yrs)		Systematic review of qualitative research (6 studies included) exploring parents' experiences of return to school with ABI	1	0-11 years	Parents experience stress when child's needs not met. Need for appropriate information, respectful communication and productive collaboration between school, health professionals and family	Return to school
Hartman et al	2015	Canada	27 CYP with ABI (4-18yrs)	45 parents/ guardians	55 education, 33 clinicians	Systematic review of qualitative studies (10 included) regarding clinician and educator experiences facilitating return to school	1	7 months - 5 years	Lack of training and education regarding transition process, lack of communication and preparation. Need for education, support, communication, collaboration.	Return to school



Jones et al	2018	UK, Australia, USA, Sweden, Canada	105 adolescents with traumatic injuries including TBI	418 parents, 302 primary carers - unspecified, 66 family members	41 health care professionals, unspecified numbers of teachers/ community providers	Scoping review of needs of children and family members after a child's traumatic injury (12 papers included)	3	3 months - 6 years	Adolescent specific needs, Support needs for emotional, cognitive, social, physical difficulties, across care transitions/return to school	Child-related impairments Support Return to education
Manning et al	2013	UK	51 critical illness survivors including ABI			Systematic review - thematic synthesis method (3 studies included)	1	8 months - 7 years	Identified number of outstanding and ongoing needs - Information to fill in missing picture, time to grieve for former self and explore and understand experiences, need to accept -adjustment to new physical, psychological and social reality	Support
McKinlay et al	2016	International	CYP with ABI		International Paediatric Brain Injury Society	Development of practice recommendations for CYP with ABI services	3	n/a	Lack of consideration to needs of child and family post discharge and at key developmental transitions. Sense of abandonment and anxiety among families. Need to support the family holistically long- term	Long-term aftercare Support

									and acknowledge ABI as a chronic condition that impacts all family members through collaborative working between all stakeholders, increased education and training and use of case managers	
Savage et al	2005	USA	CYP with TBI		4 professionals	Review of pertinent issues - 4 professional viewpoints - focus on family stress, educational, cognitive-communicative and behavioural challenges	3	n/a	Bespoke needs - Information, parent and family emotional support, liaison with school difficulties, persistent physical, cognitive and behavioural difficulties. Need for support and training and collaborative working	Child-related impairments Support Long-term aftercare

Table 2-4: Results of original research studies

Authors	Year	Country of origin	Participants			Methods	Level of Evidence	Time since injury/ diagnosis	Needs identified	Theme
			CYP	Parents/ Family	Professionals					
Aitken et al	2009	USA		312 Parents of CYP with TBI (5-15yrs)		Empirical study - 3 x telephone interviews (baseline, 3 and 12 months) using PedsQL, Child Health Questionnaire and baseline interview including questions regarding needs/unmet needs	3	0-12 months	Substantial caregiver burden. Parental perception of unmet healthcare needs strongly related to family burden outcomes	Support
Aukema et al	2011	Netherlands		42 parents of CYP with brain tumours		Survey regarding aftercare in 5 domains of long-term sequelae (neurocognitive, physical, emotional, social and parenting problems)	3	1 year post treatment end (mean 8yrs since diagnosis)	Considerable aftercare needs: physical, neurocognitive, social, emotional, parenting. Most unmet need- parenting problems. Parents had awareness of long-term sequelae but lacked knowledge of services available. Need for timely, repeated screening and specialist aftercare/ follow-up.	Long term aftercare
Gagnon et al	2008	Canada	15 adolescents with mild TBI (12-16yrs)	15 parents		Qualitative cross-sectional study focusing on experiences of adolescents and parents after mild TBI. Semi-structured in-depth	3	0-12 months	Needs related to impairments, activity limitations and participation restrictions. Information needs, need for support from professionals to optimise recovery and	Child-related impairments Support

						interviews with adolescent and parent.			needs specific to adolescence	
Gfroerer	2008	USA		Parents of 66 school age children with moderate or severe TBI		Interviews - asked to identify areas of concern and needs, whether support was available, how difficult to get it and satisfaction.	2	< 2 years	Perceived relatively few school-based supports, given the actual academic, behavioural and social challenges experienced. Need for appropriate post TBI support from hospital and school	Return to school
Glang et al	2008	USA		56 parents of CYP with mild, mod or severe TBI (4-18yrs)		Prospective study - questionnaire and interview about hospital-school transition and education services provided 3 months after return to school	2	0-12 months	Educational support needs and need for effective link between hospital and school on transition	Return to school
Greenspan and Mackenzie	2000	USA		95 parents of CYP (5-15yrs) with head injury (TBI) discharged from 2 acute Maryland hospitals.		Parental telephone interviews and review of hospital records - CYP's use of medical, rehab and social services during the year since the injury.	2	1 year	Unmet need was highest for children with least severe head injuries. Need for PT, OT and MH services was unrecognised for 33% CYP with physical limitations and 40% of CYP with behavioural problems. Need for thorough evaluation and treatment during f/up visits as well as during initial hospitalization for ABI.	Long-term aftercare

Hawley et al	2004	UK	67 CYP with mild, moderate or severe TBI (5-15yrs)	Parents (unspecified number)	Teachers (unspecified number)	Cross-sectional study. Postal questionnaires, interviews and outcome measures (KOSCHI, Children's Memory Scale, Wechsler Intelligence Scale for Children-3rd edition UK, Weschler Objective Reading Dimensions	3	0-6 years since injury	Need for hospital professionals to provide schools with info about TBI and long-term consequences so children get appropriate support	Return to school
Hermans et al	2012	Netherlands		Parents of 33 CYP with ABI (12 TBI, 21 NTBI)		Pilot study. Telephone semi-structured interviews	2	2-4 years	Ongoing problems - physical, cognitive, behavioural, social. Unmet needs evident - information, medical, family support, return to school support. Need for improved communication and holistic follow-up of CYP with ABI through collaborative models between all services and parents	Child-related impairments Support
Jackson et al	2007	Australia		53 parents of CYP < 18yrs diagnosed with a brain tumour		Prospective study. Questionnaire interview at diagnosis, 6 months, 1 yr. and 2 yrs. Parents perceptions of hospital experience	2	0-2 years	High information needs from diagnosis - 2 yr. point. Need for effective communication/support	Support
Karver et al	2014	USA		65 parents of CYP (3-7rs) with mild, moderate or severe TBI		Part of a larger prospective follow-up study. Parents completed outcome measures at 18 and	2	18-38 months	Long-term behavioural health needs following TBI and Orthopaedic Injury. Importance of monitoring and intervention	Child-related impairments

				and 74 parents of CYP with Orthopaedic Injury		38 months after injury investigating clinical need (presence of behavioural problems) and utilization of behavioural therapy services				
Kirk et al	2014	UK		29 parents/careers of children with severe TBI.		Qualitative semi-structured interviews	2	6-72 months	Unmet information and emotional support needs across care trajectory particularly following d/c home. Need for range of mechanisms to support coordination and communication- integrated care pathways, protocols, key working and case management.	Support
Limond et al	2009	UK		Parents of 47 children with mild or moderate-severe TBI		Retrospective cross sectional study. Standardised questionnaires (PedsQL, Strengths and Difficulties questionnaire) Views regarding parental experiences of care and ratings of service provision obtained.	3	1-5 years	43 % had cognitive, emotional and behavioural difficulties impact on daily life. Unmet needs in lack of specialist follow-up and support	Child-related impairments Support
Manning et al	2017	UK	3 CYP PICU survivors of critical illness (including	6 parents of CYP, 2 siblings	8 health care professionals, a commissioner and a manager	Multi-stakeholder consultation event - 2 groups parents and HCPs and children and siblings using	2	unspecified	Unmet needs - support, information, communication, emotional, social and overall well-being. CYP needing support to be 'normal' and	Child-related impairments Support

			ABI), 3 CYP who had used health services			write/draw and focus group techniques			for physical rehabilitation and accessing and engaging with peers. No support for siblings. Lack of integration in care pathway. Need for follow-up, surveillance and interventions	
Massey et al	2015	Australia	CYP with TBI		5 teachers	Semi-structured interviews	3	<5yrs	Need for collaboration between health care professionals and teachers	Return to school
Roscigno and Swanson	2011	USA		42 parents of CYP with moderate to severe TBI (6-18yrs)		Semi-structured interviews	2	4-48 months	Grappling to get what my child needs. Searching for community - no support groups	Support
Roscigno et al	2011	USA	39 CYP with TBI (6-18yrs)			Semi-structured Interviews with child x 2 12-15 months apart.	2	4-36 months	Longing for everydayness. Social support important to how adjusted to changes and losses	Child-related impairments Support
Roscigno et al	2015	USA		42 parents of CYP with moderate to severe TBI		Interviews x2 at 15 months and 27 months.	2	< 5years	Perceived needs related to planning, implementing and evaluating return to school - inappropriate state and local services that did not consider needs specific to TBI. Need for coordinated collaboration.	Return to school
Slomine et al	2006	USA		302 caregivers of CYP with TBI (288 completed full study)		Telephone interview at 2 and 12 months. Health care needs categorised as - no need, met need, unmet need unrecognised need on basis of child's use of post-acute services, caregivers	2	3-12 months	Substantial proportion had unmet or unrecognised health care needs during first year of injury. Need for paediatricians to be involved in post-acute care follow-up to ensure child's needs are addressed in timely and appropriate manner.	Long-term aftercare

						report of unmet need and caregivers report of child's functioning as measured by PedsQL				
Soanes et al	2009	UK	10 CYP with brain tumour (4-13yrs)	18 parents of CYP		Longitudinal, exploratory and descriptive case study, multiple methods of data collection (modified mosaic approach, draw and write technique, semi-structured interviews with children over 12 and parents)	2	0-12 months	Need for support and guidance from 1 key professional, recognise impact on whole family, information pathway	Support
Soo et al	2008	Australia		32 parents of CYP with ABI (27 TBI, 5 NTBI)		Validation study of Paediatric Care and Needs Scale (PCANS)	2	8-206 months	Wide range of long-term care and support needs particularly activities of daily living and psychosocial functioning	Child-related impairments Support
Swaine et al	2008	Canada	CYP with mild TBI		8 experts (focus group), 33 professionals (questionnaire)	Qualitative - focus group and questionnaire regarding identifying specific needs of adolescents with mild TBI.	2	n/a	Need for information and support for adolescents and parents when returning to activities (school and physical)	Support



Vilela et al	2008	Canada		27 parents of children with ABI		Demographic data and telephone interview including standardised questionnaires (Child Behaviour Checklist, Service and support questionnaire, Interpersonal support evaluation list, Family Environment Scale, AIMS Interview-Child Version	3	mean = 12.9 years	Unmet medical and social needs. Need for collaborative and creative partnerships between private and public sectors to meet needs.	Child-related impairments Support
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### **2.2.8.1 Literature Reviews**

Jones et al <sup>23</sup> conducted a scoping review of the needs of children and other family members after a traumatic injury. Twelve papers met the inclusion criteria, with the majority of the papers focusing on CYP with TBI. Key themes that emerged were needs specific to adolescence, support needs for emotional, cognitive and social problems, physical difficulty needs and support around care transitions and return to education.

Three qualitative systematic reviews representing level one evidence were identified. Two focussed on the experiences of return to school for parents <sup>17</sup> and clinicians and educators <sup>61</sup>. One included six studies and a total of 106 parents of CYP with mild, moderate and severe ABI (2-20yrs old), 0-11 year's post-injury <sup>17</sup>. Another included 10 studies with a total of 27 CYP, 45 parents/guardians, 55 education professionals and 33 clinicians participating <sup>61</sup>. There was no overlap of studies between the two reviews and each study's quality was assessed. Both reviews presented strong themes of the need for effective information, communication and collaboration between the child, parents and health and education professionals.

Manning et al's <sup>91</sup> systematic review of the long-term psychosocial impact reported by childhood critical illness survivors included three studies and a total of 51 participants which included CYP with ABI. A number of outstanding and ongoing needs (met and unmet) were identified regarding support (information, emotional, social and overall well-being) highlighting the need for long-term psycho-social support.

### **2.2.8.2 Expert reviews/recommendations**

Two papers were identified which presented a review of the needs of CYP with TBI and ABI along with recommendations for intervention and service provision. The first presents a review of the pertinent issues regarding paediatric TBI <sup>149</sup>. The common needs of CYP with TBI and their families (information, parent and family emotional support, school liaison difficulties, persistent physical, cognitive and behavioural difficulties) are presented whilst emphasising the bespoke needs of each CYP and family and the need for individualised support. Long-term support, training and collaborative working between the family and professionals are recommended as critical to ensuring the long-term success of this population. Practice recommendations for service provision for CYP with ABI are also provided by international group of professionals from the International Paediatric Brain Injury Society <sup>3</sup>. They advocate long-term holistic family-centred support, the need to raise awareness of the needs of the CYP with ABI, provide education to all involved in their care and for greater collaboration across the care pathway to ensure coordinated and effective provision of services <sup>160</sup>.

### **2.2.8.3 Research studies**

A variety of research designs were used within the 22 original research studies included, representing level two and three evidence, the most common data collection method being interviews (Table 2-4).

Not all studies reported participant numbers fully. From those that did, participants included CYP (n=137), parents (n=1282), siblings (n=2), and health and educational professionals (n=187). One article solely

reported needs perceived by the CYP themselves <sup>155</sup>, 15 were on parents experiences or perception of theirs and their CYPs needs<sup>24,59,60,65,88,94,95,146,150-153,157,159</sup>, two on professionals experiences and needs <sup>154,158</sup> and four a combination of the above<sup>22,61,101,156</sup>. Fifteen articles focussed specifically on the needs of CYP with TBI and their families <sup>24,25,59,60,62,65,88,94,95,146,153-155,158,161</sup>, three specifically on the needs of CYP with brain tumours <sup>150,152,156</sup>, one on the needs of CYP critical care survivors, including CYP with ABI <sup>101</sup> and three on the needs of CYP with ABI (TBI and NTBI) <sup>151,157,159</sup>.

#### **2.2.8.4 Themes**

Four themes emerged from the analysis, CYP-related impairment needs, support needs, and return to school and long-term aftercare. Identified needs were also mapped onto the International Classification of Functioning, Disability and Health (ICF) constructs to reflect evidence gaps (Figure 2-2) <sup>26</sup>.

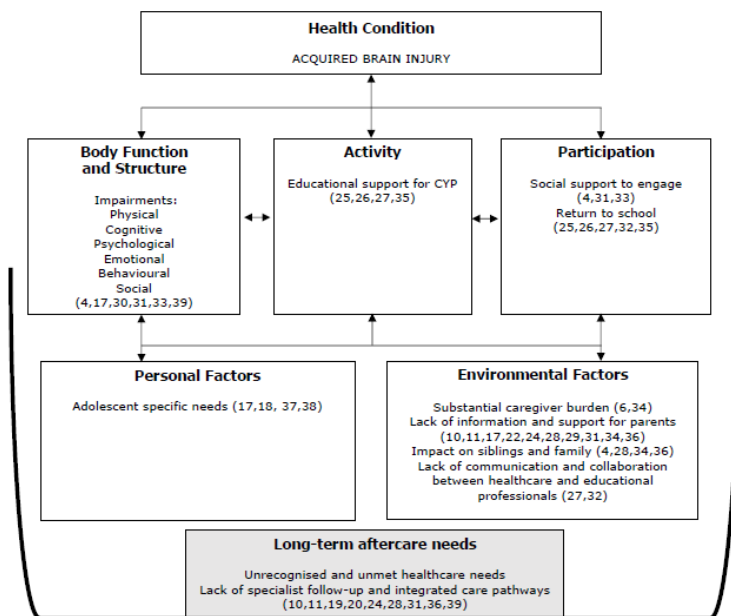


Figure 2-2: Identified needs mapped onto ICF

#### 2.2.8.4.1 CYP-related impairment needs

Significant needs were reported relating to ongoing physical, cognitive, psychological, emotional, behavioural, and social impairments that transcended and varied across the age spectrum.

Younger CYP (3-7 year olds) were found to have significant long-term behavioural needs with parents reporting unmet needs in relation to managing these <sup>153</sup>. The specific needs of CYP in adolescence, defined as a specific and important development stage between the ages of 10 and 19 <sup>162</sup> are identified in three studies. Adolescents, their parents and service providers reported needs in relation to facilitating activity and

participation and managing limitations and restrictions in activities of daily living, return to school and physical activities and psychosocial functioning<sup>22,157,158</sup>. In two studies, CYP with TBI and CYP critical care survivors (including CYP with ABI) identified 'longing for everydayness' and needing support to work towards being 'normal' including physical rehabilitation and social support to access and engage with peers<sup>91,155</sup>. Unmet needs were reported by parents of CYP with ABI in relation to CYP medical and social needs<sup>159</sup> and CYP communication, emotional, social and overall well-being, reported by CYP themselves as well as parents<sup>101</sup>.

Consistently, the need for long-term surveillance, ongoing monitoring and intervention is recommended as CYP-related impairment needs may change as different challenges present at each developmental stage particularly as they reach adolescence and transition into adulthood<sup>22,101,153</sup>.

#### *2.2.8.4.2 Support needs*

Parents of CYP with ABI experience substantial caregiver burden and this is amplified when there is the parental perception of unmet health care needs<sup>88</sup>. Parents and CYP have high needs for information and emotional support from professionals across the care trajectory, with many parents reporting a lack of support and unmet needs in this area<sup>22,94,95,101,146,150-152</sup>.

The need for bespoke information and support for adolescents and their parents was identified in two studies focusing on the needs of

adolescents with mild TBI by the adolescents themselves, their parents and service providers<sup>22,158</sup>. This was also highlighted by Jones et al<sup>23</sup> and relates to adolescents' developmental stage, the need to be recognised as an individual, to be involved and in control.

Several studies highlighted the importance of recognising the impact of the ABI on the whole family and that family and sibling support represented a significant unmet need<sup>91,151,156</sup>. Roscigno and Swanson<sup>94</sup> describe parents 'grappling' to get what their child and family needs and a fruitless search for community and parental and CYP peer support. Social support and engagement with peers are important for CYP and families as they adjust to life post-ABI, but they need help to facilitate this<sup>101,155</sup>. The need for support and guidance from one key professional was highlighted in a study of the experience of CYP with brain tumours and their parents<sup>156</sup>. The importance of effective communication and the key worker role to coordinate information and support to CYP and parents was also recommended in two other studies<sup>95,152</sup> and in the practice recommendations<sup>3</sup>.

#### *2.2.8.4.3 Return to school*

Five studies specifically investigated return to school experiences for CYP with ABI/TBI, their parents, education and healthcare professionals<sup>59,60,62,65,154</sup>. Parents describe the need for educational support for CYP with ABI, effective communication, information sharing, training and collaboration between the school, family and healthcare professionals<sup>59,60,62,65</sup>. Roscigno et al<sup>65</sup> describe parents needing to negotiate with schools to get the help their CYP needed and that where

there was coordinated collaboration this lessened their workload.

Teachers reported the need for healthcare professionals to provide schools with information about brain injury and the long-term consequences and for collaboration with healthcare professionals in planning and implementing effective returns to school <sup>62,154</sup>.

#### 2.2.8.4.4 *Long-term aftercare*

Several studies describe unmet needs in aftercare and follow-up of CYP with ABI <sup>24,25,95,101,146,150,151,156,159</sup>. Whilst one study of CYP with brain tumours reported that parents were generally aware of the long-term sequelae but lacked knowledge of services available <sup>150</sup>, other studies reported unmet or unrecognised health care needs across the care trajectory from discharge home through to 12 years post-injury <sup>24,25,95,146</sup>. Given the widely reported long-term and developing needs of CYP with ABI, specialist follow-up, particularly at key transition points (e.g. after discharge home, school transitions) is recommended to ensure needs are identified and addressed in an appropriate manner through timely and repeated screening <sup>24,25,101,150</sup>. A range of mechanisms to support coordination, communication and collaborative and creative partnerships between all stakeholders are advocated - integrated care pathways, holistic family-centred care models, protocols, key working, case management <sup>24,95,101,151,156,159</sup>.



### **2.2.9 Discussion**

This scoping review has identified extensive needs of CYP with ABI and their families, many of which are often unmet or unrecognised by those supporting the CYP across the care trajectory.

The lack of awareness and understanding of the long-term consequences of an ABI for CYP and their families reported in the evidence ultimately underpins all the reported needs, met, unmet or unrecognised. As is recommended in the majority of the articles, there is a desperate need for increased awareness of the needs of this population across health, education and social care services in order that needs are recognised and addressed in a timely and appropriate manner. There is general agreement throughout the identified articles that specialist follow-up and integrated care pathways are required to ensure all CYP have access to services to support them and their families to optimise their recovery, address needs as they arise throughout their development and realise their potential.

The voice of CYP with ABI themselves is limited within the identified studies. Perceived needs are personal and while it is important for parents to report their perceived needs of their CYP, it should be questioned as to whether this truly reflects the needs of CYP themselves. Parents and families also have specific needs relating to their ability to support their CYP and the impact that the ABI has had on them themselves as individuals. Whilst there are several studies including parents' voices, there is little evidence investigating the impact on siblings. Research including the voice of CYP is scant, however

there is increased focus and recognition of the importance of their voices being heard and represented within research. Whilst this poses ethical and methodological challenges, it is vital to include them in future research so that their perspective and needs are reported<sup>23,163,164</sup>.

As reported in the literature, teachers and healthcare professionals involved in the care of CYP with ABI also have needs in terms of supporting CYP effectively as they return to school and reintegrate into the community. Education is required to support them to assist CYP during the transition process and in the long-term, particularly to identify new or emerging needs that may become apparent years after the injury occurred. Including all members of the multi-disciplinary team across health, care and education sectors in future research is imperative when considering the holistic needs of the CYP and those supporting them.

Mapping the needs onto the ICF demonstrates the large focus on impairments (body structure and function), environmental factors and return to school (activity and participation). There is minimal focus on personal factors, such as psychological and emotional support needs of CYP themselves and out of school activity and participation, including other aspects of community life, such as clubs, hobbies, and sports. These gaps warrant further investigation. Research has shown that community participation in CYP with ABI is reduced compared to their peers, however, needs relating to this were not the focus of studies identified in this scoping review<sup>58,73,164</sup>. Future work should consider

using the ICF as a framework and incorporate the voice of CYP themselves to ensure comprehensive investigation of the holistic needs of CYP with ABI and their families <sup>165</sup>.

This scoping review has identified evidence regarding the range of needs of this population from studies conducted using a variety of research methods. Whilst three systematic reviews and the scoping review identified represent higher levels of evidence relating to the range of needs of CYP with ABI, they do not give a sense of proportion in terms of the numbers affected. No level one evidence of population-based assessments of prevalence of need or service availability, cost or use were identified representing an evidence gap. A mixed methods systematic review of the available evidence is required to develop actionable findings that can inform further research, policy and practice as well as population-based studies of the prevalence of need and service availability and use <sup>166</sup>.

#### **2.2.9.1 Strengths and limitations**

This scoping review was systematically conducted using a recognised methodology <sup>144</sup>. Extensive searches of the databases were conducted, and a broad range of literature was identified and screened by multiple reviewers to minimise bias. The search strategy and methods employed for data extraction and synthesis have been transparently reported.

Some limitations do exist. Defining need is complex and as such, it is possible that the broad search strategy did not identify all relevant articles using the search terms and key words identified. It is possible

that evidence of prevalence of need related to outcomes, problems or extent of unmet need may have been excluded through not including studies describing functional or health status related outcomes, experiences, or service provision. Grey literature was included in the search and several opinion pieces, policies and guidelines were identified but did not meet the eligibility criteria for this scoping review as did not discuss need specifically. Studies reported in languages other than English were also excluded, leading to ethnocentricity of the findings. Advice was sought from an information specialist regarding the search strategy and every attempt to identify all relevant articles was made using an iterative process, as recommended in the JBI methodology <sup>144</sup>.

#### **2.2.9.2 Implications for practice and future research**

The aim of this scoping review was to identify the extent of the evidence; therefore, the quality of the articles was not assessed. Whilst a systematic review of the evidence is required in order to inform practice and future research, this scoping review does provide an insight into the evidence regarding the range of needs of CYP with ABI and their families for clinicians. This is important in raising awareness and identifying future research directions. Only five of the studies include relatively small UK samples and none studying the CYP with ABI population as a whole meaning there is no evidence of prevalence of need within the UK. There is a need for services to evaluate the provision to CYP with ABI in their area and investigate the needs and unmet needs of the population to inform the development of services to

meet national service specifications and guidelines as well as the local needs of their specified population.

#### **2.2.10 Conclusion**

Relevant research and key themes relating to the needs of CYP with ABI and their families have been identified through this scoping review. CYP with ABI and their families have wide-ranging needs associated with CYP-related impairments, support needs, return to school and long-term aftercare. It is evident that the needs of CYP with ABI and their families transcend health, care, and educational domains across the care pathway. Their needs are about living life to the full and participation in all areas of society. Future research with this population must do the same and be child and family centred and holistic in nature.

## **2.3 Chapter Summary**

Chapter 2 has presented a scoping review of the literature, published in *Brain Injury*, which was conducted to inform the development of the next stage of the research. It identified the wide-ranging needs of CYP with ABI and their families, and gaps in the research literature regarding prevalence of need in the UK needed to inform service delivery and development.

Chapter 3 describes the methodology and methods for two empirical studies – a mixed methods study and a co-design intervention development study.

## 3 Methodology and Methods

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### 3.1 Chapter Overview

The previous chapter presented a scoping review of the literature regarding the needs of CYP with ABI and their families. This chapter presents the methodology for a mixed-methods study and a co-design intervention development study. Firstly, the aims and objectives are outlined. The ethical and methodological considerations of conducting research with children and young people and multiple stakeholders are presented and discussed. The overall study design and theoretical frameworks employed are presented and the research setting, sampling and recruitment strategy and consent process outlined.

As this thesis is presented as a PhD by published works, the methods for each study are reported within each individual publication – the mixed-methods study, presented in Chapter 4 and 5, and the co-design intervention development study, presented in Chapter 6. An overview of the methods employed is presented here with detail added where it is not covered within the publications.

## **3.2 Research aims and objectives**

The overall aim of this thesis was to explore the long-term participation and well-being needs of UK CYP with ABI (aged 5-18) and their families, and to develop a theoretically underpinned intervention to identify and address identified needs. To achieve this aim the following objectives were identified and achieved through the studies detailed in Chapters 4-6:

### **3.2.1 Study 1: Sequential explanatory mixed methods study**

**Chapter 4** presents a quantitative cross-sectional survey of HRQoL and participation outcomes and goals of CYP with ABI and their families.

The objectives were:

- To describe the participation and HRQoL outcomes of CYP with ABI in one geographical region of the UK.
- Identify goals important to CYP with ABI and their parents.
- To explore the impact of the Covid-19 pandemic restrictions on CYP with ABI and their families.

**Chapter 5** presents a qualitative multi-stakeholder interview and focus group study. The objectives were:

- To explore the impact of ABI on family HRQoL.
- To identify goals important to CYP with ABI and their parents.
- To explore participation needs (met, unmet or unrecognised) and factors impacting on participation and HRQoL (well-being) of CYP with ABI and their families.



- To define usual care for CYP with ABI and understand the local context in the East Midlands region.
- To explore the impact of the Covid-19 pandemic restrictions on CYP with ABI and their families.

### **3.2.2 Study 2: Co-design intervention development study**

**Chapter 6** reports the findings of a co-design multi-stakeholder workshop and the theoretical modelling of the intervention. The objectives were:

- To synthesise data collected from the scoping review and Study 1 and identify issues/challenges affecting the participation of CYP with ABI and their families.
- To identify solutions aimed at enabling participation in CYP with ABI and their families.
- To identify local context specific barriers/enablers to intervention delivery and guiding principles (distinctive features of the intervention that are key to intervention success).
- To produce an intervention planning table to collate findings and feedback from stakeholders in readiness for future feasibility testing.
- To iteratively develop the logic model (describing core components, necessary resources, underpinning mechanisms, short- and longer-term impacts and outcomes) for an intervention aimed at identifying and addressing needs.

### **3.3 Methodology**

#### **3.3.1 Ethical and methodological considerations**

To design an intervention aimed at CYP with ABI and their parents, it was imperative to ensure they were able to participate and contribute to the research to share their experiences and needs.

The 1989 Convention on the Rights of the Child ensured the rights of children to participate in decision-making processes and has guided research with CYP ever since <sup>167</sup>. It is vital for CYP to participate in research, to gain insight into their lives and experiences. However, there are multiple methodological and ethical considerations that need to be addressed when designing research studies with CYP.

Conducting research in an ethical manner with participants of any age means being aware of all the potential issues and taking practical steps to ensure physical and psychological safety of participants <sup>164,167,168</sup>. To ensure this research effectively and safely included the voices of CYP with ABI, several pertinent issues needed to be considered given the potential 'doubly vulnerable' (child and cognitive impairments) nature of this population <sup>163,168</sup>. These included gaining access, obtaining informed consent/assent, confidentiality, building rapport and managing risks, which will now be discussed.

### **3.3.1.1 Gaining access**

Access to CYP generally is through a 'gatekeeper' such as a parent or carer, who may have their own view as to whether they and their CYP should participate in a research study, potentially wanting to protect them from anything that could be harmful<sup>163,164</sup>. It is therefore important within research with CYP to respect these gatekeepers and gain their support for participating. In the studies in this thesis, access had to be via the parent/carer, as these were the contact details available, and I was not always able to determine the capacity of the CYP from the recruitment information. Whilst for CYP under 16 parents are the point of access and consent, I had to accept the potential restrictions of this in limiting CYP, particularly young people aged over 16 from deciding for themselves. Every effort was made to provide detailed information about the research and discuss and reassure parents regarding any concerns<sup>163</sup>. They were able to contact me with any questions or concerns and were made aware that they could withdraw at any time (although previously collected data would still be included). As a clinician in the acute clinical service, I knew many of the families which helped build rapport and trust within this research context<sup>167</sup>.

### **3.3.1.2 Obtaining informed consent/assent**

Legally, parents/legal guardians of CYP under the age of 16 must provide informed consent for participation in research however, the CYP themselves should assent (agree) to participate alongside this<sup>163,167</sup>. CYP over the age of 16 must consent for themselves and consent to their parents' involvement in the research. However,

cognitive impairments can create barriers to obtaining informed assent (under 16 years) or consent (16-18 years) <sup>163</sup>. In this research with CYP with potential cognitive impairments, it was important to consider assessment of the capacity of the CYP to participate. Parents/carers, as those who know their CYP the best, were asked to consider this within the participant information sheet and decide if they felt their CYP was able to do so. Any concerns regarding this could be supported by the research team, but the CYP had to independently choose to participate and feel fully informed regarding their participation <sup>167</sup>. In situations where CYP are unable to participate, proxy-reporting by parents is an acceptable method and therefore included as an option in this research<sup>164</sup>.

### **3.3.1.3 Anonymity and confidentiality**

Participant's rights to anonymity and confidentiality should be discussed within the consent/assent process <sup>167</sup>. There are limits to confidentiality as stipulated by The Children Act 1989 and 2004, which state it must be breached if a CYP discloses any information that places them or others at any type of risk <sup>163,164</sup>. Therefore, parents and CYP need to be informed of this and the consequences of any disclosures.

As clinicians, myself and other members of the supervisory team have expertise in working with, and interviewing CYP and parents within clinical consultations and undertake regular mandatory safeguarding training within the NHS Trust, in accordance with professional standards of proficiency <sup>169</sup>. This meant that I was aware of the process to be followed, and should information be disclosed during the research,

I would be able to discuss this at the time with participants and ascertain whether further action was required, e.g. contacting usual care team, GP or safeguarding team. I would also discuss any such issues with the supervisory team.

Therefore, information regarding confidentiality and anonymity were included in the participant information sheets and data collected within the research was anonymised during the analysis to ensure anonymity within the reporting of the findings and publications.

#### **3.3.1.4 Building rapport**

Building rapport between the researcher and a CYP is important to ensure that the CYP feels safe and comfortable to share their perspectives <sup>164,167</sup>. It is important for researchers to be aware of the potential unequal power relationship between a CYP and an adult in an interview scenario, and endeavour to create a trusting, safe and flexible space for CYP <sup>167</sup>. Considering how to achieve this in this research was a challenge, taking into account the range of ages and cognitive impairments of the CYP. I was able to draw on my clinical experience and communication skills to ensure CYP of all ages and abilities were able to participate to the best of their ability. Every effort was made to tailor questions to meet the needs of the individual CYP, relieve tension or nerves and ensure the CYP felt relaxed. I considered strategies that would support participation, such as being flexible regarding their involvement, incorporating communication devices and breaks, to ensure CYP with a range of communication and cognitive impairments could participate <sup>167,168,170</sup>.

Interviewing CYP with or without their parents has advantages and disadvantages. A CYP may speak more freely to a researcher without their parents there, however some may feel scared or uncomfortable in this scenario <sup>167</sup>. The CYP were given the choice as to whether to be interviewed with or without their parent. However, in order to comply with safeguarding procedures, if a parent/carer was not present, a second member of the research team had to be present <sup>171</sup>.

In order to collect rich data, other methods besides verbal communication can be used <sup>167</sup>. Given that some CYP, particularly younger children or those with communication difficulties, may find it difficult to express themselves through words, adapting the interview or focus group to include child-friendly activities is essential to ensure they are comfortable, remain interested and able to participate <sup>167</sup>. CYP were able to participate using their communication aids where required.

Activities such as drawing, games, crafts and photographs which can stimulate conversation that researchers can record, or document were also considered and incorporated where possible. For example, the draw and write technique, where a CYP draws a picture related to the research question and then describes this with the researcher annotating it <sup>172</sup>. Therefore, all methods of communication were considered and implemented where able to ensure CYP of all ages and abilities were able to contribute.

### **3.3.1.5 Potential risks and benefits**

Conducting research regarding participants life experiences can involve potential psychological and emotional risks <sup>167</sup>. Whilst this research was not expected to cause any undue distress; it was possible that some of the questions may have been sensitive, raising questions for the CYP and their parents regarding the impact of their ABI on their life. Equally, talking about these experiences and meeting others with similar experiences can be beneficial to the individuals themselves, in voicing their opinions and by contributing to the research, ultimately helping other families in similar situations <sup>167</sup>. Having experience of working with families in this situation within my clinical role gave me the skills to ensure topics were approached sensitively and that families knew what support was available to them. Details of who to contact with any concerns (clinical team/Patient Advisory Liaison Service) was also provided within the participant information sheet.

### **3.3.2 Reflexivity**

Being self-aware and reflective helps researchers to identify potential influences and monitor the impact of them on the research, increasing validity, rigor, credibility, and trustworthiness <sup>164,173,174</sup>. This is particularly pertinent in research when there is concern regarding the representation of participants, such as marginalised or under-represented populations <sup>174</sup>. Engaging in reflection and representation facilitates a collaborative exploration of the issues being researched, and shared interpretation and perspective <sup>174</sup>.

Reflexivity is defined by Berger <sup>173</sup> as:

*'The process of continual internal dialogue and critical self-evaluation of researcher's positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome' (p.220).*

Reflexivity is well established in qualitative research, where researchers reflect on how their role, biases, values, personal background, culture, and experiences can potentially shape their data interpretations <sup>175</sup>. It is also central to mixed methods research, ensuring transparent reporting of the research process and a thorough review of outcomes, which can inform future research practices <sup>176,177</sup>.

Self-reflection, transparency, and honesty allow readers to judge value for themselves <sup>175</sup>. Researchers should be explicit about all aspects of the research including methodological and theoretical openness, awareness of the research setting and wider social context, and reflexive about the impact of their own perspective on the research process and data analysis <sup>164,178</sup>.

As an experienced clinical specialist children's physiotherapist, I have worked for many years with CYP with ABI, providing acute neurorehabilitation in the regional centre. This has given some insight and sensitivity to the experiences of families of CYP with ABI from a clinical perspective, which can have its benefits, but can also lead to blurred boundaries and imposition of perceptions and beliefs <sup>173</sup>.



Additionally, as a mother, I understand family life and, having had a child sustain a rare traumatic injury requiring complex management, I have personal experience of needing to advocate for my child and navigate complex healthcare systems.

I employed reflexivity at every stage of the research, from design to interpretation and presentation of findings, reflecting on decisions, findings, and the process itself, with the aim of ensuring transparent decision-making and reporting <sup>164</sup>. Recognising the potential influence of my perspective, regular consultations with the research team and study steering group (experienced paediatric neurorehabilitation clinicians from the regional centre) were held to discuss findings, validate coding, and interpret emerging themes <sup>179</sup>. Field notes were maintained for the interviews, focus groups and workshop and used during analysis for context and reflexivity <sup>180</sup>. Furthermore, user and public consultation and the co-design workshop with CYP with ABI, parents and a range of stakeholders were invaluable in providing opportunities to 'sense-check' the findings and ensure there was shared interpretation and collaboration on the intervention development.

The impact of the role of the researcher will be discussed further in the strengths and limitations section of the discussion in Chapter 7.

### 3.3.3 User and public involvement and engagement

Public involvement in research is defined by the National Institute for Health and Care Research <sup>181</sup> as:

*'Research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them'.*

Actively involving and collaborating with patients, carers, and stakeholders from organisations that deliver services to a population is vital in ensuring high quality, relevant and meaningful research and mandated by funders <sup>182</sup>.

CYP with ABI and their families are at the very heart of this research and the reason it was undertaken. As a clinician working with these families, my interest in their rehabilitation journeys and awareness of the many obstacles they face drove me to conduct this research.

Extensive patient and public involvement (PPI) undertaken with CYP with ABI and families prior to commencing this research informed the focus, design, and proposed impact <sup>18</sup>. Four CYP with ABI and their parents were consulted during the development of the study design and several families have continued to be involved throughout. One young adult who sustained an ABI as a CYP has assisted with the ongoing development of the study, analysis of the data and intervention development. CYP with ABI, their parents and professionals from healthcare, education, social care and the third sector have participated in the research and contributed their life experiences, views, and opinions to the research.

Additionally, a study steering group of professionals from the acute neurorehabilitation service at the regional centre has supported the research. All had extensive experience of supporting CYP with ABI both in hospital, home, school, and community contexts and of engaging with CYP, families and stakeholders from across the health, education, and social care systems. This group supported the development of the study and were regularly consulted regarding their knowledge of rehabilitation provision and patient needs and the research findings.

### **3.4 Research Approach**

A pragmatic, patient-oriented, mixed-methods approach was selected for researching the complex problems this thesis aimed to address, and to ensure an in-depth understanding of the needs of CYP with ABI and their families <sup>175</sup>.

A pragmatic approach was chosen as it aligns well with patient-oriented research and offers researchers the freedom to choose the best methods to achieve the research objectives <sup>175,183,184</sup>. Pragmatism advocates for using the best methods of inquiry and for involving individuals with life experience to bring rich understanding of the needs and contextual issues they face, using a social justice orientated lens to research <sup>175,184</sup>.

Developing an intervention requires a systematic approach with a strong rationale and detailed reporting of the process <sup>185</sup>. This thesis contains a series of studies within an over-arching mixed-method

design. Whilst the studies developed iteratively with the findings from one informing the next, all are underpinned with the same theoretical frameworks to aid interpretation and synthesis of the findings and to navigate the intervention development process.

### **3.4.1 MRC Guidance**

This thesis aligns with the 'Develop intervention' phase of the MRC's framework for developing and evaluating complex interventions presented in Chapter 1 (section 1.7.1). The MRC framework has guided the design of the research in this thesis, with core elements incorporated into the objectives to ensure that key uncertainties were identified, and context, theory, and stakeholder engagement remained central to the research process <sup>133</sup>. The MRC framework recommends the use of theory and evidence, user and public involvement and early consideration of implementation issues as central to the successful implementation of interventions in real-world practice <sup>133,137</sup>. However, whilst the MRC framework provides general guidance, it does not provide a detailed process, particularly when there is a need to understand behaviour and how implementation of an intervention could change behaviour <sup>185</sup>. When developing a behaviour change intervention, it is important to have a theoretical understanding of behaviour, identify and understand the target behaviour, its influences, the context for intervention delivery, mechanisms of change and resources required <sup>134,136,137</sup>.

#### **3.4.1.1 Theory-, evidence- and person-based approach**

An integrated theory-, evidence- and person-based approach to developing an intervention has been employed in this thesis. This ensured a pragmatic, systematic, rigorous process to intervention development that emphasised stakeholder engagement and understanding needs, behaviour, barriers, and facilitators, and how implementation of an intervention could change behaviour <sup>135,136,186</sup>.

Methods from the person-based approach and a theory- and evidence-based approach were combined and include a scoping review (evidence-based), a mixed-methods empirical study (person and evidence-based), a co-design workshop (person-based) and theoretical modelling (theory-based). The findings from these informed the iterative development of a logic model for an intervention.

Evidence from previous research can help define the problem, understand needs and context, and identify target behaviours <sup>133</sup>.

Reviewing the literature can also identify gaps or uncertainties in the evidence which can be addressed using mixed methods empirical research, such as quantitative surveys to assess outcomes or qualitative interviews and focus groups to gain deeper understanding of needs, barriers, and facilitators <sup>137</sup>.

Engagement with stakeholders is essential to ensure population needs and context are understood. The person-based approach (PBA) was incorporated into the methodology for this research having been successfully used in several intervention development studies <sup>186-189</sup> (Figure 3-1). The PBA, designed for the development of health-related

behaviour change interventions, complements the theory-based approach, and provides a process for combining stakeholder engagement with mixed methods research <sup>137,190</sup>. The comprehensive process involves in-depth qualitative research with stakeholders to understand needs and contexts, and the formulation of guiding principles, which describe the key intervention design objectives and features of the intervention needed to achieve these. These can then be mapped to behaviour change theories, progressively refined, and inform the theoretical modelling of the intervention.

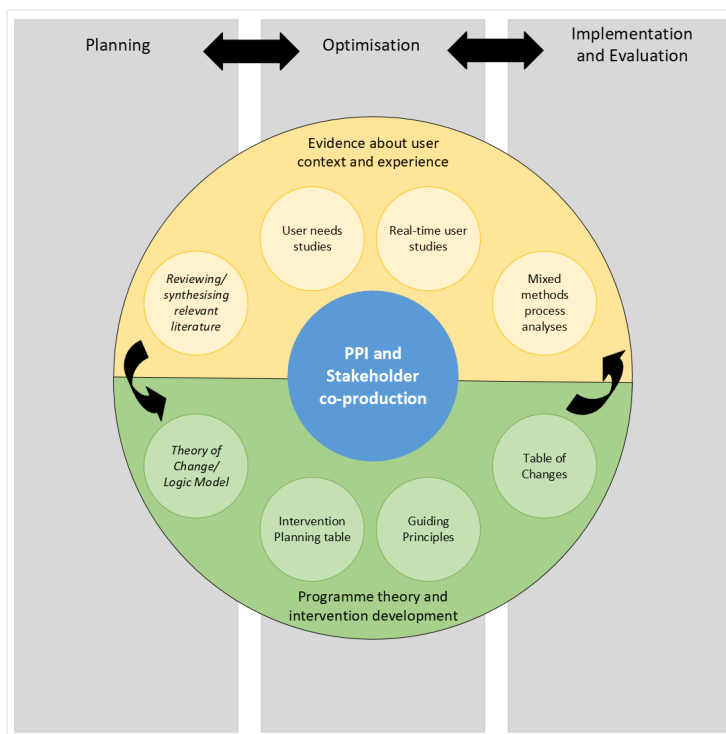


Figure 3-1: Person-Based Approach <sup>191</sup>

### 3.4.1.2 Behaviour Change Wheel

The Behaviour Change Wheel (BCW) was selected as the most appropriate theory for the theoretical modelling of this intervention. It provides a theoretical understanding of the nature of behaviour, helps to identify what internal and external factors are at play and what mechanisms are needed to bring about change<sup>192</sup>. The BCW also provides a process to follow for designing behaviour change interventions which integrates well with the PBA<sup>186</sup>.

At the core of the BCW is the COM-B model (Capability, Opportunity, Motivation - Behaviour) which describes sources of and influences on behaviour. 'Capability' describes the physical and psychological abilities of a person related to a behaviour. 'Opportunity', the properties of a person's environment that affect their ability to enact a behaviour. 'Motivation' describes influences on motivation to perform that behaviour<sup>193</sup> (Table 3-1). These domains are further subdivided into the 14 domains of the Theoretical Domains framework (TDF) (Table 3-1).

When developing interventions that are person-centred it is important to consider the behaviours of both the person and the professionals and services interacting with them. This enables identification of areas where self-management interventions can be targeted as well as those requiring other services or interventions<sup>194</sup>. Using the TDF to expand the behavioural analysis helps identify and describe influential factors and a deeper understanding of barriers and facilitators to behaviour change at an individual, organisational and system level. This is thought to be more effective than using COM-B alone<sup>193-197</sup>. The BCW has

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been used to inform multiple intervention development studies including interventions aimed at increasing physical activity in childhood cancer survivors, adolescent girls and adults <sup>194,198,199, 200</sup>, social participation of adult stroke survivors <sup>201</sup> and to identify barriers and facilitators to constraint-induced movement therapy in adults <sup>202</sup>.

The BCW intervention development process is divided into three stages. Stage 1 involves forming a 'behavioural diagnosis', with the target behaviour and barriers and facilitators influencing that behaviour at individual, organisational and community levels identified and understood<sup>193,203</sup>. Stage 2 identifies intervention functions and supporting policies. Intervention functions, defined as '*broad categories of means by which an intervention can change behaviour*' are selected to target the behaviour and barriers<sup>193</sup>. There are nine intervention functions included in the BCW: education, persuasion, incentivisation, coercion, training, enablement, modelling, environmental restructuring, restrictions. Often interventions will include more than one function, for example, a video can be educational and persuasive. Seven policy options can be selected from to support the delivery of the intervention: guidelines, environmental/social planning, communication/marketing, legislation, service provision, regulation, fiscal measures. Stage 3 involves selecting behaviour change techniques (BCT), defined as '*an active component of an intervention designed to change behaviour*', are identified <sup>193</sup>. These are the specific strategies designed to change behaviour and are an active observable, replicable and irreducible ingredient of an intervention – i.e. the proposed mechanism of change.



They can be used alone or combined with other BCTs. The BCW provides a *taxonomy* of 93 BCTs organised into 16 groups <sup>193</sup> (Table 3-1).

Integrating the BCW and PBA facilitates robust theoretical modelling of an intervention and increases the likelihood of interventions being successfully implemented in real-world practice <sup>135,188,190</sup>. However, as acknowledged by the authors, the BCW is not a 'magic bullet' and does not provide a detailed design or plan of specific behaviour change interventions <sup>193,204</sup>. Therefore, intervention developers need to be flexible, use judgement in determining what best suits the needs and context and engage with stakeholders to support this decision making <sup>205</sup>. Therefore, in designing this research, the above theory-, evidence-, and person-based approach was taken, with the BCW providing a theory and process to inform the development of the intervention.

Table 3-1: Behaviour Change Wheel components and definitions <sup>193</sup>

<b>COM-B Components</b> <i>(for any behaviour to occur there must be capability, opportunity and motivation to do it)</i>		<b>TDF Domains</b> <i>(integrative framework synthesising key theoretical constructs)</i>	<b>BCW Intervention Functions</b> <i>(broad categories of means by which an intervention can change behaviour)</i>	<b>BCW Policy Options</b> <i>(types of decisions made by authorities that help to support and enact the interventions)</i>	<b>Behaviour Change Technique (BCT) Taxonomy Groups</b> <b>(16 groups containing 93 BCTs)</b> <i>(active component of an intervention designed to change behaviour)</i>
Capability	Psychological	- Knowledge - Skills - Memory, attention, and decision processes - Behavioural regulation	- Education  - Persuasion	- Guidelines	- Goals and planning - Feedback and monitoring - Social support - Shaping knowledge
	Physical	- Skills	- Incentivisation	- Environmental/Social planning	- Natural consequences - Comparison of behaviour - Associations
Opportunity	Social	- Social influences	- Coercion	- Communication/Marketing	- Repetition and substitution - Comparison of outcomes - Reward and threat
	Physical	- Environmental context and resources	- Training  - Enablement  - Modelling  - Environmental	- Legislation  - Service Provision  - Regulation	- Regulation - Antecedents
Motivation	Reflective	- Social/professional role & identity - Beliefs about capabilities - Optimism - Beliefs about consequences - Intentions - Goals	Restructuring  - Restrictions	- Fiscal Measures	- Identity - Scheduled consequences - Self-belief - Covert learning
	Automatic	- Social/professional role & identity - Optimism - Reinforcement - Emotion			

## 3.5 Research Design

### 3.5.1 Mixed-methods research

Mixed-methods research is particularly valuable in developing interventions and is central to the MRC framework, BCW and PBA<sup>133,190,193</sup>.

Creswell and Creswell<sup>175</sup> define mixed-methods research as

*'an approach to inquiry involving collecting both quantitative and qualitative data, integrating the two forms of data, and using distinct designs that may involve philosophical assumptions and theoretical frameworks.'* (p52)

Mixed-methods research combines the strengths of both quantitative and qualitative approaches<sup>177</sup>. Integral to this methodology is how the methods complement each other and how the findings are integrated, aiding the understanding of the problem being researched<sup>175,206</sup>.

Specific objectives may be addressed with different methods, with quantitative methods being vital in identifying patterns or variables and qualitative methods delving deeper into the lived experiences of individuals, their needs, and contexts<sup>175,207</sup>. However, they must all contribute to the same overall aim. Following the rigorous collection and analysis of quantitative and qualitative data, integration of findings can occur through linking the methods of data collection and analysis in several ways – connecting, building, merging, and embedding, and at the interpretation and reporting stage<sup>206</sup>. Connecting occurs through

the sampling frame, for example, interview participants are selected from survey participants. Building occurs when results from the first phase inform the data collection approach of the next phase. Merging of data occurs when two sets of data are combined for analysis and comparison. Embedding occurs when data collection and analysis are linked at multiple points<sup>175,206</sup>. Whilst specific designs are well documented, it is also advocated that the choice of study design, methods, analysis, and integration be guided by that which is best suited to answer the research question<sup>183,184,206-208</sup>.

A sequential embedded mixed-methods design was chosen for this research to ensure the findings from each study would be synthesised and integrated to inform each other and the intervention development (Figure 3-2). The data collection methods were selected as the best fit for addressing the specific research objectives and ensuring stakeholder involvement throughout (PBA). These and the data analysis were embedded into the BCW intervention development process, with integration of data occurring at multiple points (Figure 3-3).

The scoping review identified the research aims and objectives, design of the study and the selection of outcomes. The findings of the survey informed the topic guides and selection of participants for the qualitative study. Following this, the synthesis and integration of the findings from both studies (Chapters 4 and 5) occurred using a framework method matrix to combine quantitative and qualitative data. This enabled comparison and convergence, resulting in a cohesive interpretation of the quantitative and qualitative data and identification of overall key

issues<sup>175,206</sup>. The co-design workshop with stakeholders enabled key issues to be presented and verified and validated by the participants<sup>175,206</sup>. These were then used as the basis for generating solutions.

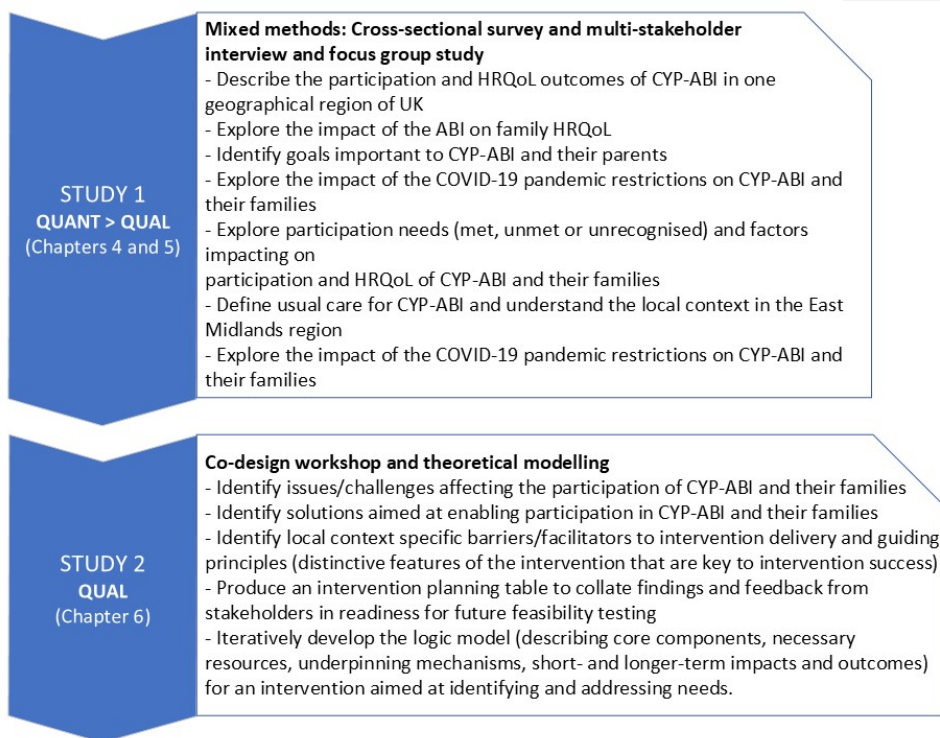


Figure 3-2: Sequential embedded mixed methods research design and objectives

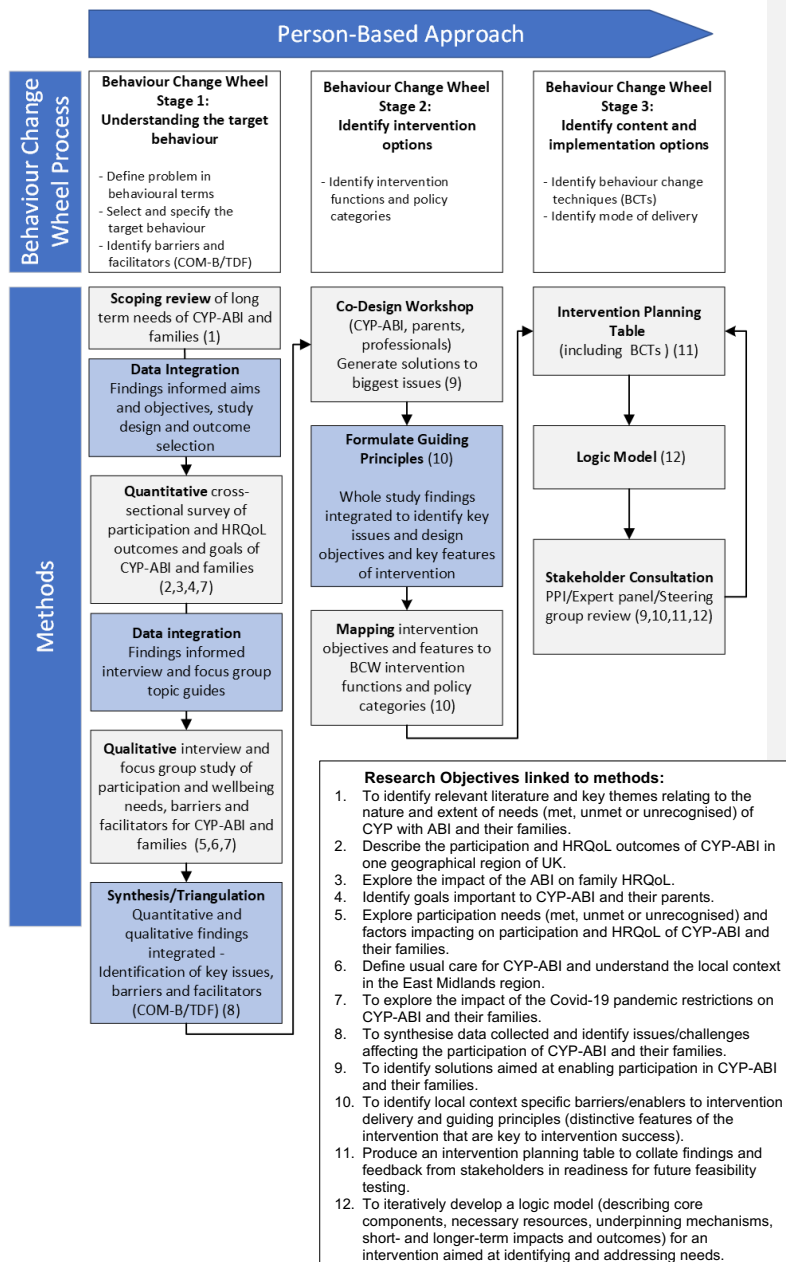


Figure 3-3: Integrated research plan and methods

## **3.6 Methods**

The methods for each of the studies are briefly presented here, with more detail provided where it is not included in the individual publications in Chapters 4-6.

### **3.6.1 Study 1: Mixed methods study (QUANT>QUAL)**

#### **3.6.1.1 Research Approach**

Having identified and synthesised the available evidence in the scoping review, gaps in the literature regarding the participation and well-being needs of CYP with ABI and their families in the UK required further investigation. To address these gaps, research investigating the prevalence of CYP with ABI, and family needs and outcomes was required as well as more in-depth understanding of the participation and well-being needs and influential factors. Additionally, to understand the local context for intervention development, usual care and current service provision for the population needed to be explored and mapped to enable service gaps related to unmet or unrecognised needs to be identified. This required both quantitative and qualitative methods. A sequential mixed-methods design was identified as the most appropriate to facilitate collection of quantitative outcome data followed by qualitative data to explore needs and understand the results <sup>209</sup>.

#### **3.6.1.2 Design**

To achieve the objectives (section 3.2), the mixed methods study consisted of a sequential design with a quantitative survey followed by a

qualitative interview and focus group study (Figure 3-4). The results of the survey informed the qualitative phase, with the topic guides for the interviews and focus groups being based on the findings of the survey. Presented here is an overview of the design, setting, sampling, recruitment, and consent procedures. Chapter 4 presents the publication of the cross-sectional survey, Chapter 5, the qualitative study.

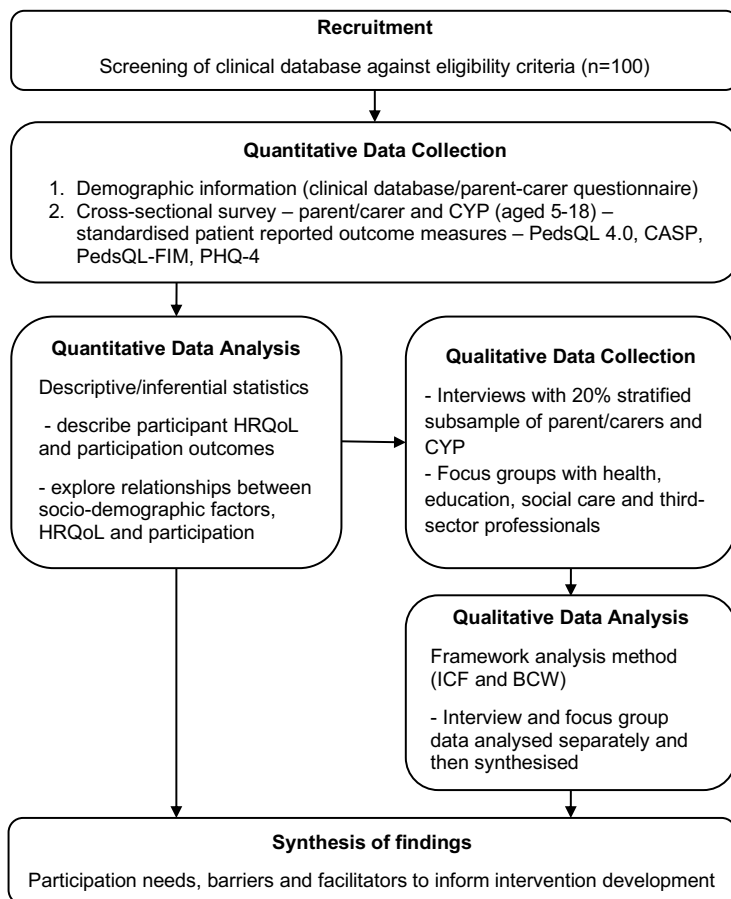


Figure 3-4: Study 1 - Explanatory sequential mixed method design



#### *3.6.1.2.5 Survey*

A cross-sectional survey explored the participation and HRQoL outcomes and needs of school-aged CYP with ABI (aged 5-18) one to four years after injury from across the region. Surveys are commonly used in healthcare research to gather information about a population and the impact of a health condition on individuals at that point in time<sup>210</sup>. Cross-sectional surveys are commonly used in mixed-methods research and are ideal for collecting demographic information, standardised outcome measures and open-ended responses<sup>209</sup>. Whilst some standardised outcome measure sets exist for audit and research of the acute care of CYP (Paediatric Intensive Care Audit Network) and of inpatient adult neurorehabilitation (UK-Rehabilitation Outcomes Collaborative), despite calls for this for audit or research with CYP with ABI, none exist<sup>211</sup>. The outcome measures included in this study were selected based on clinical knowledge and those recommended or commonly used within the CYP with ABI literature<sup>9,80,211</sup>. The survey was administered using JISC Online Surveys. Further details regarding the contents of the survey including the selected outcome measures are reported in Chapter 4.

#### *3.6.1.2.6 Interviews and focus groups*

Interviews with CYP with ABI and their parents and focus groups with stakeholders from health, education, social care and third sector organisations explored needs, barriers and facilitators and the local context in more depth. Semi-structured interviews with CYP with ABI and parents/carers were conducted to identify participation and well-

being needs (met, unmet, unrecognised) and factors impacting on participation and well-being in more detail. Interviews enable researchers to gain insight into the lived experiences of participants and were chosen as the most appropriate method for CYP with ABI and their parents to enable each family to describe their own experiences<sup>212</sup>. Interviews were semi-structured, using a topic guide to ensure focus and flexibility <sup>213</sup> (See 8.1 - Appendix 1 – Topic Guides). Focus groups with health, educational, social care and third-sector professionals explored the needs of CYP with ABI and those supporting them and aimed to define usual care and understand the local context for intervention development and implementation. Focus groups were selected for the stakeholders as they are suited to capturing the complexity and differing experiences and opinions of multiple stakeholders and can be debated through group discussion to gain consensus <sup>170</sup>. Further details regarding the interviews are focus groups are reported in Chapter 5.

### **3.6.1.3 Ethical Approval**

Study 1 was sponsored by The University of Nottingham (Ref: 20054). Health Research Authority and Research Ethics Committee (REC) approval was granted by Nottingham 2 REC on 16<sup>th</sup> November 2020. Following this, the UK entered a second COVID-19 pandemic lockdown, and a substantial amendment was requested on 11<sup>th</sup> February 2021 and approved on 18<sup>th</sup> March 2021 (REC ref: 20/EM/0258). This was to amend the survey to include questions related to how the pandemic and lockdown had affected CYP with ABI

and their families, and minor changes to the recruitment strategy.

Nottingham University Hospitals NHS Trust confirmed capacity and capability for the study (R&I reference: 20CS033).

#### **3.6.1.4 Setting**

The study was of community dwelling participants within one geographical region of the UK with a total population of approximately 4 million (800,000 <18years old).

#### **3.6.1.5 Sampling**

A purposive sampling strategy and pragmatic approach was employed as an appropriate method, as the aim was to sample a population with particular characteristics <sup>210</sup>. The clinical database of the neurorehabilitation team, at the regional specialist paediatric neurosciences centre, was used to identify CYP who had been admitted with an ABI after 01/04/2017. This date was selected to ensure completeness of data within the database. The eligible population was estimated to be 150 and a sample size of 92 CYP/parents was calculated (95% confidence interval, 5% margin of error).

Potential participants were identified from this database using inclusion/exclusion criteria:

##### **3.6.1.5.1 Inclusion criteria for parents:**

- Parent of a school-aged (5-18 years old) CYP (at the point of receiving the study invitation) diagnosed with an ABI of any cause.

- CYP received acute inpatient care and rehabilitation for an ABI at the regional specialist paediatric neurosciences centre since 01/04/2017 and were at least 1 year post injury at the time of recruitment.
- Resident of the geographical region served by the regional specialist paediatric neurosciences centre.
- Sufficient command of the English language or access to an interpreter (family or independent) to complete the survey and interview.
- Ability to give informed consent.

#### 3.6.1.5.2 *Inclusion criteria for CYP:*

- Aged 5-18 years old (at the point of receiving the invitation for participation). The CYP age was in line with the participation outcome measure (see below) and to include CYP who were in education.
- Received acute inpatient care and rehabilitation for an ABI at the regional specialist paediatric neurosciences centre since 01/04/2017 and were at least 1 year post injury at the time of recruitment.
- Resident of the geographical region served by the regional specialist paediatric neurosciences centre.
- Sufficient command of the English language or access to an interpreter (family or independent) to complete the survey and interview.
- Able to provide assent or consent for participation.

#### 3.6.1.5.3 *Exclusion criteria for parents/carers and CYP:*

- Family members or carers who did not have parental responsibility for the CYP.
- CYP under the age of 5 or over the age of 18.
- Participants identified from existing service database where the CYP was deceased.
- Participants identified from existing service database where there were ongoing safeguarding processes in place.

#### **3.6.1.6 Recruitment**

The Health Research Authority guidance on Information Governance was followed <sup>214</sup>. Permission to access the clinical database and patient records for the purpose of this research was sought, and approved, by the hospital NHS Trust research and innovation team. The usual care team ensured the database was up to date and that families of deceased children or those with ongoing safeguarding processes in place were not contacted as per the eligibility criteria.

Initial contact with potential participants was made by a member of the patient's usual care team (which included the researcher) either in person at clinic appointments (face-to-face or virtual) or via telephone or letter. Potential participants were informed of all aspects pertaining to participation in the study, given or sent a covering letter/email and Participant Information Sheets (PIS), and invited to participate. If there was no response to the initial contact or follow up call, all potential participants were contacted twice more if contact was not made on the first attempt. Those where there was no working phone number were

posted invitations and paper versions of the survey to complete and return. This therefore ensured, as far as possible, that all potential participants were contacted, either in person, by phone or by post, giving everyone equal opportunity to take part in the study.

#### *3.6.1.6.4 Consent Process*

Potential participants were asked if they would like to take part in the study and whether they would like to complete the survey on the phone, online or paper. A link to the survey was sent via email or text message or a paper copy posted. Completion either online or returned by post was taken as implied consent. Potential participants were also asked if they would like to participate in the interview section of the study and written electronic consent was provided ahead of the interviews being completed.

The initial approach to potential participants was made via the parents/carers of CYP with ABI, who were their main carers and legally must provide informed consent for CYP under the age of 16. As discussed in the ethical considerations for this study, this did potentially limit CYP, particularly those aged 16 and over, from deciding for themselves, however, this was the only option. Parents/carers were asked whether their CYP had the capacity to complete the relevant survey version. CYP aged 5-15 years needed to assent, alongside their parent/carers consent. Those CYP aged 16-18 years were asked to consent to theirs and their parent/carers participation. If parents/carers did not feel their CYP was able to complete the survey independently due to cognitive impairment, they had the option to proxy-report on

behalf of the CYP. Where there was uncertainty, there was the option of completing the survey via telephone/virtual meeting platform, with the researcher able to assist the CYP in self-reporting e.g., reading questions, assisting with completion.

Following completion of the initial survey recruitment and demographic data collection, a 20% subsample of CYP with ABI and parents who consented to be invited to participate in an interview were identified through stratified sampling to ensure demographic representation.

Potential participants were contacted to confirm that they still wished to participate in an interview and interviews were arranged at a convenient time, either via a virtual meeting platform or by telephone (due to ongoing pandemic restrictions). CYP aged 16-18 and parent/carer participants had the option of completing the interview separately or together. Either a parent or second member of the research team (if CYP aged 16-18) had to present on the call, in line with safeguarding procedures<sup>171</sup>. Topic guides were created, informed by the survey results, the ICF, and the BCW, supporting the exploration of participation needs (met, unmet, unrecognised), barriers and facilitators and goals important to CYP and parents/carers. Interviews were audio recorded and transcribed verbatim.

Stakeholders representing health, education, social care, and third-sector organisations were invited to participate in a focus group.

Participants were recruited through existing regional networks.

Invitations, PIS<sup>1</sup>, and consent forms were sent out via email informing potential participants of all aspects pertaining to participation in the

study and those wishing to take part in the focus groups were asked to contact the researcher via email and return their electronic consent form. Two focus groups (maximum of 10 participants per group) were arranged via a virtual meeting platform. Participants were informed of the dates and times of each, with them choosing which one they were able to attend. Topic guides were created, informed by the survey results and the BCW supporting the objectives of understanding needs, usual care, and local context. Focus groups were audio recorded and transcribed verbatim.

### **3.6.1.7 Analyses**

#### *3.6.1.7.1 Survey data*

Survey data was collected via the JISC Online Surveys website and downloaded into a Microsoft Excel spreadsheet before being anonymised, cleaned, and transformed into a data set to be analysed in STATA (Version 14, 2015). Data from the standardised outcome measures for participation and HRQoL and demographic differences and relationships were described using descriptive and inferential statistics. Participant goals were mapped to the ICF-CY. Free text box responses regarding the impact of the ABI on the CYP and family and the impact of the COVID-19 pandemic were analysed thematically using an inductive approach <sup>145</sup>. See Chapter 4 (Section 4.2.3.2.1) for more detail.



### 3.6.1.7.2 Interview and focus group data

All transcribed qualitative data were stored, organised, and analysed using Nvivo (version 12). Data were analysed using the Framework Analysis method, which is particularly suited to collaborative, multi-disciplinary health research <sup>215</sup>. The framework analysis method was followed, with an analytical framework developed using the ICF, COM-B/TDF frameworks to form the categories <sup>213,216</sup> (Figure 3-5). Using a systematic and iterative approach, interview and focus group data were analysed separately as two datasets, with codes and themes identified inductively. This was an iterative, rigorous process involving multiple iterations of inductive coding and identification of themes, before deductively sorting the themes into the framework and synthesising the findings. Regular consultations with the supervisory team and study steering group supported this process.

Qualitative data describing usual care and context was collated and mapped to depict patient pathways, referrals and lines of communication. The results of this are included in Chapter 6.

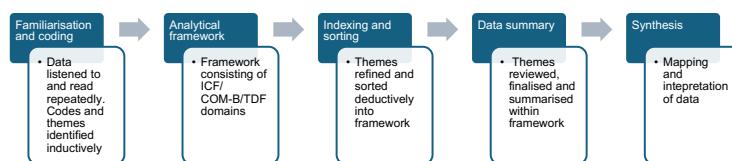


Figure 3-5: Framework analysis method

### **3.6.2 Study 2: Co-Design Intervention Development (QUAL)**

#### **3.6.2.1 Research Approach**

This study focused on the iterative development of an intervention using an integrated PBA and BCW approach, with the aim being to co-design and develop an intervention to promote participation and well-being in CYP with ABI and family caregivers.

The objectives were:

- To synthesise data collected from the mixed-methods study and scoping review and identify issues/challenges affecting the participation of CYP with ABI and their families.
- To identify solutions aimed at enabling participation in CYP with ABI and their families.
- To identify local context-specific barriers/enablers to intervention delivery and guiding principles (distinctive features of the intervention that are key to intervention success).
- To produce an intervention planning table to collate the findings and feedback from stakeholders in readiness for future feasibility testing.
- To iteratively develop the logic model (describing core components, necessary resources, underpinning mechanisms, short- and long-term impacts, and outcomes) for an intervention aimed at promoting participation in CYP with ABI.

### **3.6.2.2 Ethical Approval**

Study 2 was sponsored by The University of Nottingham and approval was granted by the Faculty of Medicine and Health Sciences Research (FMHS) Ethics Committee on 28<sup>th</sup> April 2023 (FMHS 234-0323).

### **3.6.2.3 Synthesis of findings**

Following the PBA and BCW intervention development process, the findings from the scoping review and the mixed-methods research were collated and synthesised using the framework method of analysis described above <sup>215</sup>. This was a continuation of the iterative, rigorous process described above, supported by the supervisory team and study steering group to reduce bias and ensure transparent reporting.

Synthesis of the findings from multiple stakeholders enabled the problem to be defined in behavioural terms, the target behaviour and barriers and facilitators to be identified and specified. This allowed the consideration of what needs to change and at what level. Key issues and barriers and facilitators were identified ready for presentation at the workshop.

### **3.6.2.4 Research Design**

An experience-based co-design workshop with multiple stakeholders (CYP, parents and health, education and charity professionals) was held. User-centred design is an important element of the PBA and integrated with qualitative and mixed-methods research <sup>217</sup>. Used effectively in previous research, engaging with multiple stakeholders is seen as best practice within intervention development and helps ensure it meets their needs, is relevant and acceptable <sup>135,187,218-220</sup>. The

objectives of the workshop are listed above and detail regarding the methods are presented in Chapter 6 (Section 6.6.2.1).

### 3.6.2.5 Recruitment

Participants, CYP with ABI, parents, and stakeholders, recruited from those who participated in the interview and focus group study, were invited to attend a workshop (Figure 3-6). The eligibility criteria were as per Study 1.

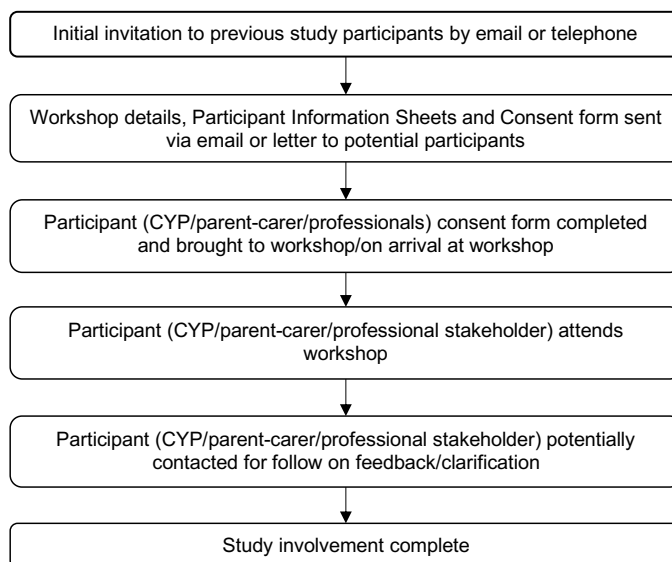


Figure 3-6: Co-design workshop study regime

The initial approach was by email or telephone from the researcher who already knew the participants from their previous participation in Study 1. Participants were invited to attend the workshop and informed of all aspects pertaining to participation. Participants received the PIS, consent forms and the date and time of the workshop via email, and participants were asked to bring completed consent forms with them to the workshop or complete on arrival. The consent procedures for CYP were as per Study 1. Additionally, members of the research team, study steering group (healthcare professionals from the acute neurorehabilitation team) and a PPI representative were present at the workshop to assist with facilitating groups and contribute. All participants completed written consent prior to the workshop commencing, with parents consenting for CYP under 16 years. A plan for the workshop was produced (Table 3-2). An external facilitator was used to run the workshop on the day to allow the researcher to listen and document discussions.

Table 3-2: Workshop Plan

<b>Workshop Plan</b>	
<ol style="list-style-type: none"> <li>1. Introduction, purpose, format and ground rules, confidentiality               <ul style="list-style-type: none"> <li>- Getting to know each other session – icebreaker activities</li> </ul> </li> <li>2. Research findings - sharing of what has been learnt so far               <ul style="list-style-type: none"> <li>- Issues/challenges identified in the literature review and mixed methods study</li> </ul> </li> <li>3. Identify solutions:               <ul style="list-style-type: none"> <li>- Split into 3 breakout groups</li> <li>- CYP – what can help me?</li> <li>- Parental support (Parents and stakeholders)</li> <li>- Pathway issues (Parents and stakeholders)</li> <li>- Discuss ideas for solutions/interventions, modes of delivery, local context-specific barriers and enablers to delivery, and guiding principles for the intervention.</li> <li>- Questions:                   <ul style="list-style-type: none"> <li>▪ What do we need to do to address this? (identify potential solutions for each identified issue)</li> <li>▪ What do you need to help you do that? (CYP specific question)</li> <li>▪ What should be included and how should it be delivered (for each potential solution)</li> <li>▪ How will that influence change? (for each potential solution)</li> <li>▪ What could stop this from working (barriers)?</li> <li>▪ What could help this work (enablers)?</li> </ul> </li> </ul> </li> <li>4. Groups feedback to whole group with open discussion regarding identified solutions, barriers and enablers and guiding principles.</li> <li>5. Summing up and close.</li> </ol>	

### 3.6.2.6 Analyses

Workshop data (notes made by the researcher from group discussions and participant notes, comments, diagrams and annotated drawings) were collated and analysed using content analysis to code and categorise the data to the COM-B/TDF using the framework method of analysis<sup>213,216</sup>. The findings and themes were then discussed with the research team and study steering group to validate coding and ensure rigour.

### **3.6.2.7 Theoretical Modelling**

As previously stated, the use of theory in this study is guided by the PBA and BCW. The theoretical modelling process followed was as follows and explained in detail in Chapter 6 (Section 6.6.2.2):

- Formulation of Guiding Principles.
- Mapping of intervention objectives and features to BCW.
- Identification of appropriate behaviour change techniques.
- Consideration of appropriate mode of delivery.
- Creation of an intervention logic model.

### **3.7 Chapter Summary**

To effectively address the aim and objectives of this thesis, a complex research plan was devised, [informed by the scoping review](#). A pragmatic, sequential embedded mixed methods study involving a cross-sectional quantitative survey and qualitative interviews and focus groups was followed by a co-design intervention development study. This included a co-design workshop and theoretical modelling. The PBA and BCW intervention development process framework guided the research. Chapters 4, 5 and 6 present the studies undertaken in published format. Chapter 7 presents a discussion of the thesis findings as a whole.



## 4 Mixed Methods Study – Quantitative Study

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### 4.1 Chapter Overview

Chapter 4 presents the first phase of Study 1 – a quantitative cross-sectional survey of health-related quality of life and participation outcomes and goals of CYP and their families after ABI.

This chapter has been published in *Brain Injury*:

Keetley, R., Manning, J.C., Williams, J., Stewart, I., Radford, K. (2024)  
Child and family health-related quality of life and participation outcomes and goals after acquired brain injury: a cross-sectional survey, *Brain Injury*, 38:3, 217-226.

DOI: [10.1080/02699052.2024.2309244](https://doi.org/10.1080/02699052.2024.2309244)

## **4.2 Child and family health-related quality of life and participation outcomes and goals after acquired brain injury: a cross-sectional survey**

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#### 4.2.1 Abstract

**Objective:** To explore longer-term health related quality of life (HRQoL) and participation outcomes and goals of children and young people (CYP) with acquired brain injuries (ABI) and their families in a region of the UK and the impact of the COVID-19 pandemic.

**Methods:** Cross-sectional survey of CYP (5-18) and their parent-carers 12-43 months following ABI. Included measures of HRQoL, participation, family function and parental well-being and demographic and free text questions.

**Results:** Ninety-five responses (30% response) were received. 67% of CYP were at risk of impaired HRQoL, 72% had severely impaired participation. 53% of parent-carers reported reduced HRQoL and family functioning, 37% of parent-carers screened positive for anxiety/depression. Relationships exist between CYP participation and HRQoL and parental HRQoL and family functioning. Goals were overwhelmingly activity and participation focused. Participants described the global impact of an ABI on the CYP and family as well as the additional impact of the COVID-19 pandemic on CYP and family well-being.

**Conclusion:** ABI significantly impacts CYP participation and both CYP and parent-carer well-being in the long-term, potentially further impacted by the COVID-19 pandemic. Rehabilitation interventions should address both participation and the psychological well-being of CYP with ABI and their parent-carers.

#### **4.2.2 Introduction**

Acquired Brain Injury (ABI) occurs because of traumatic (fall, road-traffic collision) or non-traumatic (stroke, infection, hypoxia, brain tumour) causes. It is the leading cause of morbidity and mortality in children and young people (CYP) globally, with traumatic brain injury incidence rates of 180-825 per 100,000 and 82.5 per 100,000 for non-traumatic causes<sup>4</sup>. In the UK, an estimated 40,000 CYP sustain an ABI every year<sup>7</sup>.

ABI's can lead to an array of complex physical, cognitive, social, emotional, and behavioural impairments which can result in lifelong disability. The consequences of an ABI may continue to become evident months or years after the event, with many issues under-recognised or mis-interpreted<sup>16,42,221</sup>. As childhood development progresses and educational and social demands increase through adolescence, these impairments can continue to impose a significant impact on a CYP's physical and psychological development, health-related quality of life (HRQoL), educational achievement and social participation through into adulthood<sup>8,221</sup>.

Predicting outcomes and monitoring long-term consequences poses a challenge for clinicians as childhood development and recovery of function is complex and unique to each CYP. Many factors influence recovery such as: injury characteristics, age, premorbid abilities, family functioning, environmental factors, and variability in rehabilitation service provision<sup>20,221</sup>. The International Classification of Functioning, Disability and Health (ICF) can be used to describe the impact of a health condition by mapping the needs, goals and influential factors, to

the four domains (body functions and structures, activity and participation, personal and environmental factors) and relationships between factors examined <sup>4,20</sup>. Participation in life situations is an essential component of child development, building towards increasing independence through adolescence into adulthood. It is seen as the ultimate outcome of healthcare services being associated with increased HRQoL, social and educational competence and long-term well-being <sup>27,77</sup>.

The impact of a CYP sustaining an ABI can extend to the whole family with substantial caregiver burden, distress, anxiety, stresses and reduced quality of life, well-being and family functioning <sup>88,89,95,222</sup>. Previous outcome and interview studies found that family impact is increased where there are unmet health and social care needs, and that the impact continues in 40-45% of families after the first year <sup>18,221,223</sup>. However, further research is required to explore the longer-term impact and influential factors in a UK context.

A scoping review by Keetley et al identified poor outcomes and extensive needs of CYP with ABI and their families <sup>221</sup>. Many had unmet or unrecognised needs up to 12 years post injury, which transcend ICF, health, social care and educational domains across the care pathway. Whilst there is an understandably large focus on return to school, being central to the development and education of CYP, research regarding reintegration and participation in community life, particularly activities and sports, is lacking. Furthermore, the voice of CYP is limited in the

literature meaning little is known regarding the CYP's own opinions on their outcomes and needs <sup>117,221</sup>.

The literature recommends long-term specialist follow-up and integrated care pathways; however, this is sparsely provided in the UK, with many CYP not receiving any specialist or community-based therapy or medical review. Access to this population is further complicated by the lack of any national registries, making investigating the long-term outcomes and needs of UK CYP with ABI challenging <sup>221</sup>.

Globally there is a drive to promote brain health and development, improve care pathways and support recovery, well-being and participation for people living with neurological disorders and for rehabilitation practice to be participation-focused <sup>77,223</sup>. In order to develop UK services to achieve this, further research is required to understand the outcomes and needs of CYP with ABI and their families within the UK service context <sup>221</sup>. In this study, part of a larger mixed methods study, we aimed to describe the HRQoL and participation outcomes of CYP with ABI and their families who received acute inpatient care/rehabilitation at one UK regional specialist centre. Additionally, we aimed to identify goals important to CYP with ABI and their parents and also explore the impact of the COVID-19 pandemic and national lockdowns on this population. Studies conducted in Australia investigating the impact of the pandemic on vulnerable children, including those with disabilities, and their families found a significant negative impact on health and well-being of both CYP and parents as well as reduced access to usual services and other support

structures<sup>107,224</sup>. Understanding the impact of the pandemic on UK CYP with ABI and their families is essential in supporting families, planning restoration of services and promoting full participation in society.

### **4.2.3 Methods**

#### **4.2.3.1 Study design**

This study consisted of a cross-sectional survey of community dwelling CYP with ABI and their parent-carers who were at least 12 months since discharge from hospital, as part of a mixed methods study.

#### **4.2.3.2 Participants and setting**

CYP with ABI and their parent-carers were recruited through a paediatric neuro-rehabilitation service based in a regional specialist (tertiary) paediatric neurosciences centre serving a population of approximately two million CYP. In the UK CYP with ABI remain in the care of children's services until they are aged 18 and complete their education when they then transition to adult services. Therefore, we included parent-carers of a school-aged (5-18 years) CYP (at the time of the survey) diagnosed with an ABI of any cause and resident in the UK were eligible to participate. CYP with ABI were eligible if they received acute inpatient care/rehabilitation at the regional paediatric specialist centre within the last five years and were one or more years post injury at the time of. The exclusion criteria included CYP deceased, ongoing safeguarding arrangements, insufficient command of English

language to complete survey and carers not having parental responsibility.

Due to the exploratory nature of this study, purposive sampling and a pragmatic approach to calculating sample size was employed <sup>225</sup>. The eligible population was estimated to be 150 and a sample size of 92 CYP/parent-carers was calculated (95% confidence interval, 5% margin of error).

The study opened during a national COVID-19 pandemic lockdown in March 2021 and recruitment continued until December 2021. Ethical approval was gained from the UK Health Research Authority (REC-20/EM/0258). Initial contact with potential participants was made by a member of the patient's usual care team face-to-face, by telephone, or letter and invited to participate by completing the survey online, via telephone, or by post.

#### *4.2.3.2.1 Survey*

The survey was administered using JISC 'Online Surveys' with separate versions for parent-carers (including proxy-report) and CYP age groups (5-7 years, 8-12 years, 13-18 years). Patient and public involvement (PPI) representatives were consulted on survey design and pre-tested the final version. It included demographic questions and standardised measures of CYP HRQoL and participation and parental well-being, HRQoL and family impact.

Both CYP and parent-carers were asked to state their three most important goals and free text boxes were provided to gather any other



information. Parent-carers proxy-reported for CYP unable to self-report due to cognitive impairment. Additional demographic, admission, and injury information (including measure of severity) was collected from the service database by a clinical team member following survey completion.

Measures were selected based on validity and reliability in this population, systematic review recommendations, prior clinical and research use, PPI consultation regarding ease of completion and participant burden, and child- and proxy-report version availability<sup>9,80</sup>.

The included measures were (see Table 4-1 for further details):

- Child and Adolescent Scale of Participation (CASP) to measure CYP participation<sup>226</sup>.
- Pediatric Quality of Life Inventory (PedsQL™ 4.0 Generic Core Scales SF15) to measure CYP HRQoL<sup>227</sup>.
- Pediatric Quality of Life Inventory Family Impact Module (PedsQL™ FIM) to assess family impact – parent-carer HRQoL and family functioning<sup>227</sup>.
- Patient Health Questionnaire for Anxiety and Depression (PHQ-4) to screen parent-carers for anxiety and depression<sup>228</sup>.

Survey data submitted via the JISC Online Surveys website was collated and analysed in Stata (Version 14, 2015). Participant responses were anonymised for analysis. Demographic characteristics and outcomes were analysed descriptively. Wilcoxon Rank Sum and Chi<sup>2</sup> tests compared responders to non-responders. Relationships

between outcome measures and demographic characteristics were analysed using Spearman's rho with Bonferroni correction.

Participant goals were mapped to the ICF-Child and Youth version (ICF-CY). Each goal was independently coded and assigned an alphanumeric code using chapter, first and second level descriptor codes. Coding was independently reviewed by a second reviewer and agreement reached where opinion differed. Multiple codes were used where the goal was multifaceted. Each goal was then assigned to the appropriate ICF domain and analysed descriptively.

Free text boxes were provided for participants to share comments regarding the impact of the ABI on the CYP and family and also the impact of the Covid-19 pandemic. Responses were analysed thematically using an inductive approach <sup>145</sup>.

Table 4-1: Details of selected outcome measures

Outcome	Tool	Completion	Scoring
CYP Participation	Child and Adolescent Scale of Participation (CASP)	Self-report (11+) Parent-carer-proxy report	<ul style="list-style-type: none"> <li>- 20 items in 4 sections (home participation, community participation, school participation and home and community living activities).</li> <li>- 4-point Likert scale is used to rate participation (4 = age expected (full participation), 3 = somewhat limited, 2 = very limited and 1 = unable, not applicable items = 0).</li> <li>- Total score divided by the applicable number of items and multiplied by 100 to conform to a 100-point scale.</li> <li>- Higher scores indicate higher levels of participation.</li> <li>- A score of less than 92 is deemed to represent severely impaired participation <sup>229</sup>.</li> </ul>
CYP HRQoL	Pediatric Quality of Life Inventory (PedsQL™ 4.0 Generic Core Scales SF15)	Self-report (5-7, 8-12, 13-18 versions) Parent-carer-proxy report	<ul style="list-style-type: none"> <li>- 15 items in 4 sections (physical functioning, emotional functioning, social functioning and school functioning).</li> <li>- 5-point Likert scale is used to score each item (0 = never, 1 = almost never, 2 = sometimes, 3 = often, 4 = almost always).</li> <li>- Scores transformed into a 0-100 scale - total score being the mean of all items.</li> <li>- Higher scores indicate better HRQoL.</li> <li>- A score of 72.05 or less, being greater than 1 standard deviation (SD) from a UK healthy population mean (83.89) is deemed to represent risk of impaired HRQoL for UK CYP <sup>230</sup>.</li> </ul>
Family Impact	Pediatric Quality of Life Inventory Family Impact Module (PedsQL™ FIM)	Parent-carer report	<ul style="list-style-type: none"> <li>- 36 items in 8 sections (physical functioning, emotional functioning, social functioning, cognitive functioning, communication, worry, daily activities, family relationships).</li> <li>- Scoring as per PedsQL™</li> <li>- Higher score indicates higher HRQoL/family functioning.</li> <li>- Score of 1 SD or more (59.6) from the healthy population mean (73.2) is considered to represent risk of impaired family HRQoL <sup>231</sup>.</li> </ul>
Parental well-being (anxiety and depression screener)	Patient Health Questionnaire-4 (PHQ-4)	Parent-carer report	<ul style="list-style-type: none"> <li>- 4 items: 2 for symptoms of anxiety (Generalized Anxiety Disorder 2-item (GAD-2), 2 for symptoms of depression (Patient Health Questionnaire-2 (PHQ-2).</li> <li>- 4-point Likert scale (0 = not at all, 1 = several days, 2 = more than half the days, 3 = nearly every day) with the sum of all scores being the total (0-12).</li> <li>- Total score &gt; 6 (or &gt; 3 on subscales) = 'yellow flag' for presence of a mild-moderate anxiety or depression disorder</li> <li>- Total score &gt; 9 (or &gt; 5 on subscales) = 'red flag' for moderate-severe anxiety or depression disorder <sup>232</sup>.</li> </ul>

#### 4.2.4 Results

From a possible 170 families, completed surveys were received from 51 families a response rate of 30% (Figure 4-1). A total of 95 CYP and/or their parent-carers responded. There was no missing data within the completed surveys, however two parent-carer responses were not completed where the CYP had completed their version and five CYP responses were not completed where parent-carers had responded.

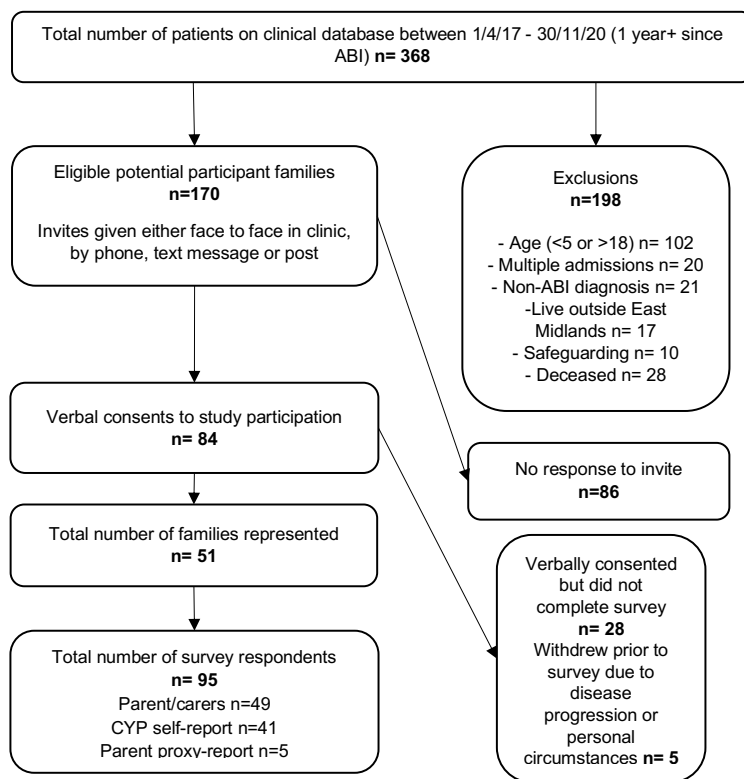


Figure 4-1: Study recruitment flowchart

The median age of CYP at the time of survey completion was 13 years (IQR 8-16) with 36 being male. The median time since injury was 2 years 11 months (IQR 1yr 11mo-3yr 7mo) with 45% having had a brain tumour. The sample included respondents from all five counties within the region, index of multiple deprivation (IMD) areas and a wide range of ethnicities (Table 4-2).

Table 4-2: Respondent characteristics

Table of respondent characteristic		n =
No. of parent respondents	Total	49
	Mothers	42
	Fathers	7
CYP Demographics		
Sex, n (%)	Female	15 (29%)
	Male	36 (71%)
Current Age, median (IQR)		13 (8-16)
Diagnosis, n (%)	Brain Tumour	23 (45%)
	Trauma	12 (24%)
	Stroke/Bleed	6 (11%)
	Infection/Inflammation	5 (10%)
	Other	5 (10%)
Severity (KOSCHI completed by clinical team at initial assessment), median (IQR)		3b (3a-4b)
Time since injury, years, median (IQR)		2yr11mo (1yr11mo-3yr7mo)
Index of Multiple Deprivation (quintiles), n (%)	5 (10/9) (highest)	11 (22%)
	4 (8/7)	9 (18%)
	3 (6/5)	9 (18%)
	2 (4/3)	12 (24%)
	1 (2/1) (lowest)	10 (20%)
Ethnicity		
Any other White background		2 (4%)
Asian or any other Asian background		7 (14%)
Black, African, Caribbean or Black British		2 (4%)
White - British-English, Welsh, Scottish, Northern Irish		39 (76%)
Prefer not to say/Not stated		1 (2%)

KOSCHI- Kings Outcome Scale of Childhood Head Injury

Outcome measure scores are presented in Table 4-3. The median PedsQL score was 64.17 (IQR 43.33-78.33, range 18.75-93.33) with 67% of CYP being at risk of impaired HRQoL. CYP also reported impaired social participation with 72% reporting severely impaired social participation (CASP median 80.63, (IQR 61,25-94.44, range 35-100)). More than half of parent-carers (53%) reported reduced parental HRQoL and family functioning (PedsQL-FIM median 56.25, (IQR 39.58-74.31, range 16.67-100)). The PHQ-4 total scores showed 37% of parent-carers screened positive for anxiety, depression or both with total scores of 6 or more). Subscale analysis revealed 29% of parent-carers screened positive for mild-moderate anxiety and 16% for moderate-severe anxiety (GAD-2 scores) and 27% of parent-carers screened positive for mild-moderate depression and 10% for moderate-severe depression (PHQ-2 scores).

Table 4-3: Outcome measure scores

Outcome measure		Median (IQR)	Mean (SD)	Freq (%)
<b>CYP, n=46</b>				
CASP	Total Score	80.63 (61.25-94.44)	77.45 (22.55)	
	- Home participation	91.67 (75.00-95.83)		
	- Neighbourhood/ community participation	75.00 (50.00-93.25)		
	- School participation	85.00 (70.00-100)		
	- Home and community living activities	75 (41.67-90.00)		
PedsQL™	Total Score	64.17 (43.33-78.33)	60.9 (21.06)	
	- Physical health subscale	60.00 (30.00-80.00)		
	- Psychosocial subscale	65.00 (50-82.50)		
<b>Parents/carers, n = 49</b>				
PedsQL™ FIM	Total Score	56.25 (39.58-74.31)	58.75 (22.63)	
	- Parental HRQoL subscale	55.00 (43.75-75.00)		
	- Family functioning subscale	65.63 (46.88-90.63)		
PHQ-4	Total Score	4 (2-6)		
	- Yellow Flag			11 (22%)
	- Red Flag			7 (15%)
	GAD-2	2 (1-4)		
	- Yellow Flag			14 (29%)
	- Red Flag			8 (16%)
	PHQ-2	1 (0-3)		
	- Yellow Flag			13 (27%)
	- Red Flag			5 (10%)

There was a strong positive relationship between CASP and PedsQL™ scores ( $\rho = 0.7137$   $p < 0.0001$ ) suggesting higher participation was related to higher HRQoL. Higher levels of CYP HRQoL and participation were also related to higher parental HRQoL and family functioning (PedsQL™ and PedsQL™-FIM  $\rho = 0.6393$   $p = 0.0001$ ; CASP and PedsQL™-FIM  $\rho = 0.5981$   $p = 0.0008$ ). Higher levels of parental anxiety and depression were related to lower CYP participation (CASP) and parental HRQoL and family functioning (PedsQL™-FIM) (PHQ-4 and CASP  $\rho = -0.4962$   $p = 0.0258$ ; PHQ-4 and PedsQL™-FIM  $\rho = -0.7557$   $p < 0.0001$ ). No statistically significant relationships were found between the demographic variables themselves (diagnosis, age, time since injury, KOSCHI score, IMD area), and only a weak positive relationship between time since injury and PedsQL™ and PedsQL™-FIM scores (See 8.2 - Appendix 2, Supplementary Table 1).

#### **4.2.4.1 Goals**

A total of 111 CYP goals and 146 parent-carer goals were mapped to the ICF-CY. Goals spanned three of the four ICF domains with the majority mapped to the Activity and Participation domain, 93% CYP, 83% parent-carers (see Table 4-4). 'Recreation and leisure' goals were the top priority for both parent-carers and CYP, with driving (which includes riding a bike), moving around (e.g., running or swimming), being the next highest priority for CYP and school education and informal social relationships for parent-carers (Figure 4-2). Comparing goals to different CYP age groups, whilst recreation and leisure goals were the top priority for all ages, there was a difference in priorities



below this. CYP aged 5-10 years reported driving (riding bike) and moving around (running/swimming) as important goals; 11–15-year-olds reported school education, informal social relationships, driving (bike) and moving around and 16–18-year-olds reported driving (car/bike) and higher education, acquiring a job, and carrying out daily routines.

Table 4-4: Goals mapped to ICF-CY Chapters

ICF-CY Chapters	CYP		Parents/carers	
	freq	%	freq	%
<b>Body Functions</b>				
Chapter 1 – Mental functions	4	3.60	12	8.22
Chapter 2 – Sensory functions and pain	1	0.90	1	0.68
Chapter 4 – Functions of the cardiovascular, haematological, immunological and respiratory systems	1	0.90	1	0.68
Chapter 5 – Functions of the digestive, metabolic, endocrine systems			3	2.05
Chapter 7 – Neuromusculoskeletal and movement-related functions			2	1.37
<b>Activity and Participation</b>				
Chapter 1 – Learning and applying knowledge	2	1.80	4	2.74
Chapter 2 – General tasks and demands	4	3.60	4	2.74
Chapter 3 – Communication	1	0.90	1	0.68
Chapter 4 – Mobility	29	26.13	11	7.53
Chapter 5 – Self-care			13	8.90
Chapter 6 – Domestic life	2	1.80	6	4.11
Chapter 7 – Interpersonal Interactions and Relationships	5	4.50	14	9.59
Chapter 8 – Major life areas	18	16.22	27	18.49
Chapter 9 – Community, social and civic life	42	37.84	41	28.08
<b>Environmental Factors</b>				
Chapter 1 – Products and technology	2	1.80	1	0.68
Chapter 3 – Support and relationships			1	0.68
Chapter 5 – Services, systems and policies			4	2.74
Total number of goals	111		146	
Body Functions goals	6	5	19	13
Activity and Participation goals	103	93	121	83
Environmental Factors goals	2	2	6	4

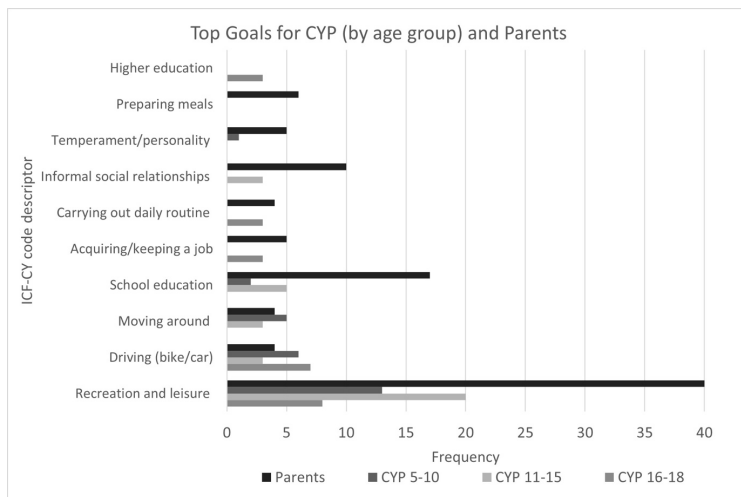


Figure 4-2: Top Goals for CYP-ABI and parents/carers

#### 4.2.4.2 Free text responses

##### 4.2.4.2.1 Impact of the ABI on CYP and family

CYP and parents detailed the global impact of the ABI on both the CYP and family. By far the largest concern for parents was the impact on their CYP’s emotional and mental health, with worries about how the ABI had affected confidence, self-esteem, increased feelings of frustration and isolation, with several families struggling to access mental health support. CYP also recognised the impact on their emotions and mental health.

*‘She has felt very isolated and alone going through it. We didn’t manage to get any mental health support for her until this year’*  
(Parent)

*'Sometimes I don't want to let people know what it's like living with it' (CYP)*

*'I get angry very easily I get scared crossing roads I forget' (CYP)*

Other concerns were impairment-related and the impact of these on education, getting the right support in place to support learning, and difficulties participating in sports and activities with friends.

*'Stress of trying to get the right support in school....he struggles to retain information...He's very behind with his year group. And it's affecting his mental health.'* (Parent)

*'It's hard being competitive with my peers. It's frustrating being last in a lot of activities'* (CYP)

The impact on the whole family was particularly evident with several parents detailing how their lives had changed forever with theirs, and their other children's well-being negatively affected. Parents also recognised the impact on the whole family's ability to participate in social activities.

*'It's difficult to put into words how our lives have been affected. I stopped living the day it happened.'* (Parent)

*'They [siblings] continue to struggle with the situation and have responded by keeping aloof and distant from X and refuse to discuss the difficulties she and we all face as a family.'* (Parent)

*'In every single way, we used to do lots together as a family but are no longer able to do this, friends have been lost and social circles disappeared.'* (Parent)

Additionally, several parents and CYP spoke of the lack of understanding regarding ABI, particularly where the injury is invisible.

*'Others don't understand as she looks fine physically but they can't see her brain and they don't know the struggles she faces daily.'* (Parent)

*'Some teachers really don't understand my new behaviour and I think I get punished when I don't mean to behave as I have. I react first but can't always help it I can't think quickly'* (CYP)

#### 4.2.4.2.2 Impact of the pandemic

CYP and parents reported positives and negatives of how the pandemic had impacted them. Whilst some participants reported that it had brought their family closer together and there were less social pressures or stress or anxiety related to having to go to school, the majority of families reported negative effects.

Increased isolation, reduced social interaction and lack of activities were major concerns along with difficult accessing home education and health and rehabilitation services, increased stress and worry for parents.

*'Like most children, X wasn't exercising enough, which wasn't great for keeping him strong and coordinated.'*(Parent)

*'I had to learn to home school which I found difficult with minimal teacher support.'* (CYP)

*'We had a disaster trying to accomplish any home-schooling. The on-line lessons and set work just didn't work for us at all and in the end I gave up (after lots of trying!), so she had no formal education.'* (Parent)

*'The family being separated during hospital stays. Very isolating for the parent who is in hospital.'* (Parent)

*'I lost all my NHS treatment and we have only just started it up, just physio now.'* (CYP)

#### **4.2.5 Discussion**

The aim of this study was to describe the long-term HRQoL and participation outcomes of CYP with ABI and their families, their goals, their views on the impact of an ABI and also how the COVID-19 pandemic had impacted them. This cross-sectional survey elicited 95 CYP and parent-carer voices representing 51 families. They report the substantial ongoing impact of an ABI on HRQoL, participation, family functioning and well-being one to four years after injury. Additionally, we gained insight into the impact the COVID-19 pandemic has had on these families. HRQoL and participation are important health outcomes, assessing CYP's well-being, mental health, physical and social functioning, however this study highlights the importance of also assessing parental well-being and family functioning and well-being<sup>9,116</sup>.

#### **4.2.5.1 Impact on CYP**

Through self-report, the voices of the CYP have been heard regarding their health and well-being, telling us that all is not well for a substantial proportion of this sample. CYP HRQoL was reduced with 67% scoring below the cut-off values of 72.05 which is comparable to or worse than reported in other studies <sup>76,230,233</sup>. CYP scored similarly across physical and psychosocial subscales demonstrating the global impact of an ABI on their HRQoL.

Reduced participation levels were reported across all domains, with 72% of CYP experiencing severe restrictions, in line with the findings of other international studies <sup>58,75,76,229,234</sup>. The greatest restrictions were in the community participation and home and community activities domains, which include participation in social, play or leisure activities with friends, structured events and activities (clubs/sports), community mobility and communication and daily life activities (managing money, daily routines, work). Participation in these types of activities may be difficult for CYP with ABI due to functional impairments but other barriers may be impacting e.g., environmental factors – physical environment, support and relationships as well as pandemic restrictions.

The significant positive relationship between CYP HRQoL and participation was expected and adds to the evidence base <sup>76</sup>. The weak positive relationship between HRQoL and time since injury suggests that there is some improvement over time, but as this was not a longitudinal study this cannot be substantiated.

Through the free text responses, we gain insight into how the CYP feel about their life after ABI and their parents' concerns. Though only brief, the impact on emotional and mental health, resultant isolation and difficulties accessing support are evident, as is the importance of supporting CYP to participate to maintain their well-being <sup>18,42,235-237</sup>. These findings warrant further exploration.

#### **4.2.5.2 Impact on family**

The findings show the substantial impact of an ABI on the family, with more than half of parent-carers reporting significantly impaired HRQoL and poor family functioning. In this study, PedsQL-FIM median scores were below those in comparable studies and mean scores were substantially below healthy population norms <sup>89,90,231</sup>. Furthermore, PHQ-4 scores revealed over a third of parent-carers screened positive for the presence of an anxiety and/or depression disorder, substantially higher than the general population, further demonstrating the lasting impact of a CYP's injury on parent-carers <sup>232</sup>. These results suggest that the parent-carers and families in this study continue to feel the impact of their CYP's ABI long after the event, with ongoing disruption to family functioning and parental HRQoL and well-being being affected. Furthermore, the significant associations found between parental well-being and family functioning and CYP participation and HRQoL outcomes point to the importance of these relationships in CYP long-term recovery. This is supported by evidence from previous research in CYP with ABI in the first-year post injury <sup>89,238</sup>. The free text responses contributed greater insight to this issue, particularly parental concerns

regarding the impact of the ABI on the well-being of the whole family, including siblings.

With parents and families being the main caregivers and source of support for a CYP with ABI, it is imperative to recognise and address the detrimental impact of the ABI on the whole family, given that parental mental health and family functioning are important predictors for the functioning and well-being of the CYP <sup>38,42,77,235,239,240</sup>.

This study was unable to determine the factors affecting the outcomes observed or the nature of these causal relationships from these results. Further exploration within the UK context is warranted to investigate influential factors, and barriers and enablers to family-centred care and to inform the development of interventions targeted at addressing the needs of the whole family unit <sup>235,241</sup>.

#### **4.2.5.3 Prioritising goals**

Goal setting is fundamental to rehabilitation. In recent years there has been increasing emphasis on the prioritisation of goals that are meaningful to CYP and their families and participation-focused <sup>80,242,243</sup>. Activity and participation goals were clearly prioritised by both CYP and parent-carers in this study, in line with previous studies which also found that families prioritised activity and participation goals during rehabilitation such as recreation and leisure, education, mobility, selfcare and communication <sup>117,244</sup>.

Families reported what is important to them in terms of their well-being – recreation and leisure (e.g., play, sports, fitness, hobbies, visiting the



cinema, sightseeing, tourism). Other important goals were driving (bike/car), moving around (e.g., running, swimming), school education and informal social relationships, with more focus on independence skills in older CYP. These and recreation and leisure cover a wide range of activities, reflected in the CASP domains where CYP scored worst. This demonstrates their importance to CYP with ABI and their families, and the need for continued monitoring and interventions targeting individual needs and goals. Further exploration of CYP and family goals and needs is required to explore influential factors and how goals change over time, particularly into adolescence.

#### **4.2.5.4 Impact of pandemic**

As this study was conducted during the Covid-19 pandemic, the additional impact of this on the well-being of CYP and families cannot be discounted and may account for the lower scores reported here. Certainly, the further social isolation and loss of support services reported by participants in the free text responses only adds to the burden families of a CYP with ABI experience, which supports international evidence regarding the vulnerability of CYP with disabilities during the pandemic <sup>107-109,139,224</sup>. Ongoing clinical assessment is vital to identify those who are in crisis or at high risk of poor outcomes. Furthermore, clinicians need to be mindful of the impact the pandemic has had on the already complex lives of CYP and families with additional needs and that the real consequences are still being uncovered <sup>109,245</sup>.

#### **4.2.5.5 Strengths and limitations**

This study, delivered with methodological rigor, has facilitated the voices of 95 CYP and parent-carers to be heard, allowing them to highlight their considerable ongoing needs. The findings add to the evidence base, particularly regarding CYP self-reported outcomes together with parent-carer reported outcomes and evidence of the relationships between these.

However, accessing and recruiting this population was challenging. We achieved a 30% response as a result of supporting families to respond by offering multiple modes of completion. We are reminded that this is higher than the general survey response rate in paediatric populations (15-25%) and, bearing in mind the study was conducted during the challenges of the Covid-19 pandemic, we are indebted to the families for their participation. We must however recognise there is still a potential risk of bias, limiting generalisability, with many CYP and parent-carer voices from this seldom-heard population remaining unheard<sup>246</sup>. Additionally, mainly mothers responded, meaning fathers' voices are under-represented. Every effort was made to reduce the burden of the survey on families, however, 28 families who initially consented verbally to completing the survey failed to do so, potentially suggesting the burden remained too high. CYP with brain tumours and their families responded in greater numbers than those with TBI or other non-traumatic causes compared to previous population data from the same region, potentially due to the centre specialising in childhood brain tumour research and a familiarity with clinical research. In

addition, there was a greater (although not statistically significant) representation from more severely affected CYP with ABI, which may be related to differences in engagement with services for those with greater need and may also have contributed to the lower scores reported (See 8.2 - Appendix 2, Supplementary Table 2).

The challenges in accessing and recruitment led to limitations in design. To reduce participant burden, the survey was cross-sectional, thereby only capturing information at a single time point, with no assessment of pre-existing outcome levels. Parents-carers were the first point of contact via the acute service and therefore contact information may not have been up to date or they may have decided not to participate without consulting their CYP. The heterogeneity of the sample, whilst representative of CYP neurorehabilitation services in the UK and research in this population, meant there were limited numbers in each diagnostic group, which limited sub analyses.

#### **4.2.6 Conclusion**

This novel study has explored outcomes for both CYP with ABI and their parent-carers one to four years post ABI during a global pandemic and adds UK findings to the international evidence base, complementing understanding of the evolving burden of this disease. CYP and parent-carers report a substantial impact on their HRQoL, participation, parental HRQoL and well-being and family functioning both in their outcome scores and free-text responses. Activity and participation goals were prioritised by both CYP and parent-carers asserting their importance. The potential impact of the pandemic on

these findings cannot be ignored and needs further exploration. The relationships between participation, HRQoL, family functioning and parental well-being exist and require further investigation. While the nature of these causal relationships remains unclear, the need for family-centred care and multidisciplinary and multimodal interventions targeting outcomes for both the CYP and parent-carer is clear. Holistic long-term care is vital to effectively monitor and address existing and emerging needs as CYP and families navigate their rehabilitation journey and re-build their lives. To do this effectively, further research is required to explore the associations between outcomes and influential factors, including barriers and enablers and develop interventions aimed at addressing family needs across the life course.

#### *Acknowledgements*

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### **4.3 Chapter Summary**

Chapter 4 has presented the results of a cross-sectional survey – the first phase of Study 1, a mixed methods study, published in *Brain Injury*.

The results demonstrated the substantial impact on the participation, HRQoL and well-being of CYP with ABI and their families and the relationships between these outcomes. CYP and their parents prioritised activity and participation goals and reported the added impact of the COVID-19 pandemic on their well-being.

The results of this survey informed the qualitative phase of Study 1, reported in Chapter 5.

## 5 Mixed Methods Study – Qualitative Study

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### 5.1 Chapter Overview

Chapter 5 presents the second phase of Study 1 – a qualitative multi-stakeholder study aiming to understand the barriers and facilitators to long-term participation needs in CYP and their families following ABI.

[The study design, participant selection and interview and focus group guides, were informed by the results of the cross-sectional survey described in Chapter 4.](#)

This chapter has been published in *Brain Impairment*:

Keetley R, Manning JC, Williams J, Bennett E, Westlake M, Radford K. (2024) Understanding barriers and facilitators to long-term participation needs in children and young people following acquired brain injuries: a qualitative multi-stakeholder study. *Brain Impairment*, 25, IB23100.

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**5.2 Understanding barriers and facilitators to long-term participation needs in children and young people following acquired brain injuries: a qualitative multi-stakeholder study**

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### 5.2.1 Abstract

**Aim:** To explore the longer-term participation needs of children and young people with acquired brain injury (CYP with ABI) and their families in one region of the UK and identify barriers and facilitators to participation and well-being to inform development of a behavioural change intervention for clinical implementation.

**Method:** Qualitative interviews with CYP with ABI and parents. Focus groups with health, education, care and charity stakeholders. The International Classification of Functioning, Disability and Health (ICF) and Behaviour Change Wheel were used to map needs, barriers, and facilitators.

**Results:** Ten CYP/parent dyads (n=20) and 17 health, education, care, and charity stakeholders. Unmet participation needs were mapped to the ICF and barriers/facilitators to the BCW. Significant unmet needs impacting CYP with ABI participation and family well-being were found. Barriers spanned 'Capability', 'Opportunity' and 'Motivation', the greatest being knowledge, skills, social influences, environmental context and resources, social identity, and emotion. Facilitators included increasing awareness and understanding, supporting parents, long-term access to specialist assessment and rehabilitation, peer support and integrated collaborative pathways.

**Discussion:** The long-term impact of ABI on CYP and families' participation and well-being were significant with barriers spanning every sector and level of society. Implementation of collaborative, cross-sector (education, health and social care) accessible, family-



centred care pathways is needed to meet the long-term needs of CYP with ABI and their families, ensuring equity of access. Multi-modal, family-centred, needs-led, theory-based interventions should be co-developed with CYP, families and stakeholders to improve health and well-being outcomes and the lives of CYP with ABI and their families.

**Keywords:** Acquired brain injury, children, participation, well-being, family, implementation

### 5.2.2 Introduction

Acquired Brain Injury (ABI) in Children and Young People (CYP) is defined as either a traumatic (e.g., a fall or road-traffic collision) or non-traumatic (e.g., a stroke, infection, or brain tumour) injury to the brain occurring since birth<sup>3</sup>. Traumatic brain injury (TBI) is the leading cause of childhood morbidity and mortality worldwide with an estimated incidence of between 47 and 280 per 100,000 depending on the country<sup>247</sup>. In the UK approximately 40,000 CYP sustain ABI annually, with over 9000 classified as moderate or severe<sup>7</sup>. Physical, cognitive, emotional and/or behavioural impairments can significantly impact physical and psychological development, quality of life (QoL) and participation outcomes<sup>19,248</sup>. As such, ABI is conceptualised as a chronic condition with functional changes occurring over a decade after injury<sup>39</sup>. A scoping review identified extensive unmet and unrecognised needs up to 12 years post injury with needs relating to CYP's impairments, parent and family support, return to school and long-term after-care<sup>221</sup>. Furthermore, there are increased risks of long-term poor health and psychosocial outcomes in adulthood which present the need for long-term rehabilitation and support<sup>3,40-42</sup>.

Participation, a key domain in the International Classification of Functioning, Disability and Health (ICF), is a complex multidimensional construct, defined as 'involvement in a life situation'<sup>26</sup>. Participation in home, school and community activities is a fundamental right and enhances the well-being of all, including children with disabilities<sup>27</sup>.

However, CYP with ABI and their families report reduced participation and QoL in the years after injury <sup>75,76,221,249,250</sup>. A cross-sectional survey of CYP with ABI and their parents one-four years post-injury found a significant long-term impact of an ABI on CYP participation and both CYP and parent well-being <sup>250</sup>. Of the CYP participants, 72% had severely restricted participation and 67% reported reduced health-related QoL. Of the parent participants, 53% reported reduced health-related QoL and family functioning and 37% of parents screened positive for anxiety/depression. Reduced participation and well-being can isolate families and increase CYP disability <sup>42,251-253</sup>. Improving survival rates for many childhood ABIs e.g., brain tumour, mean more CYPs are living with the long-term impact of ABI and require paediatric rehabilitation services and support throughout their life course <sup>11</sup>.

Rehabilitation aims to maximise functional recovery and well-being, with participation in individual life contexts (home, school, community) seen as both the means of skill development and the outcome <sup>27,77,80,252,254</sup>.

Widespread variability in paediatric rehabilitation results in uncertainty regarding the long-term outcomes of CYP with ABI and their families. It is unclear how services should be designed to meet needs and optimise their participation and well-being <sup>35,249</sup>.

Diener et al <sup>122</sup> described the community reintegration (participation) needs of a small sample of US CYP with ABI and their families.

Through qualitative interviews with caregivers of 6 CYP with ABI and 14 outpatient and community providers, they found substantial unmet

needs including issues related to CYP's impairment and identity, social isolation and a lack of education for parents, peers and teachers. Additionally, they found a lack of coordinated family-centred care and access to funding and resources. Similarly, qualitative interview study of 14 Australian rehabilitation services for CYP with TBI and spinal cord injury, found multiple challenges to family-centred care delivery including poor communication and understanding of needs across sectors <sup>123,255</sup>. Both studies conclude collaborative multi-system interventions and broader-scale system improvements are required to address the needs of CYP with ABI and their families in the long-term. However, to develop interventions that address needs and improve outcomes, a greater understanding of influential factors is required<sup>221,249</sup>.

The Medical Research Council's (MRC) framework for developing and evaluating complex interventions recommends using theory and evidence when developing interventions <sup>133</sup>. Implementation science offers a pragmatic, systematic, theoretical approach to healthcare research that incorporates the use of theories, models and frameworks to guide the process of translating research into evidence-based practice <sup>134,135</sup>. It draws on a range of theories, such as psychological theories, to help identify and define core components of complex interventions and ensure that the integrity of these is maintained regardless of the context for intervention <sup>133</sup>. Theoretical frameworks, such as the Behaviour Change Wheel (BCW), help us to understand

target behaviour(s), barriers and facilitators to behaviour and mechanisms likely to lead to successful implementation of evidence-based behaviour change interventions<sup>134,136</sup>. Additionally, engaging stakeholders using qualitative methods when developing theory-informed interventions ensures the needs, barriers and facilitators to the target behaviour and the real-world context are well understood. This detailed understanding guides intervention development and implementation by ensuring new interventions are acceptable, address the target population's needs, and identify potential implementation barriers and facilitators<sup>136</sup>.

This study aimed to explore the longer-term participation and well-being needs of CYP with ABI and their families in one region of the UK and to identify barriers and facilitators to participation (target behaviour) and well-being to inform the development of a participation-focused intervention.

### **5.2.3 Method**

#### **5.2.3.1 Design**

We conducted a qualitative exploratory study, using a pragmatic approach and semi-structured interviews with community-dwelling CYP with ABI and parents, as well as focus groups with health, education and social care professionals to identify and understand participation needs, barriers and facilitators<sup>136,213</sup>. Ethical approval was gained from the UK Health Research Authority (REC-20/EM/0258).

### **5.2.3.2 Methodology**

Two theoretical frameworks informed this study. The ICF biopsychosocial model was used to map the impact of the brain injury on the CYP/family in four domains 'body functions and structures', 'activity and participation', 'personal factors' and 'environmental factors' and to describe participants' unmet participation needs<sup>26</sup>. The BCW<sup>193</sup>, which incorporates the COM-B model of behaviour and the Theoretical Domains Framework (TDF), provides a systematic process for using theory and evidence in the design of interventions. It has been used to inform multiple intervention development studies including physical activity interventions for adolescent girls and adults<sup>198,199</sup> and increase social participation of adult stroke survivors<sup>201</sup>. We chose it to guide the design of the intervention and identification of determinants of the target behaviour (participation), barriers and facilitators to participation, how behaviour change might be achieved and the context for intervention delivery. The COM-B, at the centre of the BCW, describes sources of behaviour. '*Capability*' describes the physical and psychological abilities of a person related to a behaviour, '*Opportunity*', the properties of a person's environment that affect their ability to enact a behaviour and '*Motivation*' describes influences on motivation to perform that behaviour<sup>193</sup>. The TDF, a determinant framework, subdivides the COM-B components and aids greater understanding of barriers and facilitators at individual, organisational and community levels (Table 5-1)<sup>136</sup>.

Table 5-1: Behaviour Change Wheel – COM-B components and TDF Domains

Behaviour Change Wheel – COM-B components and TDF Domains		
COM-B Components		TDF Domains
Capability	Psychological	- Knowledge - Skills - Memory, attention, and decision processes - Behavioural regulation
	Physical	- Skills
Opportunity	Social	- Social influences
	Physical	- Environmental context and resources
Motivation	Reflective	- Social/professional role & identity - Beliefs about capabilities - Optimism - Beliefs about consequences - Intentions - Goals
	Automatic	- Social/professional role & identity - Optimism - Reinforcement - Emotion

### 5.2.3.3 Participants

CYP with ABI, their parents, and health-, education-, social care- and third sector-professionals participated in this study. CYP with ABI and their parents were identified from 95 participants who had completed an earlier survey of participation and QoL outcomes<sup>250</sup>. CYP were aged 5-18 years with moderate to severe ABI, sustained 1-4 years previously (to capture persistent longer-term needs) and they received inpatient care at a regional specialist paediatric neurosciences centre. Survey participants who had expressed interest in being included in a further interview were purposively sampled using a sampling frame (including sex, diagnosis, county, ethnicity, injury severity and deprivation) taken from survey responses and the clinical registry data used in the survey<sup>213</sup>. A 20% subsample was identified, following the principles of

sample adequacy, ensuring cases were 'information-rich', diverse and representative of this heterogeneous population <sup>256</sup>.

Stakeholders representing health, education, social care and charity providers were recruited through existing regional referral networks and persons known to the research team and invited to participate in a focus group.

#### **5.2.3.4 Procedure**

The study was conducted online using the Microsoft Teams platform. Interviews were completed between August 2021 and May 2022 and focus groups were completed in November 2022. All data were collected online using Microsoft Teams. Participants completed an online consent form before participation, with parents consenting for CYP under 16-years. Topic guides for interviews and focus groups included questions aligned to the theoretical framework domains and survey findings. Interview format and timings were led by the CYP and parents. Interviews commenced with CYP and parents together, with those over 16 being able to choose whether they wanted parents present or not. CYP participated as much or as little as they wished and were free to leave at any point. Parents were then interviewed alone. All interviews and focus groups were conducted by RK, with the assistance of a co-facilitator (EB) and chat moderator/note taker (MW) for the focus groups. Microsoft Teams chat and whiteboard functions were also used within the focus groups. Interviews and focus groups were audio recorded, and transcribed verbatim by RK or a professional transcriber,



with these being crosschecked by RK and a peer researcher (LR). Transcripts and chat/whiteboard contributions were anonymised with pseudonyms or professional roles used to protect participant privacy.

### 5.2.3.5 Analysis

Transcripts were imported into NVivo (ver. 12). Data were analysed using framework analysis, with the domains of the ICF and COM-B/TDF forming the preliminary framework (Figure 5-1) <sup>213,216</sup>. Through a systematic and iterative approach, interview and focus group data were analysed separately as two datasets, with codes and themes identified inductively. Themes were then refined and deductively mapped to the framework before synthesising the data sets.

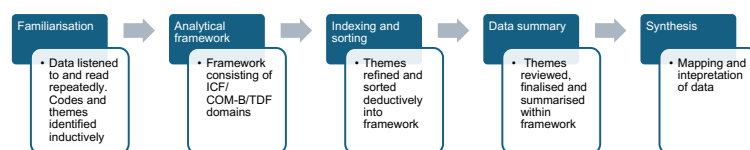


Figure 5-1: Data analysis plan <sup>213</sup>

### 5.2.3.6 Researcher characteristics, trustworthiness and reflexivity

The lead researcher is an experienced children's neurorehabilitation physiotherapist. Recognising the potential influence of the researcher's perspective, regular consultations with the research team and study steering group (experienced paediatric neurorehabilitation clinicians from the regional centre) were held to validate coding and interpret

emerging themes <sup>179</sup>. Field notes were maintained for interviews and focus groups and used during analysis alongside the transcripts for context and reflexivity <sup>180</sup>.

#### **5.2.4 Results**

Eleven interviews and two focus groups were conducted. Ten CYP/parent dyads participated in the interviews. Interviews were adapted where necessary to enable CYP participation and ranged from 13-73 minutes, the shortest due to splitting one interview into two parts to accommodate the CYP's needs. Seventeen stakeholders participated in focus groups lasting 73-78 minutes. Participant characteristics are shown in Table 5-2. Key themes identified from the framework analysis relating to unmet participation needs and barriers and facilitators to participation and well-being are presented here.

Table 5-2: Participant variables

Table 2. Participant variables			n
CYP			10
	Sex	Male	7
		Female	3
	Age	5-10	4
		11-15	3
		16-18	3
	Diagnosis	Non traumatic brain injury	7
		Traumatic brain injury	3
	Severity*	2 – 3b (disorder of consciousness- severe disability)	8
4a-5b (moderate-mild disability)		2	
Length of hospital stay	Median (days) (Range)	18.5 (4-102)	
Indices of Multiple Deprivation Quintiles (IMD)**	1-2	3	
	3	3	
	4-5	4	
Parents	Mother/Female foster carer	10	
Stakeholders	Professional	17	
	Nurse	3	
	Allied Health professions *** & Neuropsychologists (AHPN)	7	
	Education professionals and support staff (EPS)	5	
	Social care/charity partners (SCP)	2	

KEY: \*Severity measured using Kings Outcome Scale of Childhood Head Injury <sup>257</sup>

\*\*IMD (measure of relative deprivation for small areas in the UK – 1 most deprived <sup>258</sup>

\*\*\* Allied health professionals including acute and community physiotherapists, occupational therapists and speech therapists

#### 5.2.4.1 Unmet participation needs

Using the analytical framework, themes relating to participant's needs were deductively refined and sorted into the framework. Participants reported multiple unmet participation needs impacting CYP with ABI and family participation and well-being. Restrictions in participation were reported in every ICF sub-domain of Activity and Participation at home, school and community settings and unmet needs were related to addressing these or accessing support to overcome barriers (Table 5-3).

#### **5.2.4.2 Mapping barriers and facilitators to the COM-B/TDF**

Barrier and facilitator themes inductively identified included issues related to well-being, support, information, and resources (Figure 5-2). These themes were deductively sorted into the analytical framework and spanned the COM-B 'Capability', 'Opportunity' and 'Motivation' domains and nine of the TDF domains (Table 5-4). The main barrier and facilitator themes are presented here under within their COM-B and TDF domains with additional themes and quotes found in Table 5-4 and Section 8.3 – Appendix 3, Supplementary Table 1.

Table 5-3: Participation unmet needs

Participation unmet needs		
ICF Participation sub-domains	Unmet needs	Example Quotes
Learning and applying knowledge	- Access to additional learning support	'X struggles a bit with his memory and sometimes he struggles with trying to find the right words to say so he'll take a while to answer something to try and get the right words' (Elijah's Mother)
General tasks and demands	- Support to develop independence in daily routines	'It's more so when he's tired or he's not concentrating...he hasn't got the memory to remember what tablets he has' (Barney's Mother)  'My mom helps me with like stuff that I need to pack. Or if I need to go over and remember some things'(Elijah)
Communication	- Support with communication difficulties	'She's lost all her confidence completely now talking to other people. She's looking to me all the time....'(Megan's Mother)  'Banter sometimes can be a bit tricky. The filter's not on and he says what he's thinking out loud, and sometimes that can be, oh my gosh, should he have said that?' (Hamza's Mother)
Mobility	- Developing skills: - Walking - Fine motor skills - Driving car/riding bike	'Because he's struggling with buttons and his tie and laces and what have you' (Robert's Mother)  'Probably go back to physio try to get some more use in my body.' (Barney)  Driving, I want to work because I've got a placement with college soon what involves working and driving and it's always been a thing I've wanted to do... (Jack)
Self-care	- Developing washing and dressing skills - Safety awareness	'It's not the actual journey of knowing the direction that you're going to walk to and from, it's the actual crossings, being aware of whose right is where and being aware of give-ways, being aware of three-way junctions..' (Hamza's Mother)
Domestic life	- Preparing meals	'Because I want to cook things by myself and just get ready if you're not going to be there to cook anything.' (Oscar talking about developing independence at home)

Interpersonal interactions and relationships	- Difficulties with friendships or lack of friends	<i>'He's become a bit of a recluse to be fair' (Barney's Mother)</i>
Major life areas	<ul style="list-style-type: none"> <li>- Education:</li> <li>- Developing independence in school</li> <li>- Needs not being understood</li> <li>- Reduced physical activity (lesson based and playground/breaktimes)</li> </ul>	<p><i>'But once he went up to high school, because X looks fine and he doesn't look like he's had a brain injury, really, you know...and I think they think, oh it's fine and everything's OK when, well no, it's not' (Elijah's Mother)</i></p> <p><i>'I want her to be outside, to get some fresh air and see her friends, she's not seen anybody; and they were saying, but we can't watch her outside, we can't keep her safe' (Megan's Mother talking about safety at playtimes)</i></p>
Community, social and civic life	<ul style="list-style-type: none"> <li>- Recreation/leisure activities</li> <li>- Support to identify and access appropriate activities</li> <li>- Developing independence within community settings</li> </ul>	<p><i>'That one can be a bit tricky can't it, I don't like you to go too far do I' (Amelia's Mother talking about her playing outside with friends)</i></p> <p><i>'She is interested in doing something but how do I, how do I do that, and you know, I, what can I do for her and I don't know what I can do for her, I don't know where I can go to get help for her.' (Megan's Mother)</i></p> <p><i>'Buses has come up in our conversations, but just she wants to make sure I'm there safe, that I don't catch the wrong bus and that.' (Jack)</i></p>

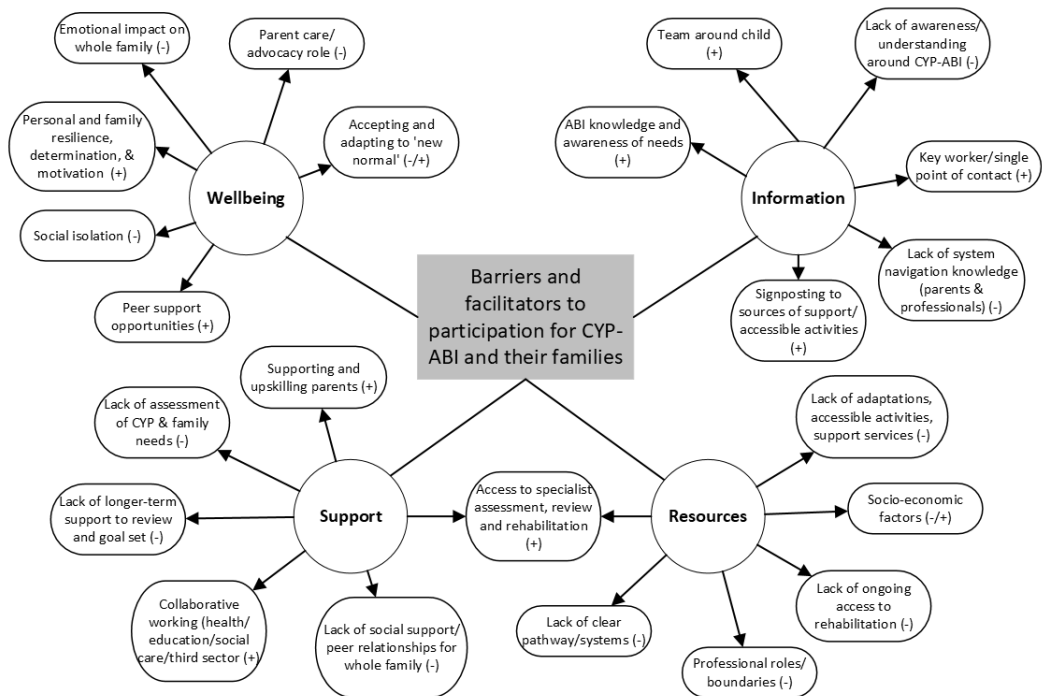


Figure 5-2: Barriers and facilitators to participation for CYP-ABI and their families (- = barrier, + = facilitator)  
 Table 5-4: Identified barriers and facilitators mapped to Behaviour Change Wheel/Theoretical Domains Framework

Identified barriers and facilitators mapped to Behaviour Change Wheel/Theoretical Domains Framework				
COM-B/TDF domain	TDF Construct	Barrier/Facilitator	Theme	Quotes
Capability	Knowledge	Barrier	Lack of awareness and understanding	<i>'They're also then going into contexts where there's also a lack of understanding, so they go back to school, they go back to community settings, where people also don't understand acquired brain injury and don't know about making sure that things are accessible...'</i> (AHPN-7)
				<i>'It's hard to describe but it's something that you've got to carry on living with. But most people, unless they've come across a brain injury, they haven't got a clue'</i> (Robert's Mother)
		Facilitator	Education and training for families and professionals	<i>'And it's just that education that encouragement that it's not the end of your life, it's a challenge, yes, we need to make adjustments and with the help of somebody supporting you, you can move that forward.'</i> (Nurse-3)
				<i>'I think training staff, particularly school staff, to feel empowered to know how to adapt their environment...just really subtle approaches that can be used to help children'</i> (AHPN-5)
	Procedural knowledge	Barrier	Lack of knowledge regarding system navigation	<i>'I just, I feel that school is a category and, you know, social life is a category, and medical is a category and the dots are not joined up for a brain injury, and a brain injury's everything isn't it, it's everything, it's everything in your life.'</i> (Megan's Mother)
				Facilitator
Skills	Skill assessment	Barrier	Lack of recognition or assessment of needs	



				<p><i>they'd be doing X, Y and Z as well. We're almost closing their world in a little bit, aren't we, as a system around that child.'</i> (AHPN-7)</p> <p><i>'And so as they're going through the education process, you may hit a particular aspect of the curriculum or a cognitive step that you want them to take, and suddenly you find that they have lost that knowledge or they can't bridge that gap, or they've lost that function. But you and they don't know that until they reach that benchmark, milestone, challenge what, whatever it might be, so it's a really unpredictable kind of future for them.'</i> (EPS-1)</p>
			Facilitator	<p>Access to specialist assessment and review</p> <p><i>'I think for me, it's something about – it probably comes down to money and time and all of those things, about being able to offer longevity of support. This ongoing support for these families, so that they know who they can come back, they can come back and that when new needs are identified, there is something to do about that need, so you can go to the right person and you can offer that support, so sort of the ongoing support, but also the network around that, that allows if I identify a need in a child, to say okay, they need this, I can then refer them to that or I can signpost them to that or I can put them in the right direction'</i> (Nurse-1)</p>
		Ability/Skill development	Barrier	<p>Lack of ongoing rehabilitation access to address impairments</p> <p><i>As time's gone on, I realise more and more how important it is he gets out there and picks up on those skills, how to talk to people, how to handle situations, how to be more independent.'</i> (Hamza's Mother)</p> <p><i>'There is certainly a frustration around not being able to offer as much as one might like to. So we're very much based on episodes of care in the community. We set the goal, we do it, we discharge and then we might reopen again if there is another need, but that very much relies on the families and/or the schools being able to communicate that to you and if they're not identifying that as a need.'</i> (AHPN-1)</p>
			Facilitator	<p>Access to specialist rehabilitation support</p> <p><i>'...because if it was just up to me, I would've thought, well other people would think I probably wouldn't drive, I probably wouldn't be riding a bike..., so over the past year the physio, all their help and the support they got me they definitely...I can do things, I can do it or try and do it.'</i> (Jack)</p> <p><i>'personal trainer and that was really, really good for his self-esteem, physical health, and that was really good.'</i> (Jack's Mother)</p>

Opportunity	Memory, attention, and decision processes	Cognitive overload/tiredness	Barrier	Impact of Fatigue	'Much more tired, after school and stuff' (Elijah).  'If you've got a child who's very, very fatigued and is really struggling, the parent's priority might be school and getting them to do the best at school and anything outside that might just seem too much to ask for, almost, because I think for a lot of families, the focus is on education and if a child is too tired to manage in school, then they're not even thinking about anything outside of that.' (Nurse-1)
			Facilitators	Education and training regarding managing fatigue	'Managing their fatigue - I don't know if anybody has, that's such an under researched area and actually for schools to manage children and for children themselves actually. I don't know what it's like in the primary sector, I would imagine difficult, but for children to learn how to pace themselves and to manage their fatigues extremely difficult in the school context because of the way that the day works.' (AHPN-7)
				Support with learning	'he's got an EHCP and he's got a one-to-one in each lesson.' (Robert's Mother)
	Social influences	Social support	Barrier	Social isolation/Lack of CYP peer relationships	'I think they have emotional challenges relating to peer relationships that can be very impactful, particularly if they're in adolescence, but not solely if they're in adolescence.' (EPS-1)
				Lack of peer support for parents/families	'And actually...there's not an awful lot of support for the siblings of children with brain injuries, or you know cancer treatments, it's not there, and actually they've gone through a massive emotional turmoil as well. And then that can affect the relationship between the two siblings, or, however, many siblings there are.' (EPS-2)
			Facilitator	Peer support for whole family	'For schools this is probably slightly easier, but it's trying to tap into peer support, trying to use the friendship groups that you've got around that child to then encourage their progress from that point of view.' (AHP-4))  'I think there is some scope and opportunity to do it [online peer support], and we've done some, you know, we haven't done patient led ones, but sibling things, and actually they've worked, if you get it right, they've worked really, really well and you can engage people you know who are geographically a long way apart.... So there's, I think possibly the scope to use that and expand that going forward in order

					<p><i>to, you know, to get people together that otherwise wouldn't get the opportunity.'</i> (SCP-2)</p> <p><i>'In a regional network it would be a project to look at to find those links for families that come from our area and to link up better both for the children and for their parents as well.'</i> (AHPN-6)</p>
	<b>Environmental context and resources</b>	Environmental stressors	Barriers	Substantial parent care and advocacy role	<p><i>'It does, now obviously it does involve twenty-four-hour care, I mean you know, I was up at 4.00 am this morning, suctioning and things like that, so she does need full assistance with manoeuvring and her mobility's very reduced'</i> (Charlotte's Mother)</p> <p><i>'I think in terms of brain injury I think there's no consistency of support, the consistency's not there... You don't have any point of contact, you don't have one person who can help you with all these things'</i> (Megan's Mother)</p> <p><i>'I think the families and the young people I worry about more are perhaps those who can't express those things [needs and views] in the same way, or who perhaps don't have that support'</i> (AHPN-7)</p>
				Lack of clear pathways/ systems (health/social care/ education)	<p><i>'I think it's really hard because you can see the need, but you don't know where to go...it's where you go, that parent is taking a case manager's role in trying to deal with things but they haven't got that understanding of the system and the professionals involved and they don't have access to it... you need this service but they just – where do you go to get that? It's really hard.'</i> (AHPN-3)</p> <p><i>'I just think, especially because... he's transitioning from child to adult services sort of within the next six months, yeah, six to eight months he'll be transitioning over, I just think the communication needs to be a lot clearer'</i> (Barney's Mother)</p>

			Impact of Covid-19 pandemic	<p><i>'He'd only just sort of started with his whole time one-to-one when we went into lockdown, so he sort of fell even further behind.'</i> (Robert's Mother)</p> <p><i>'It stopped everything really. There was no more support. It was all of a sudden, down to you to self-manage. So that was really, really hard work.'</i> (Hamza's Mother)</p>
		Facilitator	Point of contact/ support for parents	<i>"I think that's the thing, isn't it? They need somebody that's got that time to look up stuff for them, point them in the right direction.'</i> (Nurse-2)
			Care pathway/ policies	<i>'I think national and local pathways and policies...So everybody knows this is what we need to do and that's where they need to go and it would be the same for everywhere.'</i> (Nurse-2)
	Resources/ material resources	Barrier	Lack of resources (adaptation delays, lack of accessible activities, services and support, socio-economic factors)	<p><i>'I find families find it very difficult to find groups and activities and I find it very difficult to know where to find that information.'</i> (AHPN-3)</p> <p><i>'I'm still waiting for my adaptations to be done...Three months ago I emailed the architect that's doing the work on Barney's adaptations and I've still yet to have a response from him'</i> (Barney's Mother)</p> <p><i>That's [social care access] a big issue at the moment and I think we've really noticed recently, it's nigh on impossible, it's resource based, isn't it? ...I mean the thresholds are - ...they basically said if it's not safeguarding, we're not touching it. But this child has a permanent disability.'</i> (SCP-2)</p> <p><i>'I've definitely experienced socioeconomic difficulties and have really had to work in a bit of a social work capacity.'</i> (AHPN-1)</p>
		Facilitator	Information resources	<i>' some kind of information sheet which said, you've sustained a possible acquired brain injury, these are the symptoms, these are the people that can help you, these are the services that you could be referred to, this is who can help you at school, this, because every single bit of the way I feel like I've had to dig away trying to find which direction to go into, and everyone has their area of expertise, which they've helped me with, but it's been very difficult to connect all the dots up.'</i> (Megan's Mother)

<b>Motivation</b>	<b>Social/ professional role &amp; identity</b>	Social identity	Barrier	'New normal'	<i>'The hidden bit in terms of a lot of these children do quite well from their motor skill recovery, but actually it's then - they're walking and talking and look fine. They want to get back to normality, but actually there's still a long way to go.'</i> (AHPN-7)  <i>'So they've got to completely re-change and re-focus where they're going. So adapting to the new normal and working out what their expectations need to be now...There's a whole re-shaping of expectations, not only within the child, but also with all the support staff and the parents and staff'</i> (AHPN-5)	
			Facilitator	CYP motivation	<i>'Walking home from school, there is no hard road for me to cross because I've done it before. There was a time last year where my French intervention wasn't on and I deliberately didn't call my parents - I just didn't want to - so I walked it by myself.'</i> (Hamza)  <i>'She does try and maintain her independence as much as possible and sometimes I'm a bit guilty of, like for instance, you know, in the bath, I'll get the puffer and the shower gel and I'll go to give her a wash and she'll grab it off me as if to say, I can do that, and she'll do it herself.'</i> (Charlotte's Mother)	
		Professional role/ boundaries	Barriers	Professional roles and boundaries	<i>'They need somebody that's got that time to look up stuff for them, point them in the right direction, which a lot of clinicians, if you've not got a specialist role, haven't got that time to be doing and helping them think outside the box.'</i> (Nurse-2)	
			Facilitator	Collaborative cross-sector working	<i>'So some of it, I think, is just awareness of when other professionals can get involved and just that collaborative working, so that people can access more therapy and more of their lives, really.'</i> (AHPN-5)	
		<b>Beliefs about capabilities/ Beliefs about consequences</b>	Self- confidence/ Perceived competence	Barriers	Lack of parental or CYP confidence	<i>'I would've loved to have taken her swimming....absolutely not...there's a lot of things that I'm confident in, and then there's things like that.'</i> (Charlotte's Mother)
					Lack of insight	<i>Barney's Mother: 'Because I don't know if he's going to have, if he has a seizure, and [he] doesn't understand that.'</i> Barney: <i>'I could call myself an ambulance'</i>
	Safety concerns				<i>'I want her to be outside, to get some fresh air and see her friends, she's not seen anybody; and they [school] were saying, but we can't watch her outside, we can't keep her safe...'</i> (Megan's Mother)	

		Facilitator	Access to rehabilitation support	<i>'We could be supporting these challenges with participation that we often see further down the line, we could be supporting that so much more effectively if there was just investment in that longer term perspective, but we often get kind of a huge investment in that acute sort of side, which is really needed but then it thins out, doesn't it?'</i> (AHPN-7)
<b>Goals</b>	Goals (distal/proximal)	Barrier	Lack of support to achieve longer-term goals	<i>'I think most challenges extend into education and other settings as well, because you think about that sudden change of needs of an ABI and the education system is not set up to deal with that. So you know, you've often got kids going back in where they can't get any EHCP. They probably won't even meet the criteria..., but also they've missed the funding pots because it's not the start of term when they had their brain injury.... They're trying to get them back into school to get them participating, to get them seeing friends, to get them doing all those things we want them to do but they can't because they've not got a TA or they've not got the support and they're having to just juggle things within education because the system is not fit for purpose when you've got that change in needs.'</i> (AHPN-7)
		Facilitator	CYP motivation/goals	<i>'So I think it's more driven by Jack .... if he wants to do something then we set a goal that he'll be able to do it.'</i> (Jack's Mother) <i>'Because I want to cook things by myself and just get ready if you're not going to be there to cook anything.'</i> (Oscar) <i>'Maybe because I just like doing sports, I just like being active; and my dream is to be in the [professional sports association] at the moment, so that's what I'm trying to work up to.'</i> (Fred)
<b>Emotion</b>	Affect	Barriers	CYP emotional impact	<i>Barney: Yeah, I'm sick of being inside 24/7.'</i> <i>'It's a long time of him worrying'</i> (Elijah's Mother)
			Parental emotional impact	<i>'You think the hospital's going to be the hardest time, but I think it's...I don't even know what sorts of things, but it's when you go home and, like I say, we're nearly four years in....since starting the secondary school, this has probably been the hardest time since, the most challenging.'</i> (Robert's Mother)
			Family impact	<i>'I find that a lot of my families, there can be relationship breakdowns as well and quite often, it tends to be the mum within the family that feels that she needs to take all of this on and then that breaks down relationships. It's a really hard time for them.'</i> (SCP-1)

				<p><i>'And actually...there's not an awful lot of support for the siblings of children with brain injuries, or you know cancer treatments, it's not there, and actually they've gone through a massive emotional turmoil as well. And then that can affect the relationship between the two siblings, or, however, many siblings there are.'</i> (EPS-2)</p>
			Facilitators	<p><i>'So I think you've got to take the positive out of it, because as the trouble is, you're always going to live in the past aren't you, and you never – because I say to myself, I needed to let him ride his bike again, you know, I need to let him go out and see his friends because, you know, I don't want him to stay in the past of the accident as well.'</i> (Fred's Mother)</p> <p><i>'There is a need to be brave to do something new, do a new activity, join a new group and that can require a lot of energy and resilience'. (SCP-2)</i></p>
				<p><i>'I think there's a lot out there for siblings. Like we use [charity] a lot for siblings but again, doesn't quite allow the young person with a brain injury, depending on their severity, to go to camp.'</i> (Nurse-2)</p> <p><i>'I think maybe just, maybe information about support groups really.'</i> (Robert's Mother)</p> <p><i>'I think, if there's something for people with common experiences that give their tips, I don't know, or professionals that can advise, I think that would be useful'</i> (Oscar's Mother)</p> <p><i>'We belong to [charity]. They've been absolutely brilliant. Yeah, they've been really, really good, like really quite a good like source of help for me as well.'</i> (Amelia's Mother)</p>

#### 5.2.4.2.1 Capability Barriers

##### Knowledge

An overwhelming lack of awareness and understanding about the impact of ABI across every level of society caused barriers to participation, especially in school and community settings. Hidden impairments (e.g., cognitive impairments) and new or emerging needs posed particular challenges especially in education settings and through educational stages.

To address these deficits, parents reported needing to rapidly develop expertise about the impact of ABI, and the array of potential effects, which stakeholders also recognised:

*'They've [parents] never had to deal with any of this before and I think there's a complete lack of understanding out there from other professionals that aren't necessarily specialists that they have all this to cope with on a daily basis.'* (Nurse-2)

Parents described the initial information overload in the acute phase post injury, but the need for more timely information and support in the longer-term.

Parents also reported system navigation difficulties, and having to learn how to navigate complex health, education and social care systems, which many have no previous experience of:

*'I feel that school is a category and, you know, social life is a category, and medical is a category and the dots are not joined up*



*for a brain injury, and a brain injury's everything isn't it, it's everything, it's everything in your life.'* (Megan's Mother)

Similarly, professional stakeholders described systems as hard to understand and navigate which affected their ability to effectively advocate and access support for families.

### Skills

Participants felt that a lack of long-term monitoring and assessment was a barrier to accessing the support CYP and families needed:

*'I think it's even harder with ABI seen as such a hidden disability...there's nowhere really to turn because nobody's really understanding what needs we have.'* (SCP-1)

CYP and parents described the need to address participation barriers by developing skills and strategies to manage them and achieve goals. It was felt this required practice, exposure to new contexts and support from family and rehabilitation professionals. Parents and stakeholders described frustration at limited access to rehabilitation in the years post-injury and saw this as a major barrier to CYP with ABI's development and participation:

*'I do believe that physio should have continued more for him... Occupational, I believe they could've taken more part in his daily activities, like walking, crossing roads...'* (Hamza's Mother)

### Memory, attention and decision processes

The impact of fatigue was discussed by almost all participants as a significant barrier to participation:

*'If you've got a child who's very fatigued and is really struggling, the parent's priority might be school and getting them to do the best at school and anything outside that might just seem too much to ask...because I think for a lot of families, the focus is on education and if a child is too tired to manage in school, then they're not even thinking about anything outside of that.'*

*(Nurse-1)*

#### 5.2.4.2.2 Capability Facilitators

All participants identified targeted education and training for peers, professionals and families across the health, education and social care systems is essential to address the aforementioned knowledge and awareness deficits. This includes clear and timely signposting and access to relevant information and sources of support and education (primary care, social care and charitable organisations). Additionally, access to timely and appropriate support from specialists is required to assist schools in understanding and addressing the specific needs of individual CYP.

*'I think training staff, particularly school staff, to feel empowered to know how to adapt their environment...just really subtle approaches that can be used to help children' (AHPN-5)*

Participants recognised the need to support, upskill and empower parents to identify their CYP's needs, navigate complex systems, self-advocate and self-manage are required. Additionally, they felt long-term access to specialist support is necessary for assessment of needs and skills, realistic goal setting and rehabilitation planning to enable CYP participation. A specific need for fatigue management support to enable prioritising or balancing activities more equally across education and sports, hobbies and socialising was identified.

Therefore, interventions need to address the knowledge and skills of those supporting CYP with ABI to ensure they have the capability to advocate effectively for needs to be met.

#### *5.2.4.2.3 Opportunity Barriers*

##### Social influences

Long periods away from school following ABI and the impact of impairments limiting the ability to go out with friends were viewed as social barriers, impacting pre-injury friendships, and resulting in social isolation and mental health and well-being concerns:

*'Those sports and hobbies that you would have done before for that like kind of mental well-being as well as...social interaction that maybe aren't as accessible to you now.'* (AHPN-6)

Although health professionals felt school was ideally placed to address unmet socialisation needs, education staff disagreed and were very aware having one-to-one support in school impacted CYP's ability to

interact with friends. All participants recognised an inability to participate in sports and activities also affected socialisation.

Parents and stakeholders spoke about the lack of peer support for parents and siblings. Parents described living with the isolating after-effects of their CYP's ABI and how support from peers who understood would be invaluable:

*'Most people, unless they've come across a brain injury, they haven't got a clue...I suppose maybe speaking to people that actually understand what you're talking about rather than just, "well, you know, he looks fine". He is fine, but it is quite isolating and lonely really'. (Robert's Mother)*

There was also shared concern for siblings of CYP with ABI, the emotional impact on them and the lack of support (including peers) available.

#### Environmental context and resources

Parent's substantial care and advocacy roles were seen as huge issues impacting the whole family. Care needs ranged from assisting CYP with organisation for school to complex healthcare needs and constant supervision. Some parents had stopped working or altered their working patterns accordingly. None of the families interviewed had employed carers, either choosing not to or because they experienced difficulties accessing care packages.

Parents described their experiences of advocating for their CYP as a 'battle'. Stakeholders were acutely aware of the lack of support and complexity parents managed, voicing concerns regarding its overwhelming nature, particularly for more vulnerable families e.g., lower socioeconomic status:

*'I think that's absolutely massive, that sense of feeling very, very overwhelmed and yes, some parents are able to almost do that project management bit themselves, and other parents just are not at all and need someone to project manage for them...Just not knowing which way to turn and which door to open or avenue to go down, really.'* (AHPN-1)

The lack of clear pathways or systems for CYP with ABI added to complexity. Transitions between hospital and home, return to education, education stages and into adult services presented major challenges, and could occur any time after ABI. Issues faced were often caused by procedural or funding issues regarding CYP's additional support needs:

*'But once he went up to high school because he looks fine and he doesn't look like he's had a brain injury... You wouldn't even know if you didn't know. And I think they think, oh it's fine and everything's OK when, well no, it's not. And he does need, you know the extra support...'* (Elijah's Mother)

Stakeholders confirmed systems were structurally inflexible, and they struggled to adapt to sudden changes in needs. The absence of key

worker or coordinator roles and difficulties re-accessing health and social care services as new needs emerged compounded this. A lack of communication, collaboration and understanding regarding the needs of CYP with ABI within commissioning and across organisations was reported as a barrier to CYP and schools accessing appropriate support.

*'I wonder if that's part of the gaps, though...where the professionals can't refer to each other and there's not that kind of ability, is there, to be able to kind of work across departments in the same way. Much as we all want to, I think it is an endless frustration' (AHP-7)*

A lack of resources available to families was reported as a significant barrier to participation. This included housing adaptation delays, limited appropriate/accessible activities (e.g., community groups/activities), gaps in or lack of services/professional support and individual family socio-economic factors, affecting a family's ability to engage with support offered, e.g., travel costs:

*'...financially as well for families because ABI is really difficult for them to fight for in terms of benefits and what fits on that criteria. When it changes circumstances and parents can't work full time or they need long term sickness, it really does kind of put a hold on those finances ....and it can make it really difficult.'* (SCP-1)

#### 5.2.4.2.4 Opportunity Facilitators

All participants recognised the need to reduce social isolation for CYP with ABI, through supporting them to develop friendships both at school and in accessing extracurricular sport or activity clubs. They also felt that increasing opportunities for peer support for CYP with ABI families was important in enabling them to support each other and reduce feelings of isolation.

Participants identified that professionals supporting parents in advocating was important in overcoming opportunity-related barriers. They also felt that a point of contact and access to longer-term, flexible specialist assessment, review and rehabilitation was important.

*‘So having one person that families can go to, that health can go to, that school can go to, to relay information and collaborate care and things can be really useful.’ (AHPN-6)*

Participants also described the need to improve communication and collaboration between health, education, social care and charitable organisations. They felt the development of CYP with ABI care pathways could facilitate this and ensure the needs of the whole family are recognised and addressed holistically.

Therefore, interventions need to include facilitating opportunities for CYP with ABI and their families to access peer support and social activities and professional support through collaborative care pathways.

#### 5.2.4.2.5 Motivation Barriers

##### Social role and identity

Although CYP and parents aimed to return to 'normal', there was a necessity to adjust expectations and adapt to a 'new normal'. While CYP didn't want to be seen as different, stakeholders acknowledged the importance of reshaping expectations. Parents and stakeholders recognised the complexity of changing and emerging needs combined with natural childhood development, expected milestones, comparisons with peers and societal norms:

*'I would imagine that...the majority of these young people do not want to be defined by this, do they? So, they want to keep it quiet. And I suspect that's a really big problem for lots of them when they transition to another phase of education or a different school or a different setting where there's no context or background and where they can be a fresh or you know, kind of not quite reinvent themselves, but nobody knows, and that sets up another level of challenge.'* (EPS-1)

##### Goals

A lack of support to achieve longer-term goals was reported. CYP and parents were very clear on desired longer-term rehabilitation goals, with the majority being activity and participation focused e.g., returning to sports, success at school, socialising with friends, and community independence. Stakeholders recognised more long-term holistic, participation-focused goal-setting is needed and noted limited support



available regarding this, particularly after discharge from community therapy services.

*'I think as health professionals, we almost sometimes dismiss that sort of stuff, don't we, as like the cherry on the top of the cake... We almost don't even think of any of that extended stuff because we're so focused on...do whatever treatment we need to do, let's keep you alive, let's get you sorted, let's get you home.'* (Nurse-1)

In the UK, education-focused goal setting for children with additional needs should occur within the UK system via Individual Education Plans or Education, Health and Care Plans (EHCP). Participants reported mixed success with appropriate goal setting and frustrations regarding the EHCP process for newly acquired or changed needs:

*'I had a young person that we couldn't get the EHCP off the ground because her needs didn't exist before her brain injury and I'm like well, yes.'* (Nurse-2)

### Emotions

A lack of support for emotional and mental health for the entire family unit was described as a barrier to families' well-being and participation.

Whilst CYP themselves struggled to talk about the emotional impact of their ABI, some were able to talk about what worried them or their frustrations. The impact was recognised by parents and stakeholders.

Parents were more open about the emotional impact, describing feelings of trauma, grief, frustration and anxieties about their CYP's safety and/or future:

*'I worry about everything. I worry about her at comp [secondary school], like at uni, all of that' (Amelia's Mum)*

The impact was substantial and continued in the years after the ABI; something also witnessed by stakeholders.

The impact on the entire family's well-being was a concern. Participants were concerned for the emotional health of siblings, the breakdown of relationships, family life becoming fractured, limited or compromised:

*'It's like we've got our life with the boys...and then we've got our separate existence with Megan' (Megan's Mother)*

#### 5.2.4.2.6 Motivation Facilitators

CYP and family resilience, determination and motivation regarding achieving goals, ongoing skill development and independence were all identified as important facilitators. However, participants felt investment was needed to support families who faced participation challenges:

*'We could be supporting these challenges with participation that we often see further down the line; we could be supporting that so much more effectively if there was just investment in that longer-term perspective, but we often get kind of a huge*

*investment in that acute sort of side, which is really needed but then it thins out, doesn't it?' (AHPN-7)*

Accessing emotional support such as counselling was reported as a facilitator although this is not readily available to all. Ensuring families can access emotional support is essential to helping them address the substantial emotional impact of the ABI and adjust to the 'new normal', particularly where families' expectations were unrealistically focused on returning to pre-ABI normal.

Interventions targeting participation need to be personalised to the CYP and families' goals and include emotional support for the whole family to address motivation barriers.

### **5.2.5 Discussion**

This study explored the longer-term participation needs of UK CYP with ABI and their families and barriers and facilitators to participation and well-being to inform intervention development.

Qualitative interviews and focus groups offered unique insights into the needs and challenges those affected by an ABI and service providers face. For this population, unmet needs and barriers span every sector and level of society impacting CYP with ABI participation and family well-being.

Barriers and facilitators to participation and well-being mapped across every Capability, Opportunity, Motivation and Behaviour (COM-B) domain, clearly identifying what needs to change. *Capability* barriers included a lack of understanding and awareness of the impact of an

ABI, particularly within the school and the community. Both parents and professionals lacked knowledge of how to navigate systems and struggled to get their needs assessed or to access ongoing rehabilitation. CYP with ABI and their families needed to be able to (re)access support and information as needs or circumstances changed. Parents needed a point of contact, help to coordinate care and transitions, and upskilling and empowerment to independently navigate systems and advocate for their CYP and family's needs.

Case coordinator/management roles have been found effective in assisting adults with other long-term health conditions. In a systematic review of case management interventions, Hudon et al<sup>259</sup> identified interdisciplinary care plans and meetings were important aspects of case management and recommended frequent contact, multidisciplinary team meetings and the development of inter-agency care plans. A CYP with ABI case manager could help to navigate systems, facilitate access to services and offer education, training and mentorship about ABI to healthcare professionals, teachers and schools, thus overcoming some of these capability barriers. Further research should explore the feasibility, utility and clinical and cost-effectiveness of CYP with ABI case management.

Increasing knowledge and awareness about the long-term needs of CYP with ABI should be at the heart of any intervention - addressing *capability* and *opportunity* barriers. School is the focal point for CYP and their families yet, it can act as both a barrier and facilitator to participation and well-being. Our findings suggest school is one of the

places where the needs of CYP with ABI are least well understood. Training and education of teachers and support staff is key to improving this. Further work is required to investigate the best way of implementing ABI-educational interventions in schools. Glang et al's<sup>260</sup> randomised controlled trial compared an online instructional 'In the Classroom' intervention for TBI to a web-based ABI resource for 100 educators in the United States. Statistically significant greater gains in TBI knowledge and application and general self-efficacy were found for the 'In the Classroom' recipients, however, the application of knowledge was not maintained at 60-day follow-up, indicating the need for ongoing support mechanisms. Further research could build on this study to explore the impact of ongoing support for schools.

*Opportunity* barriers included CYP with ABI and their families feeling socially isolated and having a lack of peer support. Additionally, participants reported the impact of the substantial parent care and advocacy role, the lack of clear pathways, systems and resources, including access to rehabilitation services. Longer-term access to specialist rehabilitation, assessment and review would address barriers across all three COM-B domains. Telerehabilitation interventions have shown promising results in rehabilitation and family therapy and offer great potential to expand access to services<sup>261,262</sup>. Rohrer-Baumgartner et al.'s<sup>38</sup> Child In Context intervention offers goal-orientated rehabilitation, using in-person and virtual sessions and involves coaching, education, training and collaboration with CYP,

families and schools. Further research could explore the feasibility of implementing and evaluating this intervention in the UK.

The introduction of integrated collaborative health/education/social care pathways and improving communication between sectors through the development of regional networks could address multiple COM-B barriers. These would facilitate the cross-sector collaboration necessary to support the whole family and facilitate timely return to school and transitions between educational stages and into adult services.

Alderwick et al's <sup>263</sup> systematic review of the health impacts of cross-sector collaboration found that whilst there was little evidence for improving health outcomes, there was evidence to suggest it improves access to services and patient satisfaction. Additionally, more positive impacts were found for more locally targeted interventions, where interventions link professionals and families, such as home-based rehabilitation <sup>264</sup> and return to school interventions <sup>63</sup>. Further research is needed to develop contextually relevant local pathways and networks with clear guidelines, processes, professional networks and communication strategies.

*Motivation* barriers related to *social role and identity, goals and emotions*, had a huge impact on CYP and family well-being which in turn, impacted on participation. Interventions are needed that address family well-being through therapeutic support and or meaningful peer support, also tackling social isolation (*opportunity*) barriers. Family system interventions focusing on education, skill building and emotional support may be of benefit, as reported by Gan et al <sup>265</sup> in their

preliminary evaluation of the Brain Injury Family Intervention. They reported a small sample of participants (families and clinicians) favourably rated the intervention in terms of helpfulness, importance and satisfaction, however further research to determine impact on outcomes is required.

The unmet participation needs of CYP with ABI and their families identified in this study are not unique to the UK. CYP with ABI face similar challenges regardless of health and social care or education system context or country, as identified in two scoping reviews and one systematic review <sup>19,221,249</sup>. This study builds on the findings of Diener et al <sup>122</sup> and Botchway et al <sup>255</sup> and, by following the BCW's systematic process has uniquely enabled in-depth theoretical analysis and identification of key barriers and facilitators to participation and well-being, identifying where change needs to happen, whose behaviour needs to change and how this might be achieved <sup>193</sup>. These findings provide targets for intervention development, highlighting the barriers that need addressing and potential facilitators to so doing, for example education and training, support for parents and implementing integrated collaborative rehabilitation pathways. Intervention development work is underway with stakeholders to identify context-specific solutions, using these findings and the BCW to identify the relevant intervention functions and policies and behaviour change techniques required to ensure effective implementation.

#### **5.2.5.1 Strengths and limitations**

This novel study was conducted with methodological rigour and included the voices of CYP with ABI, parents, and varied stakeholders, who offered personal insights into their lived experiences and the complexity of childhood ABI and the issues they face. The use of the ICF and BCW to synthesise and map the findings has enabled a 'system view' and the clear identification of participation needs, barriers and facilitators which will inform future intervention development <sup>193,252</sup>.

This study set out to ensure a diverse, representative sample of the spectrum of ABI diagnoses, severity, length of time since injury and socio-demography. However, it was conducted in one region of UK with a small sample and hence findings may not be representative of the broader UK CYP with ABI population. Additionally, recruitment was limited via an inpatient database and therefore the findings do not capture CYP with ABI with milder TBI's/concussion not admitted to hospital. With only mothers participating, the findings lack the voice of fathers.

The challenges of recruiting participants who have knowledge of childhood ABI via the NHS, means there is some dependency on known contacts and networks. While there is potential for bias in recruiting stakeholders through existing networks and collaborations with research team members; having research team embedded in the regional clinical service facilitated deeper understanding of the local context, systems and processes and stakeholder engagement.



Interviewing CYP with their parents may have restricted their ability to speak freely, however, this was an ethical requirement for CYP under 16 due to interviewing online and the potential vulnerability of CYP with ABI, and those over 16 all chose to be interviewed with their parents. It is a possibility that those less happy with their outcome may be more likely to participate. However, representation from people whose voices are rarely heard in research, including those from lower socioeconomic groups and more severe ABI, may be considered a strength in terms of capturing the most complex and impactful unmet need.

#### **5.2.5.2 Clinical implications**

The findings of this study are important for health, education and social care professionals and commissioners in raising awareness of the needs and barriers that families face in the years after ABI. Clinicians need to be mindful of the wider impact of the CYP's ABI on the whole family and how family well-being impacts on the CYP's rehabilitation and participation. When commissioning services, the long-term needs of this population must be considered to ensure families can access support for as long as they need it, potentially throughout their life course.

#### **5.2.6 Conclusion**

CYP with ABI have unmet long-term participation needs. They, their families, and professionals working with them, experience substantial and numerous barriers in attempting to meet these needs and the CYP's goals. Participation and well-being are inextricably linked; participation barriers impact on well-being, and poor family well-being

impacts CYP with ABI participation. Therefore, addressing the needs of the whole family is essential. Using an implementation science informed approach in this study has provided a theoretical foundation to the intervention development process and ensured implementation is considered from the very beginning of the intervention development process. This has kept the needs of the population and context for intervention delivery central to the process, informing every stage of development. The next step is to co-develop with users a multi-modal, family-centred intervention that addresses unmet participation needs and improves health and well-being outcomes for CYP with ABI and their families.

#### *Author Contributions*

RK conducted all the interviews and focus groups and the primary data analysis.

EB and MW assisted with the focus groups in co-facilitating and chat moderation.

JM, JW and KR assisted with the data analysis, reviewing transcripts, coding and framework mapping as well as providing supervision.

#### *Acknowledgements*

Our thanks goes to the children and young people, their parents/carers and the stakeholders that took part in this study, our patient and public involvement families and clinical team for their ongoing support and to Lal Russell for assisting with cross-checking the interview transcripts.

### 5.3 Chapter Summary

Chapter 5 has presented the findings from the second phase of Study 1 - a multi-stakeholder qualitative study, published in *Brain Impairment*. Interviews and focus groups revealed extensive unmet participation needs and identified barriers and facilitators to participation and well-being. The findings from both parts of this mixed methods study were integrated to inform Study 2, which focuses on the development of an intervention, reported in Chapter 6.

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## 6 Co-Design Intervention Development Study

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### 6.1 Chapter Overview

Chapter 6 synthesises the findings from the scoping review and the mixed methods study presented in Chapters 4 and 5. It presents how these synthesised findings and the findings from a co-design workshop were used to inform the theoretical modelling of an intervention designed to improve participation and well-being of CYP with ABI and their families.

This chapter is written in the format of a publication which has been submitted to *BMJ Open* for publication.

**6.2 Enabling participation in community-dwelling children and young people with acquired brain injuries and their families – a theory-, evidence- and person-based approach to intervention development**

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### 6.2.1 Abstract

**Objective:** To co-design and develop an intervention to promote participation and well-being in Children and Young People (CYP) with Acquired Brain Injury (ABI) and family caregivers.

**Design:** A complex intervention development study including a scoping review, mixed methods study, co-design workshop and theoretical modelling.

**Setting:** Community dwelling participants in one geographical region of the UK

**Participants:** CYP with ABI (5 - 18 years) and their parents, health, education, social care and voluntary/third sector practitioners

**Results:** The intervention development process using a theory driven and evidence informed approach, combining the Behaviour Change Wheel and the Person-Based Approach is described. Findings from the scoping review and mixed methods study were analysed and synthesised using the framework method and the International Classification of Functioning, Health and Disability (ICF) and the Behaviour Change Wheel. Evidence of identified participation needs, barriers and facilitators was presented at the co-design workshop. The findings demonstrate the significant long-term impact of an ABI on CYP participation and both CYP and parent wellbeing with significant unmet family needs. Barriers and facilitators were identified, with key barriers being lack of knowledge and understanding, lack of parental and family support, and a need for cross-sector collaboration and communication.

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Stakeholders identified potential solutions and intervention ingredients, such as the need for education for families and schools regarding long-term impact of ABI, and longer-term practical and emotional support for families. Findings from the workshop were analysed using the framework method and synthesised with previous findings using the Behaviour Change Wheel. Theoretical modelling enabled guiding principles to be identified and an intervention logic model to be produced. 'ABI-Participate' is a novel, multi-faceted intervention, developed with CYP with ABI, their parents and professionals from across health, education, social care and charity sectors. Using a case coordination model, ABI-Participate aims to address the unmet needs and barriers of this population and includes needs assessment, goal setting, action planning, health coaching, practical and emotional support for families and multi-agency liaison and collaboration, adopting an individualised needs-based approach.

**Conclusion:** A systematic process using a theory-, evidence- and person-based approach resulted in a novel, co-designed, multi-faceted intervention, grounded in an in-depth understanding of CYP with ABI participation needs, barriers and facilitators. Further development and refinement of the individual elements of ABI-Participate and the care pathway to support its implementation is now required prior to feasibility testing.

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**Strengths and limitations of this study:**

- Involving CYP, parents and stakeholders from across health, education, social care and voluntary/third sectors at every stage of this research ensured their views and needs remained at the centre of the process and the intervention.
- Use of a theory, evidence and person-based approach ensured a detailed and rigorous intervention development process and a theoretically and contextually informed complex intervention.
- The findings from this study may not generalisable, however, understanding the specific needs within the region are important in planning services and delivering care close to home.
- Feasibility and effectiveness testing is now required.

**Keywords:** Children and young people, Acquired Brain Injury, Participation, Well-being, Intervention

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## 6.2.2 Background

Sustaining an ABI as a CYP as a result of traumatic or non-traumatic causes (e.g. infection, stroke, tumour) can lead to an array of physical, cognitive, emotional and behavioural sequelae <sup>249</sup>. These sequelae can impact on wellbeing and participation in activities at home, school and the community <sup>239,249</sup>. Outcomes within this population are heterogeneous with a range of influential factors such as injury severity, location, age at injury, premorbid abilities and personal, socioeconomic and environmental factors (e.g. family functioning) <sup>16,239</sup>. Many CYP under the age of 18 experience persistent or life-long effects, which impact on physical and psychological development, quality of life, educational achievement and social inclusion. These continue to emerge months or years after the event as developmental, education and social demands increase <sup>3,12,83,266</sup>.

The International Classification of Functioning, Disability and Health (ICF) defines participation as involvement in life situations, which enhances well-being. It is both a fundamental right and essential part of child development <sup>26,27</sup>. Research has shown that participation is associated with improved quality of life, social competence, educational success, future life outcomes, and overall well-being of CYP with and without disabilities <sup>58,73,74</sup>. CYP with ABI and their families have reported experiencing participation restrictions, negatively impacting on their well-being with extensive unmet and unrecognised needs found to persist up to 12 years post injury <sup>75,76,221,249,250</sup>. The impact of a CYP sustaining an ABI on the family is well documented. Sudden change in

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roles, routines and lifestyle for families affected by ABI intensifies stress for the entire family, impacting family functioning and well-being <sup>85</sup>.

Participation restrictions for a CYP with ABI lead to loss of social interaction, isolation and marginalisation, impacting participation and well-being for the whole family unit <sup>86, 87</sup>. Additionally, sudden health literacy needs, increased caregiver burden, parental stress and financial hardship can impact the mental and emotional health of the whole family, including siblings <sup>75,239,267</sup>. Rehabilitation interventions must consider the entire family's needs, recognising the interconnectedness of family members' and that addressing needs may improve CYP outcomes <sup>250,267</sup>.

Rehabilitation following an ABI aims to enable individuals to achieve optimal levels of participation by reducing the impact of difficulties and maximising well-being, activities of daily living, functional ability, and social integration <sup>19,120,254</sup>. However, international variability in paediatric rehabilitation provision and follow-up leads to uncertainty regarding long-term CYP with ABI outcomes and the best way to provide long-term support <sup>3,124</sup>. Identifying and addressing individual family psychosocial and systemic issues is essential to ensure rehabilitation interventions can be effective <sup>83</sup>. The literature recommends family-centred rehabilitation care models, collaborative multi-system interventions and long-term regular follow-up <sup>38,122,123,255,268</sup>. However, it remains unclear what components should be included and how these should be delivered to meet the needs of CYP with ABI and their families, and optimise the participation and wellbeing of CYP with ABI.

Rehabilitation interventions are typically complex with multiple needs and factors to be addressed <sup>38</sup>. Complexity is defined by the number of interacting components, the range of possible outcomes, the need to tailor the intervention to different contexts, and dependency on the behaviours of those delivering and receiving the intervention <sup>133,269</sup>. This makes complex interventions difficult to implement. Factors likely to affect implementation need to be understood and addressed during intervention development. When developing interventions that aim to result in a behaviour change (e.g., increasing parental confidence to support their CYP with ABI), we need to understand the target behaviour, its influences, the context for delivery, as well as identify the mechanisms of change and resources required <sup>137</sup>.

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The Medical Research Council's framework for developing and evaluating complex interventions recommends the use of theory and evidence when designing an intervention <sup>133</sup>. Drawing on existing theories, such as the Behaviour Change Wheel, can help identify important and relevant factors and inform the content and delivery of an intervention <sup>134,136</sup>. Evidence from previous research can help define the problem, understand context, and identify target behaviours.

Uncertainties or gaps in the literature can be addressed using primary data collection, such as quantitative surveys to assess outcomes or qualitative interviews and focus groups to gain deeper understanding of needs, barriers and facilitators <sup>137</sup>. Engagement with stakeholders through primary data collection is essential to ensure population needs

and context are understood and guide intervention design and implementation into real-world practice<sup>135</sup>.

We describe the intervention development process for the 'ABI-Participate' intervention using an integrated theory-, evidence- and person-based approach<sup>137</sup>. This approach ensured a pragmatic, systematic, rigorous intervention development process was adhered to. The process necessitates stakeholder engagement and an in-depth understanding of behaviour, its barriers and facilitators, and how implementation of an intervention could change behaviour<sup>135,136</sup>. The aim was to co-design and develop an intervention to promote participation and well-being in community dwelling CYP with ABI ([all causes and severities](#)) and family caregivers.

### 6.2.3 Theoretical frameworks

We integrated the Behaviour Change Wheel and Person-Based Approach in our intervention development process. The [Behaviour Change Wheel](#) was selected as the most appropriate theory for developing our intervention for CYP [with](#) ABI as it provides a systematic process using theory and evidence to develop interventions<sup>193</sup>. It incorporates the COM-B model of behaviour which aids description of how *capability*, *opportunity* and *motivation* influence *behaviour*, and the Theoretical Domains Framework which subdivides the COM-B components to aid greater understanding of barriers and facilitators at individual, organisational and community levels<sup>193,203</sup>. Once these have been identified, the [Behaviour Change Wheel](#) leads developers through a process identifying the components required for the intervention. [It](#)

aids identification of 'intervention functions' to target the behaviour and barriers and '*policies*' to support intervention delivery. This leads to the selection of '*behaviour change techniques*', specific strategies designed to change behaviour which are the active, observable, replicable and irreducible ingredient of an intervention – i.e., the proposed mechanism of change <sup>193</sup> (Table 6-1).

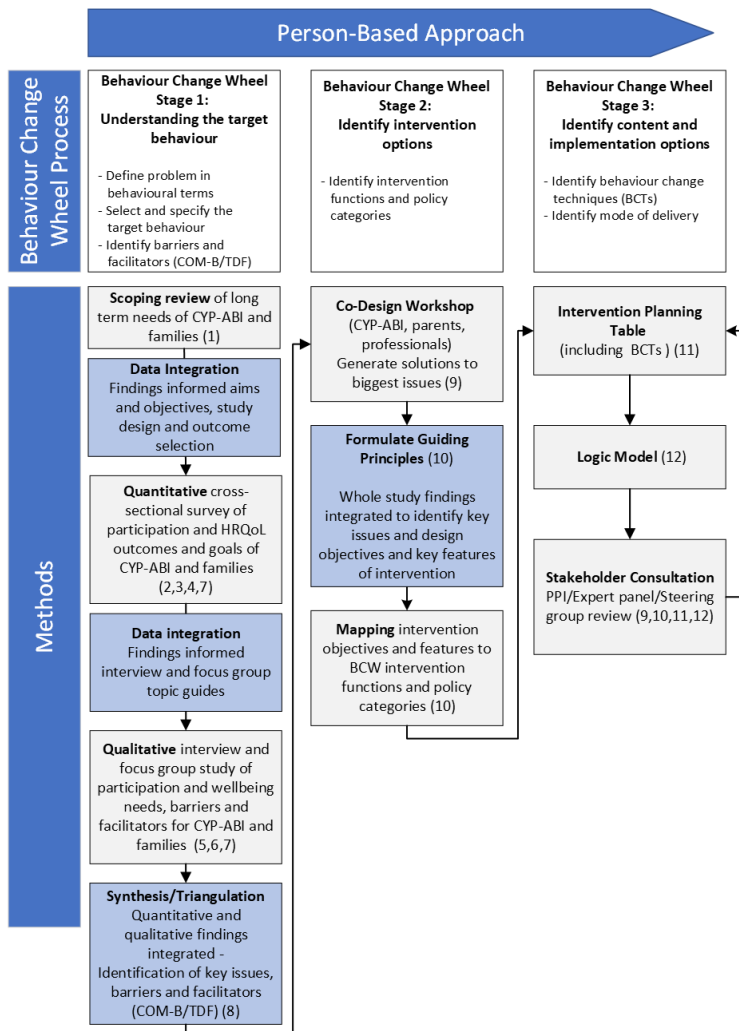
Table 6-1: Behaviour Change Wheel components and definitions <sup>193</sup>

<b>Behaviour Change Wheel (BCW) components and definitions</b> <sup>193</sup>					
<b>COM-B Components</b> <i>(for any behaviour to occur there must be capability, opportunity and motivation to do it)</i>		<b>Theoretical Domains Framework Domains</b> <i>(integrative framework synthesising key theoretical constructs)</i>	<b>BCW Intervention Functions</b> <i>(broad categories of means by which an intervention can change behaviour)</i>	<b>BCW Policy Options</b> <i>(types of decisions made by authorities that help to support and enact the interventions)</i>	<b>Behaviour Change Technique (BCT) Taxonomy Groups (16 groups containing 93 BCTs)</b> <i>(active component of an intervention designed to change behaviour)</i>
Capability	Psychological	- Knowledge - Skills - Memory, attention, and decision processes - Behavioural regulation	- Education - Persuasion - Incentivisation - Coercion - Training - Enablement - Modelling - Environmental Restructuring - Restrictions	- Guidelines - Environmental/Social planning - Communication/Marketing - Legislation - Service Provision - Regulation - Fiscal Measures	- Goals and planning - Feedback and monitoring - Social support - Shaping knowledge - Natural consequences - Comparison of behaviour - Associations - Repetition and substitution - Comparison of outcomes - Reward and threat - Regulation - Antecedents - Identity - Scheduled consequences - Self-belief - Covert learning
	Physical	- Skills			
Opportunity	Social	- Social influences			
	Physical	- Environmental context and resources			
Motivation	Reflective	- Social/professional role & identity - Beliefs about capabilities - Optimism - Beliefs about consequences - Intentions - Goals			
	Automatic	- Social/professional role & identity - Optimism - Reinforcement - Emotion			

The [Person Based Approach](#), designed for the development of health-related behaviour change interventions, integrates well with the [Behaviour Change Wheel](#) and provides a process for combining stakeholder co-production with mixed-methods research <sup>270</sup>. It ensures that the views of individuals who will interact with the intervention (i.e. key stakeholders [such as CYP, parents, health, education, social care and charity practitioners](#)) are included throughout, increasing the likelihood of the intervention being successfully implemented in real-world practice. Guiding principles are formulated, describing the key intervention design objectives which can be mapped to Behaviour Change Wheel intervention functions and behaviour change techniques. This theoretical modelling process facilitated the development of a logic model to describe the intervention, planned mechanisms of change, resources required and impact on outcomes<sup>190</sup>.

#### **6.2.4 Methods and Results**

Using the GUIDED framework for reporting intervention development, we describe the methods and results for each stage of the intervention development process following the BCW/PBA process as depicted in Figure 6-1 <sup>271</sup>.





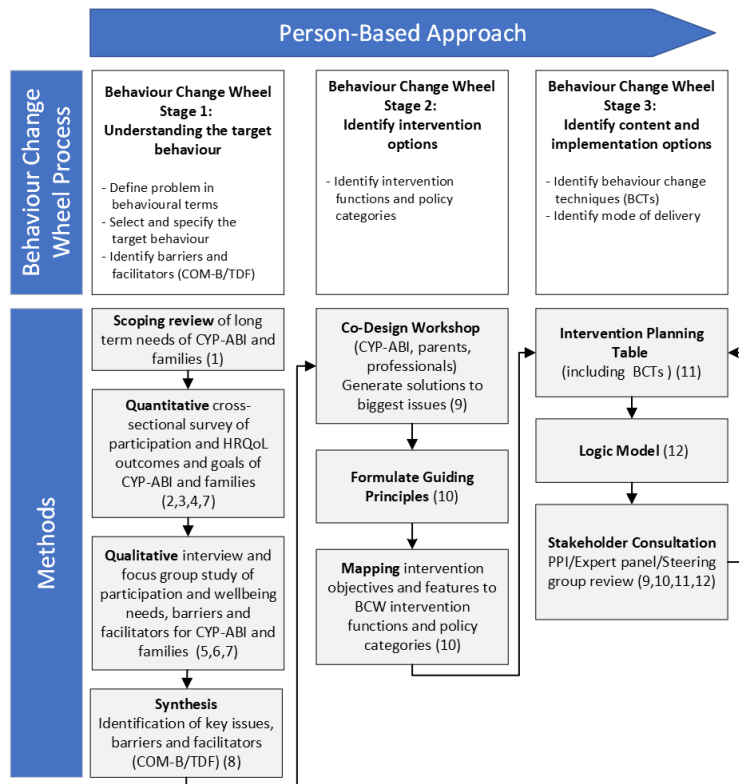


Figure 6-1: Intervention development process and methods employed

#### 6.2.4.1 Patient and Public Involvement

CYP with ABI, their parents and stakeholders representing health, education, social care and voluntary/third sectors were involved throughout the study. Four families were involved in identifying the research question and design of the study. One young adult with ABI assisted with the data analysis and synthesis, and dissemination, including being a co-author on this paper. Findings from each stage were disseminated to study participants during the co-design workshop.

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The findings and recommendations will be disseminated further via the production of a lay summary video.

#### **6.2.4.2 Stage 1 – Understanding the target behaviour**

To understand the target behaviour, the problem needs to be defined, target behaviour selected and specified, and barriers and enablers identified. A scoping review of the literature and primary mixed methods research was conducted to address this aim.

##### *6.2.4.2.1 Synthesis of relevant literature – Scoping Review*

We conducted a scoping review to identify relevant literature regarding the needs of CYP with ABI and their families, and whether needs were met, unmet or unrecognised. The methods and findings of this are reported elsewhere <sup>221</sup>. Four themes were found regarding needs related to CYP's impairments, parent and family support, return to school and long-term after-care. Needs were mapped onto the ICF, with a substantial proportion of needs relating to participation and contextual factors. Key findings were the impact on parents and family and the lack of communication, collaboration and long-term follow-up. A lack of awareness and understanding underpinned all reported needs and led to many needs being unrecognised. Recommendations within the majority of the articles reviewed included the need for specialist follow-up and integrated care pathways that are CYP and family centred. However, there were gaps in the literature. The voices of CYP are limited, there is a lack of focus on personal factors such as

psychological and emotional needs for the CYP and families, a lack of focus on community participation, including recreation and leisure activities, and a lack of data regarding outcomes and needs within a UK National Health Service context. These findings led to the development of a mixed methods research study.

#### Mixed methods research study

An exploratory sequential mixed-methods study was designed to explore the long-term participation and well-being needs of CYP with ABI (5-18 years) and their families, one to four years after injury, in one geographical region in the UK.

The study consisted of a quantitative cross-sectional survey which explored participation and well-being outcomes and goals of CYP with ABI and their parents. Qualitative interviews and focus groups were conducted with CYP with ABI, parents, and stakeholders to explore needs, local context, and barriers and facilitators in more depth. We began recruitment in March 2021 with all surveys, interviews and focus groups completed by November 2022. Ethical approval was gained from the UK Health Research Authority, [East Midlands-Nottingham 2 Research Ethics committee](#) (REC-20/EM/0258). [Informed consent/assent was gained from all participants via survey completion and written consent forms.](#) The methods and findings from each of these studies are summarised below and reported fully elsewhere <sup>250,272</sup>

#### Quantitative Study

Survey results demonstrated the significant long-term impact of an ABI on CYP participation and both CYP and parent well-being; 72% of CYP

had severely restricted participation, 67% had reduced [Health-Related Quality of Life \(HRQoL\)](#) <sup>250</sup>. Around half (53%) of parents reported reduced HRQoL and family functioning and 37% of parents screened positive for anxiety/depression. Relationships were found between CYP [and parental outcomes. Higher CYP participation and HRQoL was related to higher parental HRQoL and family functioning. Higher levels of parental anxiety/depression were related to lower CYP participation and parental HRQoL and family functioning.](#) CYP and parents reported goals that mapped to the activity and participation domains of the ICF, demonstrating the importance of these activities to their well-being.

#### Qualitative Study

The qualitative study involved CYP with ABI and their parents who had participated in the survey and health, education, social care and [voluntary/third sector](#) stakeholders. Significant unmet participation needs were found, impacting CYP with ABI and family well-being <sup>272</sup>. Barriers and facilitators, mapped to the [Behaviour Change Wheel](#), spanned '*capability, 'opportunity' and 'motivation'*'. The greatest barriers aligned to the [Theoretical Domains Framework](#) domains of knowledge, skills, social influences, environmental context and resources, social identity and emotion. Identified facilitators included increasing awareness and understanding, supporting parents, long-term access to specialist assessment and rehabilitation, peer support and integrated collaborative pathways.

#### 6.2.4.2.2 Mapping of current service provision

Current service provision and pathways were mapped out of the information provided by stakeholders and members of the research team and study steering group who work within the clinical service (See 8.4 – Appendix 4, Supplementary Figure 1). The mapping demonstrated the complexity of communication and referral routes from acute to community health services, and between health, education and social care providers. Additionally, the lack of provision or capacity of long-term specialist support services and collaborative care pathways was clear.

#### Synthesis of findings

Following the Person Based Approach and Behaviour Change Wheel intervention development process, the findings of the literature review and mixed-methods research were collated, integrated and synthesised using the Framework Method of analysis to map the findings and themes to the ICF, COM-B and Theoretical Domains Framework<sup>213,216</sup>.

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This enabled us to define the problem in behavioural terms, identify the target behaviour and identify and specify barriers and facilitators (See 8.4 - Appendix 4, Supplementary Table 1). This also allowed us to consider what needs to change and at what level. Specifying the barriers provided clarity regarding those that were individual factors (CYP/family), external organisational level (health/education systems) and community level (society) factors. Although there were individual factors with every CYP with ABI and family experiencing unique circumstances, there were many commonalities and a multitude of

external factors that impacted on families in similar ways. Four key issues were identified and used to inform the design of the intervention:

1. Reduced CYP with ABI and family participation and well-being - support needed to enable participation and improve well-being by addressing unmet needs.
2. Lack of practical, psychological and emotional support for parents - support needed for parents to enable them to navigate systems and processes and support their CYP.
3. Lack of understanding and awareness - training and education needed for those who support CYP with ABI across health, education, social care, [voluntary/third and](#) community sectors.
4. Lack of cross-sector collaboration – a need to improve communication and collaboration between sectors and access to support in the years after ABI.

A [multi-faceted](#) intervention was required to target key issues that are common across the CYP [with](#) ABI population whilst also providing individually tailored support to meet the specific needs of CYP and their families.

#### **6.2.4.3 Stage 2 – Identify intervention options**

The next stage in the Behaviour Change Wheel process was to link the 'behavioural diagnosis' (See 8.4 -Appendix 4, Supplementary Tables 2 and 3) with intervention functions likely to be effective and policy categories that can aid implementation <sup>193</sup>.

As we had identified a large number of barriers and facilitators, there was a need to prioritise which were to be targeted. We therefore consulted CYP, parents and stakeholders on this and asked for their help in generating potential solutions.

#### *6.2.4.3.1 Co-Design Workshop*

An experience-based co-design workshop with multiple stakeholders (CYP, parents and health, education, and [voluntary/third sector practitioners](#)) was held in person in July 2023. The aim was to co-design and develop an intervention to promote participation and well-being in CYP with ABI and family caregivers. The objectives were to present and confirm the key issues identified, discuss priorities, and generate possible solutions and identify local context-specific barriers/enablers to intervention delivery <sup>190</sup>. The data collected informed the guiding principles and theoretical modelling of the intervention. Ethical approval was gained in May 2023 [from the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics Committee \(FMHS 234-0323\)](#).

#### Procedure

Participants were recruited from those who participated in the interview and focus group study with an invitation to attend the workshop sent by email. Additionally, members of the research team, study steering group (healthcare professionals from the acute neurorehabilitation team) and a Patient and Public Involvement representative were

present at the workshop to both contribute and assist with facilitating groups.

All participants provided written consent/assent prior to the workshop, with parents consenting for CYP under 16 years alongside their CYP's assent. An external facilitator (AH) ran the workshop on the day, to allow the research team to listen and document discussions. The four main issues identified from the previous research, and the aims of the workshop were conveyed to the participants by the researcher (RK). Three break-out groups discussed solutions focused on the main issues, each group was facilitated by a member of the research team and study steering group (KR, JM, DC, MD). Parents and professionals were divided between two groups, one focusing on parental support and the other on cross-sector collaboration/pathway. A separate group for the CYP was supported by a facilitator, a PPI representative (VL) and play specialist (AP). A range of resources were provided to each group – paper, post-it notes, pens and Lego. The 'draw, write, tell' technique was used within the CYP group with the facilitators ensuring CYP's artwork or verbal contributions were well described in written form<sup>172</sup>. The groups reconvened and each fed back to the whole group, where potential solutions were discussed.

The workshop findings were collated and analysed by RK using content analysis to code and categorise the data to the COM-B/Theoretical Domains Framework using the Framework method of analysis<sup>213,216</sup>. The findings and themes were discussed with the research team and



study steering group to ensure rigour by reviewing and triangulating the findings, validate the coding and reduce potential biases.

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### Findings

In total, 17 participants attended the workshop including four CYP aged 6-17, four parents (mothers), eight health, education, social care and voluntary/third sector practitioners (including members of study steering group) and one young person PPI representative.

Ten themes emerged regarding possible solutions for the identified issues which were mapped to the COM-B/Theoretical Domains Framework (Table 6-2). Within these themes the priorities for intervention were identified as ongoing monitoring of CYP needs and goal setting; a single point of contact; support for parents; and communication and coordination between sectors. These findings were used to inform the theoretical modelling of the intervention.

#### *6.2.4.3.2 Theoretical Modelling*

##### Formulate Guiding Principles

Using the previously synthesised findings and the findings from the co-design workshop, we developed guiding principles. These detail the key issues to be addressed, and the intervention design objectives and distinctive features that are key to successfully addressing these (Table 6-3).

Table 6-2: Workshop findings mapped to COM-B/TDF

Table 2: Workshop findings mapped to COM-B/TDF				
	TDF domain	TDF Construct	Theme	Workshop participant comments
Capability	Knowledge/ Skills	Knowledge (about condition)	Education/Training	<p><b>Parent-directed</b></p> <ul style="list-style-type: none"> <li>• Individualised approach – options – online, face-to-face, one-to-one, groups</li> <li>• Themed educational sessions on aspects of ABI impact, 'how to' guides e.g., Education Health Care Plan (EHCP), where to go for help, looking after yourself, what to expect, what could happen</li> <li>• Understand triggers for seeking help and how with different options – website, charities, nurse specialist/case manager, clinic</li> <li>• Impairment related management strategies e.g., fatigue</li> </ul> <p><b>School-directed</b></p> <ul style="list-style-type: none"> <li>• Teacher education re: ABI and impact for return to school and ongoing education e.g., fatigue, cognitive impairments</li> <li>• Peer training e.g., 'ABI Ambassadors' in schools, school to school support</li> <li>• Link schools to sources of training and support e.g., charities, local authority and community health training teams</li> <li>• 'Friends don't understand' - CYP peer awareness sessions</li> </ul> <p><b>Professional-directed</b></p> <ul style="list-style-type: none"> <li>• Professional education days</li> <li>• Educate primary care – so GP's know where to go for help</li> </ul>
		Procedural knowledge		
		Skills/skills development		
		Ability/Competence		
Opportunity	Social influences	Social support	Peer support opportunities (whole family)	<p><b>Whole family</b></p> <ul style="list-style-type: none"> <li>• Family fun/support days</li> <li>• Social opportunities for CYP and siblings – shared activities</li> </ul> <p><b>Parent-directed</b></p> <ul style="list-style-type: none"> <li>• Parent support groups (options - local, online, face-to-face, individual, group, therapeutic)</li> </ul> <p><b>Professional-directed</b></p> <ul style="list-style-type: none"> <li>• Peer support/networks (health/education/social care/charity)</li> </ul>

<b>Environmental context and resources</b>	Resources/material resources	Digital resources	<p><b>Support parents/professionals with advocacy</b></p> <ul style="list-style-type: none"> <li>• Regional 'hub' – website – co-develop with parents</li> <li>• Information for parents, professionals, schools</li> <li>• Information/signposting to sources of support e.g., charities, local authority services, SENCOs etc.</li> <li>• Idea sharing – e.g., accessible activities – families able to add to</li> <li>• Videos/quotes from other parents</li> <li>• Educational sections – see education/training theme</li> <li>• Timing of accessing information – need to be able to access when need it, even years after</li> </ul>
		Practical resources	<ul style="list-style-type: none"> <li>• Financial support – e.g., help with benefits</li> <li>• Support with return to school (e.g., case manager)</li> <li>• Point of contact and know who can help e.g., specialist nurse/case manager/SENCO/charities</li> <li>• 1:1 support to access activities (for CYP) e.g., support worker</li> <li>• 'Disability passport' – individualised working document – needs and strategies</li> </ul>
		Clinical service provision	<ul style="list-style-type: none"> <li>• Routine check-ups for CYP and parent – 4/8 weeks, 3/6/9/12 months with team (prevent getting lost)</li> <li>• Re-access options - need ways back in when need it</li> <li>• Goal setting – reviews and encouragement</li> </ul>
		School support	<p><b>Return to school pathway</b></p> <ul style="list-style-type: none"> <li>• Need for a plan -it's complex and need to reduce delays</li> <li>• Multi-disciplinary team meetings to share information and signpost to support</li> <li>• Special Educational Needs Team involvement/Special Educational Needs Register (SEN-K code)</li> <li>• 'Reasonable adjustments' e.g., phased return, small groups, reduced timetable</li> <li>• Support with EHCP process (see <b>Communication</b>)</li> <li>• Importance of time with friends – restoring friendships</li> <li>• CYP voiced wanting to be 'treated as equal'</li> </ul> <p><b>Transitions</b></p> <ul style="list-style-type: none"> <li>• MDT meetings - importance of communication and early planning including SEN Team</li> </ul>

		Person x environment interaction	Communication strategies	<ul style="list-style-type: none"> <li>• Social media – educational links/signposting to charities/accessible activities</li> <li>• Central point of access/contact – Case manager/key worker role</li> <li>• Website – easy to find information – all in one place</li> <li>• Multi-agency meetings involving parents regarding return to school and transitions</li> <li>• Signposting – professional responsibility to signpost/safety net parents/resources for professionals</li> </ul>
<b>Motivation</b>	<b>Beliefs about capabilities</b>	Self-confidence	Confidence building (CYP)	<ul style="list-style-type: none"> <li>• Recognition of needs and that going back to school is hard</li> <li>• Strategies to support – CYP know plan, small groups, phased</li> <li>• Support from parents, siblings, school staff, peers</li> </ul>
	<b>Goals</b>	Goal/target setting	Goal setting	<ul style="list-style-type: none"> <li>• Independence is important (CYP)</li> <li>• Sports and activities – restrictions because of diagnosis but need to ‘focus on what can do’ (CYP)</li> <li>• Need help to set goals and encouragement to follow them (CYP)</li> </ul>
	<b>Emotion</b>	Affect	Emotional support	<ul style="list-style-type: none"> <li>• Individualised approach – options important (1:1, peers, online, informal groups)</li> <li>• Access to counselling – flexible timing e.g., in hospital, may not be ready until years after</li> <li>• Post Traumatic Stress Disorder support</li> <li>• Targeted support for different family members</li> <li>• CYP Support – emotional strategies – how to cope (CYP)</li> <li>• Sibling support – flexible timing</li> <li>• Family support worker (charity provided)</li> </ul>

### Mapping intervention design objectives and features to Behaviour Change Wheel

Using the Behaviour Change Wheel, we mapped the intervention design objectives to the nine intervention functions. We identified the corresponding intervention functions that are likely to be effective in addressing the identified barriers and achieving the intervention objectives. Three intervention functions, 'education', 'training' and 'enablement' were identified that could address multiple barriers (See 8.4 – Appendix 4, Supplementary Table 2).

The next step was to consider which of the seven Behaviour Change Wheel policy options would support the delivery of the identified intervention functions<sup>193</sup>. We identified three policy options appropriate for supporting the delivery of the selected intervention functions - 'communication/marketing' (using print, electronic, telephonic or broadcast media), 'guidelines' (creating documents that recommend or mandate practice) and 'service provision' (delivering a service) (See 8.4 – Appendix 4, Supplementary Table 3).

#### **6.2.4.4 Stage 3 – Identify content and implementation options**

##### *6.2.4.4.1 Behaviour change techniques*

The next step was to identify which 'behaviour change techniques' are most appropriate for the intervention objectives and functions, and which mode of delivery was best suited. Using the [Behaviour Change Technique](#) taxonomy (v1) we identified [Behaviour Change Techniques](#)

required for each intervention objective and function, ensuring these also correlated with the COM-B/[Theoretical Domains Framework](#) domains that were originally identified as important to target <sup>193</sup>. The guiding principles combined with the [identification of behaviour change techniques and intervention components](#) enabled a detailed intervention plan to be added to the guiding principles table (Table 6-3).

#### *6.2.4.4.2 Mode of delivery*

Deciding on the mode of intervention delivery was important. Considering the workshop findings, participants wanted a range of options, including face-to-face as individuals or in group settings, and 'distance' meetings via telephone or virtual meeting platforms. As the target population have differing needs and reside across a large geographical region, covering five counties, a range of intervention delivery modes were needed. For example, education and training for a school could be delivered virtually or in a group face-to-face. It will be important to assess the acceptability, practicality, and affordability of intervention delivery within feasibility testing to ensure it is effective for families living across the region <sup>270</sup>.

#### *6.2.4.4.3 Logic Model*

Following the systematic and detailed Behaviour Change Wheel intervention design process enabled the key objectives and active ingredients for the intervention to be identified leading to the production of a logic model that included a description of the core components, necessary resources, mechanisms of change and identification of short- and long-term impacts and outcomes for the intervention (Table 6-4).

This was developed iteratively, through review with the research team, study steering group and patient and public representative, and refinements made. The TIDieR Checklist informed the description of the intervention <sup>273</sup>.

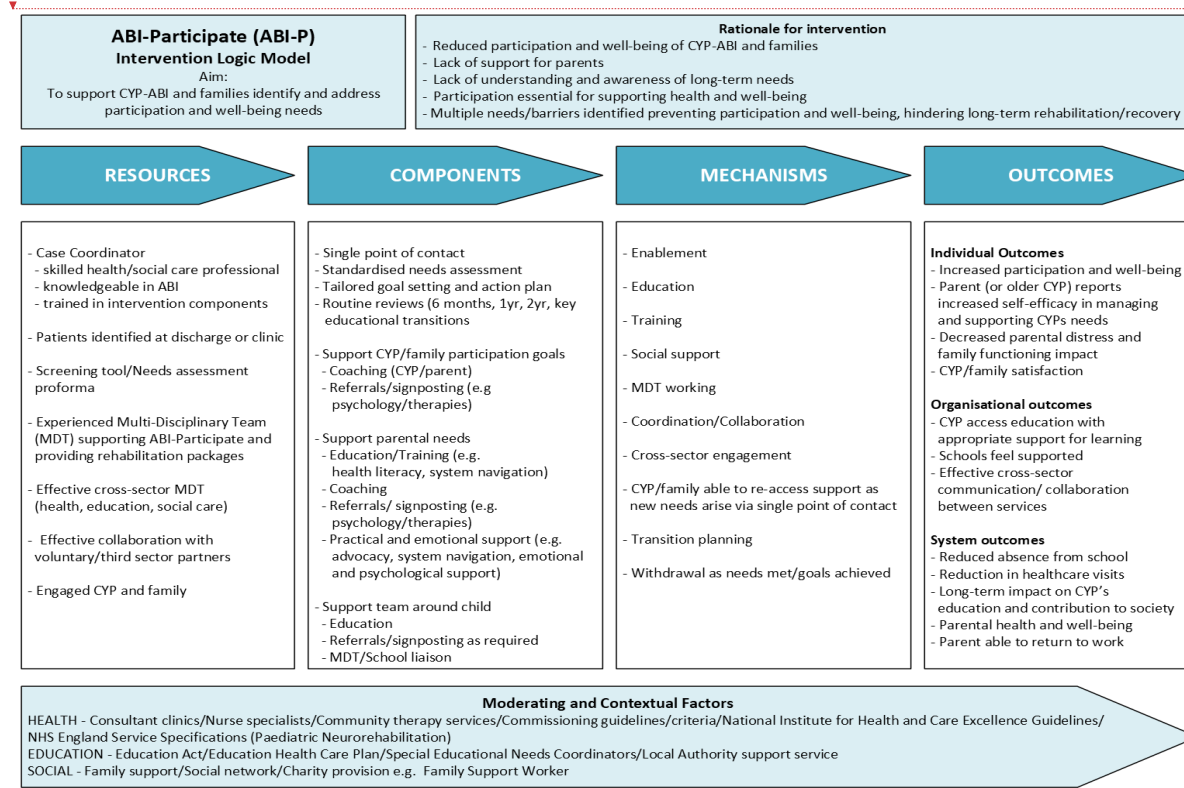
Table 6-3: Guiding Principles/Intervention Planning Table

Guiding Principles/Intervention Planning Table					
	Key issues identified in mixed methods study	Intervention Design objectives	Key features of intervention to achieve objective	Mechanisms	
				Behaviour Change Technique Taxonomy (v1)	BCW Intervention functions
1	CYP-ABI experience severely restricted participation as a result of multiple interacting barriers	To identify and address participation restrictions of CYP-ABI and their families	Routine needs assessments	Social support (practical)	Enablement
			Identification of unmet needs	Problem solving	
			Goal setting/coaching (CYP/Parents)	Goal setting (behaviour)	
			Action Planning	Action planning	
			Liaison with MDT/Team around child	Social support (practical)	
			Referrals/signposting	Social support (practical)	
Support parents	Social support (practical & emotional)				
2	Parents and those supporting CYP-ABI lack of awareness and understanding of impact of ABI which leads to under-recognition of needs	To increase understanding about impact of ABI of those supporting CYP-ABI increase recognition of needs	Support parents to develop health literacy	Instruction on how to perform the behaviour	Training
			Support parents to understand impact of ABI and recognise needs	Information about health consequences	Education
				Information about social and environmental consequences	
			Provide education re: impact of ABI to those supporting CYP and family e.g. school staff	Information about health consequences	
Information about social and environmental consequences					



3	CYP-ABI and their families experience reduced HRQoL/well-being which impacts family functioning	To support family well-being	Offer needs-based emotional and practical support	Social support (practical & emotional)	Enablement
			Signpost to sources of support/groups etc	Social support (practical)	
			Liaise with MDT/Team around child	Social support (practical)	
4	Parents have a substantial care and advocacy role and experience difficulty navigating systems	To support parents to navigate systems/services effectively	Upskill parents in system navigation	Instruction on how to perform the behaviour (impart skills)	Training
			Support and empower parents	Social support (practical)	Enablement
			Signposting to resources	Social support (practical)	
			Advocacy as needed	Social support (practical)	
			Point of contact for families	Problem solving	
5	Parents and professionals experience difficulty with coordinating and communicating across sectors	Facilitate cross-sector collaboration/communication	Liaison/point of contact between services across sectors	Social support (practical)	Enablement

Table 6-4: ABI-Participate (ABI-P) Intervention Logic Model



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The 'ABI Participate' (ABI-P) intervention aims to support CYP with ABI and their families identify and address participation and well-being needs. [Using a case coordination model](#), needs assessments and individualised goal setting and action planning would be completed with CYP and families, [considering development stage and family context](#) <sup>160, 274, 275</sup>. This includes supporting participation goals through coaching CYP and parents, and ensuring referrals for additional therapy or support are made when needs are identified, such as to psychology. Families and professionals wanted a single point of contact and signposting to sources of information and support. 'ABI-Participate' also includes information sharing, referral and team meeting coordination, liaison with CYP's school/college and supporting parental practical and emotional needs. The intervention would continue until needs were met or goals achieved, with a single point of contact in the long-term should families or those working with a CYP with ABI need advice or support. Other features included reassessment of needs at routine reviews in a follow-up clinic, ahead of key educational stage transitions or as new needs emerge. Coordination of transition to adult services would also be provided. The intervention would help to improve understanding and awareness of long-term needs. It would increase support for parents and CYP to improve their participation and well-being by identifying and addressing needs of the whole family. It would help families and health, education, social care, and [voluntary/third sector practitioners](#) working with CYP with ABI and their families to overcome barriers by helping to coordinate cross-sector communication and collaboration. The

intervention needs to be situated within and supported by a multi-disciplinary neuro-rehabilitation service. The multi-disciplinary team would need capacity to support the assessment of needs and provide targeted rehabilitation interventions, when needs are identified, such as neuro-cognitive interventions or higher-level physical skills training required for return to sport.

#### **6.2.5 Discussion**

This paper has described how we used a theory-, evidence- and person-based approach to develop a complex intervention aimed at improving participation in CYP with ABI and their families. As recommended by the MRC guidance, underpinning the development of complex interventions with theory and evidence is essential to ensure interventions are evidence informed and grounded in a theoretical understanding of behaviour change <sup>133,137</sup>. The addition of the PBA ensured an in-depth understanding of the life experiences of the population and stakeholders, their needs and views on acceptable solutions <sup>190</sup>. As the PBA focuses specifically on the development of complex behavioural interventions, it was well suited to be combined with the theory and evidence approach in this work <sup>187</sup>.

The intervention we have developed is founded on the biopsychosocial model of the ICF and multidisciplinary teamwork. It is multi-faceted, family-centred, and tailored to developmental stage, individual needs and contexts, It follows a rehabilitation process, involving assessment, goal setting, intervention delivery, monitoring and review <sup>120</sup>. Based on

[a case coordination model, ABI-Participate also](#) includes a therapeutic element of goal-oriented coaching, which aims [to identify and address the participation needs of the whole family](#). As found in this study, [and recommended by the World Health Organisation](#), there is an increasing acknowledgement of the need for care to be coordinated to support those living with long-term conditions and their family caregivers due to the complexity of coordinating care, ensuring needs are met and undue stress prevented <sup>259, 267,275-277</sup>.

Gagnon et al <sup>161</sup> identified six key supportive roles that family members of adult traumatic brain injury survivors undertake – researcher, advocate, case manager, coach, activities of daily living supporter and emotional supporter. They concluded that family members require ongoing counselling, support and education about system navigation, accessing community programs and workplace rights to prevent burnout. [A scoping review by](#) Gardiner et al <sup>275</sup> explored patient navigation within children with neuro-disabilities. Their scoping review found a diversity of terminology and descriptions used for navigation-type models for children with neuro-disabilities. However, each was characterised by four central domains: *facilitate* – integration/ coordination of resources, supports and services, *provide* – information, advice and education, *intended outcomes* – improved health, behaviour and capacity and reduced patient and family distress, and *guiding principles* – client-directed, family-centred and collaborative. These

findings align with the findings of our study and are incorporated into the proposed 'ABI-Participate' intervention.

An additional element identified in our study, and by Gagnon and colleagues' <sup>161</sup>, was coaching and supporting CYP and families in identifying and achieving participation goals. Palisano et al <sup>278</sup> proposed a conceptual framework for optimal participation of children with physical disabilities that considers the dynamic interaction of determinants (child, family, and environment) and dimensions (physical, social, and self-engagement) of participation. Their recommendation that interventions need to be goal-oriented, family-centred, collaborative, strengths-based and ecological also align with our findings. ABI-Participate could be used flexibly and at different time points, recognising that the needs of CYP with ABI can change at different developmental stages and points of transition (i.e. more intensive support needed during educational transitions, particularly into secondary school and transition to adult services and or employment).

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Health coaching is defined by Olsen <sup>279</sup> as:

*'A goal-oriented, client-centred partnership that is health-focused and occurs through a process of client-enlightenment and empowerment.'*  
(p24)

Coaching can help patients and families identify and achieve their goals and has been shown to be effective in positively influencing health

status, health behaviours and costs <sup>267</sup>. There is increasing evidence supporting coaching in promoting parental self-management and empowerment, addressing parental health literacy and advocacy skills, and CYP participation in parents of CYP with chronic disabilities <sup>267,280</sup>. Ogourtsova et al's <sup>267</sup> systematic review of health coaching for parents of children with developmental disabilities found heterogeneity within the interventions with some being CYP-directed, some parent-directed and some mixed. They recommended further research exploring the outcomes of the different modes of delivery and the effectiveness of these on CYP and parental outcomes, recognising that these are linked with CYP outcomes improving when parent-related outcomes improve.

Existing interventions could be integrated with ABI-Participate. For example, goal-directed interventions (e.g. PREP - Pathways and Resources for Engagement and Participation), coaching interventions (e.g. CO-OP - Cognitive Orientation to Occupational Performance), parent interventions (e.g. Stepping Stones Triple P), or psychological interventions (e.g. Acceptance and Commitment Therapy <sup>280-282</sup>.

However further research is recommended to further explore the acceptability and effectiveness of integrating them in this intervention.

The technological advances enabling the widespread use of virtual meeting platforms for health consultations during the COVID-19 pandemic, have made telehealth delivery of some components of 'ABI-Participate' possible <sup>261,262</sup>. Not only are most patients and families now familiar with these platforms, but workshop participants suggested them

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as plausible modes of delivery. This enables specialist rehabilitation in tertiary settings to be made accessible to people living at long geographical distances and also offers an opportunity to upskill and support local providers with education and training delivered virtually. This delivery mode is in use in Rohrer-Baumgartner et al's 'Child in Context' study<sup>38</sup>. A future feasibility study should include exploration of both its acceptability and utility, [as well as how to deliver this to those without access to the internet](#).

#### Strengths and Limitations

The strengths and limitations of the scoping review, survey and qualitative study are reported elsewhere<sup>221,250,272</sup>. Involving CYP, parents and stakeholders from across health, education, social care and [voluntary/third](#) sectors at every stage of this research is a strength, ensuring their views and needs remained at the centre of the process and the intervention. To our knowledge, this is the first intervention development study within the CYP with ABI literature to have used a theory, evidence and person-based approach. This novel paper demonstrates the value of combining these approaches to develop a complex intervention for addressing participation needs in CYP with ABI and their families. By following the [Person Based Approach](#) and [Behaviour Change Wheel](#) process, a detailed and rigorous approach was employed to understand needs, identify barriers and facilitators, and design the intervention (including the active ingredients/mechanisms). The mixed methods design enabled us to



define the problem further, understand the local context and, using theory, provide a detailed description of the barriers and facilitators to participation. The addition of the co-design workshop with stakeholders to prioritise and generate solutions was invaluable in ensuring the most pertinent targets were selected. The theoretical modelling process and use of guiding principles enabled us to clearly and systematically articulate and document the process of identifying the key objectives, features and functions of the intervention, and selection of the policy options for implementing it. Finally, the logic model presented an overview of the intervention, the resources, core components and mechanisms as well as the contextual factors that must be considered and the outcomes that could be measured to assess effectiveness.

This study was conducted in one region within the UK and therefore findings may not generalisable, however, understanding the specific needs within the region are important in planning services and delivering care close to home. Whilst every attempt was made to ensure diverse representation at every stage, this did not occur within the workshop, partly due to some participants being unable to attend on the day. However, the reported needs, barriers and facilitators align with those reported internationally and many of the themes from the qualitative study, which had more diverse representation, were repeated, and affirmed at the workshop. This intervention has been developed iteratively, with CYP, parents and stakeholders. Further stakeholder, patient and public representative consultation and expert

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consensus development workshops are now required to refine, specify and confirm intervention components prior to feasibility testing.

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#### Future directions

There is evidence of effectiveness for the different components of our intervention, but research is needed to test the feasibility of the intervention in our target population and context, and to investigate its acceptability, deliverability and effectiveness. Within this, identification of standardised outcome measures and methods of determining whether needs are met, is required to measure effectiveness. Further consideration also needs to be given to the overall care pathway for CYP with ABI in which this intervention would be situated following hospital discharge. Given the barriers reported and lack of access to rehabilitation, this intervention would not be adequate in isolation, and other elements need to be developed and delivered alongside this intervention. For example, specialist neuro-rehabilitation and review clinics, particularly for those CYP whose needs cannot be met within primary care, mental health or community therapy services (e.g., cognitive, neuropsychological or higher-level motor therapy needs that do not meet referral criteria). For 'ABI-Participate' to be effective, there needs to be appropriate specialist service provision and referral pathways for CYP with these needs. The mapping of regional service provision demonstrated that these do not exist, except for a very limited regional ABI medical follow-up clinic and neuropsychology service, with long waiting lists, further delaying access to support.

## 6.2.6 Conclusions

This research has provided an in-depth understanding of the participation and wellbeing needs of CYP with ABI and their families.

The findings demonstrate the significant long-term impact of an ABI on CYP participation and CYP and parent wellbeing, with significant unmet family needs. The barriers and facilitators that families and stakeholders face in accessing support and rehabilitation were identified. Key

barriers identified were a lack of knowledge and understanding of the impact of ABI across every level of society, lack of parental and family support, and a need for cross-sector collaboration and communication.

Providing parental support, long-term access to specialist assessment and rehabilitation, peer support and integrated collaborative pathways were identified as facilitators.

We have iteratively developed a novel, multifaceted intervention the 'ABI-Participate' intervention with CYP with ABI, their parents and stakeholders from across health, education, social care and voluntary/third sectors with the aim of addressing the unmet needs and barriers of this population. Adopting a case coordination model and an individualised needs-based approach, ABI-Participate includes needs assessment, goal setting, action planning, health coaching, practical and emotional support for families and multi-agency liaison and collaboration. Further refinement of the components of ABI-Participate

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and development of the care pathway to support its implementation are now required prior to feasibility testing.

#### *Author contributions*

RK conducted the workshop and the primary data analysis and wrote the manuscript.

KR, JM, EB and VL, assisted with the workshop in facilitating the groups and contributed to writing the manuscript.

KR, JM, JK, JW supervised the research, assisted with the data analysis, framework mapping and contributed to writing the manuscript.

All authors assisted with the intervention development.

#### *Acknowledgements*

Angela Horsley for facilitating the co-design workshop.

Denise Crozier and Melanie Dean for assisting with the workshop in facilitating the groups.

Alison Price for providing play specialist support to the CYP workshop participants.

Our thanks go to the children and young people, their parents/carers and the stakeholders that took part in this study, our patient and public involvement families, the study steering group and clinical team for their ongoing support.

### **6.3 Chapter Summary**

Chapter 6 has presented the findings from a co-design intervention development study. It presents the synthesis of the findings from the scoping review and mixed-methods study, and the theoretical modelling of the 'ABI-Participate' intervention.

Chapter 7 will now discuss the overall thesis findings, the strengths and limitations of this research and make recommendations for further research.

## 7 Discussion

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### 7.1 Chapter Overview

This chapter provides an overall discussion for the thesis. In each of the papers presented in Chapters 2, 4, 5 and 6, the findings have been analysed, synthesised, compared to the literature, and discussed. In this chapter, the overall findings are discussed, and recommendations made for practice, policy and research. The strengths and limitations of this thesis, the researcher's reflexivity and impact of the COVID-19 pandemic are reflected upon. An overall conclusion concludes the chapter.

## **7.2 Summary of Findings**

Chapter 2 presents a scoping review conducted to identify relevant literature and key themes relating to the nature and extent of needs (met, unmet or unrecognised) of CYP with ABI and their families. Four themes were identified: needs related to CYP's impairments, parent and family support, return to school, and long-term after-care. The literature recommends increasing knowledge and awareness of the needs of CYP with ABI and their families to ensure needs are recognised.

Additionally, specialist follow-up and integrated care pathways are proposed to ensure long-term access to services and support.

However, there were gaps in the literature, with research including the voice of CYP scant, and minimal focus on psychological and emotional support needs and out of school activity and participation, including other aspects of community life, such as clubs, hobbies, and sports.

Chapters 4 and 5 describe Study 1; a mixed methods study which explored the participation needs of school aged CYP with ABI and the impact on well-being for the CYP and family one to four years after injury. The results of a cross-sectional survey demonstrated severely restricted participation and reduced HRQoL for CYP and reduced parental HRQoL and family functioning. Activity and participation goals were identified as most important to CYP and their parents, with recreation and leisure activities being the highest priority. Interviews with CYP with ABI and their parents and focus groups with health, education, social care, and charity professionals explored participation

and well-being needs, barriers, and facilitators in more depth. The findings demonstrated barriers at every level of society, spanning 'Capability', 'Opportunity' and 'Motivation'. The greatest barriers related to the TDF domains of knowledge, skills, social influences, environmental context and resources, social identity and emotion. Facilitators included increased awareness and understanding of the long-term impact of ABI among those supporting CYP with ABI, parental support, ongoing access to specialist assessment and rehabilitation and integrated collaborative pathways.

Chapter 6 describes Study 2, a co-design intervention development study. Key issues and priorities were identified as lack of knowledge and understanding, lack of parental and family support and a need for cross-sector communication and collaboration. Stakeholders identified potential solutions and intervention ingredients. These included education for families and schools regarding the long-term impact of ABI, practical and emotional support for families, and facilitation of cross-sector communication and collaboration. The theoretical modelling process included the development of guiding principles and mapping to relevant BCW intervention functions, policy options and behaviour change techniques. Finally, a logic model describing the 'ABI-Participate' intervention is presented, developed from the guiding principles, and underpinned by the BCW intervention functions of enablement, education, and training. 'ABI-Participate' aims to support CYP with ABI and their families identify and address participation and



well-being needs, set goals and action plan. It aims to provide support to CYP and parents, tailored to needs, including a single point of contact, signposting and referrals, education and training, coaching, and cross-sector liaison and coordination. Situated within, and supported by, a multi-disciplinary neuro-rehabilitation service, 'ABI-Participate' would identify CYP with ABI and their families with unmet rehabilitation needs that could be addressed through targeted interventions, provided by the multi-disciplinary team.

### **7.3 Overall Findings**

This thesis aimed to develop an intervention to identify and address the long-term participation needs of CYP with ABI and their families. It found a significant long-term detrimental impact of ABI on CYP participation and both CYP and family well-being. CYP with ABI and their families face a multitude of barriers to participation and well-being, spanning every level of society, which have substantial long-term implications. A lack of understanding and awareness of CYP and family needs underpinned the majority of the barriers at individual, organisational, and societal levels, with a lack of long-term access to support and services also being significant.

Discussed here are the overall themes from the findings, followed by recommendations for practice and policy.

### **7.3.1 Participation matters - Rehabilitation should be personalised and participation-focused.**

The participation needs of CYP with ABI and their families are substantial, wide-ranging, complex, and individual to every CYP and their family. As identified in every study within this thesis, participation is crucial to well-being, and CYP and families can require long-term, even life-long, support to enable them to participate and improve their well-being. Whilst the significant positive relationship between the CYP CASP and PedsQL scores could demonstrate that CYP HRQoL and participation are linked, it must also be recognised that this may be explained by the scales measuring similar concepts and this must be taken into account when choosing tools to measure these outcomes.

In the context of the ICF, CYP did not prioritise goals related to their body structure and function impairments, but rather activity and participation goals, in particular recreation and leisure, friendships, and school. CYP knew what they wanted to do. What mattered to them was participating in activities that were fun, active, with friends and where they could be independent and feel included. CYP, their parents and stakeholders were clear on what would facilitate improved participation. They wanted access to rehabilitation services, when they needed it, for advice and support to achieve their goals. This highlights what is important to CYP and their families and where the focus of longer-term rehabilitation interventions should be.

This finding contributes to the literature regarding the participation needs of CYP with ABI and has highlighted the substantial contextual barriers preventing CYP with ABI and their families from achieving their participation goals<sup>19,77,248,283</sup>. CYP participation and well-being and parental well-being are inherently linked, demonstrated by the correlations found between these outcomes in the survey results. Therefore, participation matters to the whole family and needs addressing as such.

These findings support the need for participation focused rehabilitation for CYP with ABI, ensuring contextual factors are addressed, and aligns with previous research. Imms et al<sup>50</sup> and Anaby et al.<sup>77</sup> advocate for participation to be at the forefront of CYP rehabilitation, recognising the importance of contextual and environmental factors, both within the family and externally<sup>27</sup>.

However, the lack of long-term comprehensive rehabilitation provision for CYP with ABI means many participation needs go unrecognised and unmet, thus increasing the risk of poor health outcomes and well-being<sup>38</sup>. Rehabilitation does not just stop when a CYP leaves hospital and returns to school, nor is full participation achieved. Ongoing access to neurorehabilitation services skilled in assessing CYP with ABI is necessary, to ensure needs are identified and addressed, to support their ongoing development, and reduce the impact on their health and well-being. Assessment of needs and goal setting should be carried out by an experienced healthcare professional who is knowledgeable in ABI

in CYP and the potential visible and hidden impacts. They need to be able to accurately assess needs and support the CYP and family to set realistic and achievable goals. Following this, CYP and their families require both practical and emotional support to overcome barriers and develop skills, enabling them to achieve their goals and improve participation and well-being outcomes. 'ABI-Participate' aims to meet these needs through providing tailored support to CYP with ABI and their families. However, 'ABI-Participate' requires an infrastructure to ensure comprehensive support and long-term access to a specialist neurorehabilitation team. This includes a care pathway and multi-disciplinary team that can provide long-term follow-up and neurorehabilitation where needs cannot be met by community services. This pathway needs initiating by the healthcare team when the CYP is discharged from hospital but requires ongoing communication and collaboration, across all sectors, in the long-term.

Future research should look to continue to develop the 'ABI-Participate' intervention and test the feasibility of its implementation. To support this, research is required to identify or develop a standardised needs assessment to ensure equity of assessment and collection of data regarding needs. An agreed set of outcome measures is required that are effective in measuring impact and change, yet not too onerous for families. The British Paediatric Neurology Association Paediatric Neurorehabilitation special interest group, of which I am a member, is working to establish a national database for CYP with ABI outcome

data. Therefore, outcome measurement needs to align with this strategy and contribute to national data collection. Additionally, further development of the coaching and parental support elements of the intervention and the development of a multi-disciplinary infrastructure and care pathway are required.

### **7.3.2 Family-centred care matters: poor parental well-being impacts on CYP and family participation and well-being**

The importance of family-centred models of care and interventions cannot be understated. The long-term impact of a CYP's ABI on the health and well-being of the whole family, seen throughout the studies, is concerning. This finding highlights the importance of considering the whole family's needs, not only during the CYP's hospital stay, but also in the years that follow.

Participation in community activities is essential to the recovery process of CYP with ABI and their families <sup>122</sup>. We cannot just provide treatment for the child with the brain injury. Interventions targeting the longer-term participation and well-being needs of CYP with ABI and their families must address the needs of the whole family.

One of the most substantial findings identified in this thesis is that of poor parental well-being and the impact this has on CYP with ABI, their rehabilitation, participation, and well-being. Additionally, the ongoing impact on family functioning and well-being was highlighted within the

qualitative study, with participants describing their concern for the mental and emotional health of parents and siblings, disruption to family life, and the potential for family relationship breakdown. This finding corroborates with previous research regarding the impact of an ABI on the family <sup>41,85,86,88-90,255</sup>. Furthermore, the in-depth exploration of the needs and barriers families experience has added to the evidence base regarding family impact, in understanding the factors that increase the impact felt.

Parental mental health and family functioning are important predictors of CYP functioning and well-being <sup>38</sup>. As found in this thesis, poor parental well-being and family functioning is not conducive to being able to advocate well for and support their CYP <sup>38,104,122</sup>. Due to the lack of long-term support, as discussed above, the management of CYP with ABI's symptoms and ongoing needs is left largely to parents <sup>38,284</sup>.

Parents of CYP with ABI are catapulted into this changed parenting and additional new caregiver role, which causes parents immense psychological distress and affects confidence <sup>85,285</sup>. Suddenly having to learn how to navigate health and education systems, and access support for their CYP, is a huge undertaking, when they just want the best care for their CYP. A lack of support and information can increase anxiety and worry for parents <sup>286</sup>.

Facilitators for participation and well-being identified in families with higher outcome scores in the survey were resilience and greater levels of self-efficacy and health literacy. However, the majority of parents who

participated in the interviews were struggling with one or more of these elements, as well as coming to terms with their CYP's additional needs. In line with previous research, parents who participated in the survey and interviews reported poor well-being, emotional or mental health issues, feeling isolated and stuck, with no idea where to access help<sup>92,284</sup>. Many parents lacked self-efficacy, reporting a lack of confidence in their ability to recognise needs, navigate complex health and education systems and advocate and support their CYP's rehabilitation effectively <sup>92,104</sup>. This was so, even if, in other aspects of their lives, they reported the opposite, for example, a mother with a professional career struggling to navigate the EHCP process for their CYP <sup>97</sup>. Additionally, there is often a loss of independence for the parents as well as the CYP, who move suddenly to caring for their CYP full time. This is most prominent when the CYP returns home from hospital and does not return to school immediately, however it can continue in the long-term, leading to feelings of isolation and exclusion from their work and friendships.

Parents were very clear that they continued to need practical, emotional, and psychological support in the years after their CYP's ABI, and in varying amounts at different times. They asked for support to learn how to best to support their CYP, navigate systems, build confidence in advocating for the CYP's needs and address their emotional health issues.

For parents to be actively engaged and empowered in managing their CYP's brain injury recovery, they need to be able to understand the injury, its impact and the recommendations made to support the CYP and family <sup>92</sup>. They then need to be able to act on the recommendations, including finding and accessing additional support from professionals where required. A systematic review by Zaidman et al <sup>96</sup> found a clear link between parental health literacy, health behaviour and health outcomes for children with chronic disease, impacted by contextual factors such as socioeconomic, culture and family factors. In fact, across all child health conditions, it has been found that one in four parents have low health literacy <sup>96,287</sup>. This affects their acquisition of knowledge about their CYP's health condition and their ability to make health decisions, which in turn affects child health outcomes. Lundine et al's <sup>92</sup> scoping review found parental understanding to be one of the multiple factors influencing follow-up care for families of CYP with ABI. Both studies recommend further research to develop interventions aimed at delivering disease-specific education, including later-developing consequences, to improve parental health literacy and child health outcomes.

Additionally, the timing of the support and training is important. Parents reported 'information overload' in hospital, which suggests the information is not retained. Alternatively, parents reported they felt they needed the information later, with the real impact of the ABI not becoming evident until they are home and returning to usual activities.



Many CYP and families strive for 'normality', wanting to return to life before the injury. The emotional impact and acceptance of this not being the case, can take a long time to come to terms with. As found in the literature, parents in this study reported the need for support years after the event as new needs emerge <sup>3,16,19,221</sup>. For example, a CYP sustaining an ABI in primary school may need increased support in secondary school as executive functioning impairments emerge. Timely, ongoing access to support, training and education is required to enable parents to increase their health literacy and self-efficacy. Providing practical support to parents to assist in system navigation, upskill and empower them is essential as they come to terms with a new health condition <sup>259,275</sup>. Alongside this, emotional and psychological support is required to ensure they are able to engage effectively with this and their CYP's rehabilitation and recovery.

The need for rehabilitation services for CYP with ABI to be family-focused is being increasingly recognised within the literature. Shen et al's <sup>104</sup> systematic review and meta-analysis found small to medium positive effects of family-oriented interventions on child and parent outcomes across cognition, emotion, and behaviour. However, they found little impact on family functioning and recommended greater focus on family interactions in future research.

Solutions identified by families and stakeholders included establishing peer support networks, with parents expressing a desire to connect with other parents who understand what they are experiencing. Further

research is required to establish the most effective methods of connecting parents, whether that is virtual, face-to-face, one-to-one or in group settings. Parents also recognised the need at times for more formal psychological support to address specific issues, such as post-traumatic stress disorder or ongoing emotional trauma. This also requires further research.

Furthermore, families and professionals from health, education, social care, and charities wanted easy access to information and sources of support, such as a digital platform. Further research is required to investigate and develop this further.

### **7.3.3 Organisational structures and boundaries limit access to rehabilitation and recovery**

Whilst individual factors such as impairments and the specific contextual factors of each family are influential on participation and well-being, external contextual factors at an organisational level present many barriers. A lack of services, clear pathways or systems and cross-sector communication and collaboration were barriers to parents trying to access support for their CYP and family, which they found hugely frustrating. A lack of organisational awareness and understanding of the needs of CYP with ABI and a lack of access to rehabilitation support were the two most striking issues.

### **7.3.3.1 *Lack of organisational understanding and awareness***

A lack of understanding and awareness of the impact of an ABI underpins many of the organisational issues found in this thesis. Whilst physical impairments are often more visible and therefore recognised and supported by clinical services and schools, it is the invisible 'hidden' disabilities that are often more impactful. These are often not understood and are poorly recognised <sup>288</sup>.

Not all needs are evident immediately after injury, with the potential for skills to not develop and needs to emerge or change throughout childhood and adolescent development and into adulthood <sup>38</sup>. Families need to understand the injury and implications, however, so do healthcare, education and social care professionals and the organisations they work for <sup>92</sup>. Whilst education staff are aware when a CYP has sustained an ABI, many lack understanding of hidden disabilities, the long-term impact, potential for emergent needs or where to seek support <sup>289</sup>. Some CYP experienced long delays in return to school, refusal to make reasonable adjustments, or provide additional support within school, which further impacted on their participation and well-being. Some families experienced long-term difficulties accessing continued or increased educational support for their CYP with ABI. They reported feeling as though schools had forgotten the ABI had happened, or that they weren't making connections between the child's brain injury and behavioural, learning, or cognitive difficulties associated with it.

Social interaction is a major part of school life that contributes to a CYP's development. CYP with ABI experienced social interaction restrictions due to concerns for their safety, for example, being unable to be with friends in the playground at break times due to the risk of seizures. This isolated them from their peers, compounding the social isolation and marginalisation that they face.

Participants also reported that education staff may recognise the need for additional support for a CYP or for themselves, but not know where to access that support. Stakeholders reported this was an issue across health, education and social care organisations and a lack of information, training, education, services, and clear pathways compounds this. Even professionals working in specialist services reported not always know where to direct teams supporting CYP to in order to access support.

This requirement for ongoing information and education for families and school staff to enable CYP needs to be recognised and addressed, was apparent and is corroborated in the literature<sup>92,288</sup>. With an estimated one CYP in every UK classroom having sustained an ABI by the end of compulsory schooling, increasing understanding and awareness across the sectors, and in families, is imperative<sup>288</sup>. Further research is required to establish the most effective methods of doing this.

### **7.3.3.2 Lack of access to long-term rehabilitation support**

The lack of access to long-term rehabilitation support, particularly for CYP with ABI without significant motor impairments, was a concern raised repeatedly by families and stakeholders across the studies.

Many CYP with ABI and their families had little, if any, support or access to community rehabilitation. Additionally, health, social care and education professionals did not always know where to access the support or how to help families.

Outside of the family and home environment, education settings become the main context for rehabilitation following discharge home and return to school. Experiencing a positive transition back into school is linked to increased likelihood of remaining in education, which in turn is likely to positively influence future QoL and outcomes<sup>290</sup>. Health and education need to work in close collaboration to ensure return to school is positive, and that support continues throughout their education. Indeed, limited communication from healthcare providers supporting CYP with ABI when they return to school, or at key transition points, has been shown to compound the lack of awareness and understanding found in schools<sup>57</sup>.

A lack of information sharing within and across sectors, training for those supporting CYP with ABI, and care pathways designed to ensure rehabilitation, education and social support through to adulthood, exacerbate the lack of understanding of the needs<sup>3</sup>. Health, education, social care, and charity stakeholders reported organisational structures

and boundaries between organisations and sectors prevent clear communication and collaboration. Education staff reported have limited options for additional support within their school or local authority, with county-wide educational support services varying from county to county. Health professionals reported limited options within primary care for GP's and school nurses to refer families to for support, with no direct access back to specialist neurorehabilitation services and long waiting lists resulting in issues escalating prior to appointments. Participants from across the sectors reported a lack of resources and time compounded this, adding to the level of stress they felt in trying to advocate for CYP and their families.

This finding aligns with the findings of the scoping review and previous literature <sup>221</sup>. There is widespread recognition of the inequity of access to rehabilitation nationally for CYP with ABI and increasing recognition of the need to provide long-term, if not life-long support <sup>221</sup>. Additionally, as in other complex health conditions, there is increasing acknowledgement that improved communication, liaison, follow-up, and practical and emotional support is required for CYP with ABI and their families, delivered in a developmentally appropriate and timely manner<sup>263,286,291</sup>. To effectively address the long-term needs of CYP with ABI, overcome organisational barriers and establish multi-disciplinary, cross-sector collaboration requires commitment and effort across health, education and social care systems <sup>124</sup>. This is not a

unique challenge to this population, but across every complex health and care population <sup>292,293</sup>.

Access to education, health and care services for all is an issue of equality and social justice that needs addressing, particularly for those who require assistance navigating complex systems and advocating for themselves <sup>294</sup>. Society invests more in emergency and acute care services than in the long-term care of people with brain injuries, with ABI being equal to other chronic illnesses <sup>294,295</sup>. The growing knowledge of psychosocial risk in CYP with ABI is compelling evidence for the need for an integrated, cross-sector, systemic approach <sup>37</sup>. Furthermore, there is a financial argument for early intervention and prevention with the lifetime cost to care for a CYP with severe TBI estimated to be £4.9 million, including medical costs, social care, educational costs, government benefits and missed employment opportunities <sup>37</sup>. There is a desire for change. The Chief Medical Officers report in 2012 entitled 'Our children deserve better' called for early intervention and prevention, proactive innovation and interventions with lasting impact, optimising well-being later in life. Commissioner's awareness of rehabilitation has increased with rehabilitation commissioning guidance published in 2016 <sup>128</sup> and the increased need for rehabilitation in the wake of the COVID-19 pandemic.

Ensuring equitable funding for the delivery of paediatric neurorehabilitation would reduce the variation and postcode lottery that exists nationally and improve equity of access to neurorehabilitation for

CYP with ABI, spinal cord injuries and other acquired neurological conditions. Whilst NHS England provide service specifications for tertiary centres delivering paediatric neurorehabilitation, currently the funding for such services varies greatly from centre to centre <sup>35</sup>. The advent of Integrated Care Systems (ICS) within the UK may offer a forum through which to ensure funding for services within each area. Instigated through the Health and Care Act 2022, ICS are area-based agencies responsible for collaborating across health and social care to plan and coordinate local services to improve health, care and well-being and reduce inequalities <sup>291</sup>. ICS are run by an Integrated Care Board (ICB) who are responsible for local budgets, with the aim of joining up local partners (NHS, councils, voluntary sector and others) to work together to improve local services based on local needs <sup>296</sup>. Paediatric neurorehabilitation has been identified as one service whose funding will transfer to ICBs, although NHS England will still provide the service specification for regional specialised services <sup>297</sup>. With approximately 40,000 CYP with brain or spinal injury requiring access to neurorehabilitation every year, spread across 42 ICS's, ICB's are ideally placed to facilitate and finance cross-sector collaboration. However, this demands much greater ICB awareness of this population's needs.

Whilst many of these organisational barriers require high level changes that feel insurmountable, we can continue to advocate for the CYP with ABI and address the lack of understanding and awareness at a local level. Training schools, community health teams and social care



professionals on the hidden impacts of an ABI, how it can affect learning and behaviour, and how needs can change or emerge over time would mean these needs are better recognised and addressed <sup>92</sup>. Additionally, ensuring there are sources of support available for professionals working with CYP with ABI is essential, to help them advocate for and navigate the complex systems that they work within, and to ensure the right support is in place for the CYP. Further research is required to develop training packages and digital information platforms.

#### **7.3.4 Societal lack of awareness impacts access to community activities and increases exclusion**

A lack of understanding and awareness of the long-term, often hidden impacts of an ABI within society in general results in significant barriers to participation and well-being for CYP with ABI and their families. This lack of awareness increases exclusion from community activities and isolates families further.

Participants reported a lack of availability of accessible, inclusive, community activities for CYP with ABI. This was particularly problematic for CYP with cognitive impairments who are physically able. In these cases, access to mainstream sports and activities remained difficult due to a lack of understanding or support, but disability orientated groups were also unsuitable. Participants also reported finding family activities

equally difficult to access and this led to increased isolation and a lack of peer support and friendships.

As seen in the literature, cognitive impairments are known to be a restricting factor in participation in activities for CYP with ABI of all severities<sup>19,73,298,299</sup>. However, as the studies in this thesis have shown, it is contextual, societal and organisational barriers that compound this and need to be the focus of participation-focused interventions for CYP with ABI and their families<sup>300</sup>. This aligns with the social model of disability, which views disability as a result of environmental and social barriers that are imposed on top of a person's impairments, unnecessarily isolating and excluding them from full participation in society<sup>300,301</sup>. In 2009, the UK ratified the United Nations Convention on the Rights of Persons with Disabilities which stated a change of perceptions was needed to improve the situation for people with disabilities, especially to address prejudices, and stereotypes and promote greater awareness of the abilities of people with disabilities<sup>42</sup>. Fifteen years on, whilst some progress has been made there is still much room for improvement.

The All-Party Parliamentary Group for Acquired Brain Injury, formed in 2017, aims to raise key issues affecting people living with ABI in the UK and seek improvements. In their report entitled *Acquired Brain Injury and Neurorehabilitation: Time for Change* they raise the issue of ABI being a hidden epidemic affecting hundreds of thousands of children, young people and adults and impacting multiple government

departments. They called for the Government to coordinate a task-force to address the issues and recommendations they make, which include patient-held rehabilitation prescriptions for all, a minimum level of awareness and understanding for all educational professionals, training and information across all public services, including the criminal justice system, and collaborative research aimed at improving understanding of ABI recovery and assessment<sup>302</sup>. In 2021, the Government committed to publishing an ABI strategy. This is being led by the Department of Health and Social Care and, following a call for evidence in 2022, the strategy is awaited. Future research needs to align with this strategy and focus on interventions to support community participation and increasing societal understanding and awareness of the needs of CYP with ABI and their families to improve inclusivity.

### **7.3.5 The impact of an ABI is not limited to childhood – CYP need long-term support across the life course**

The studies in this thesis, which included CYP with ABI one to four years after ABI, demonstrated high levels of unmet and ongoing participation and well-being needs. Participants reported the barriers to accessing rehabilitation and support only increased for CYP aged 16-18, for whom there were gaping holes in service provision.

These findings suggest that the impact of an ABI during childhood does not go away on the child's 18<sup>th</sup> birthday. CYP need support across the

life course and an effective, well-managed and supported transition between child and adult services. CYP in this age group may be deemed too old for children's services and too young for adult's services<sup>303</sup>. This can lead to CYP with ABI and their families experiencing fragmentation of care, being lost to follow up and having no support, when, in fact, there is even greater need for care coordination during transition to ensure continuity<sup>95,303-305</sup>. These findings are supported by Shankar et al<sup>306</sup>, who found a wide gap between what caregivers need and what is available during the transition process, with many reporting this to be overwhelming and all-encompassing.

The Royal College of Paediatrics and Child Health advocate for a well-planned, integrated and supported transition period<sup>307</sup>. The National Institute for Health and Care Excellence (NICE) have produced a guideline regarding transition and several best practice transition programmes exist aiming to improve the process of transition<sup>305,307</sup>. Colver et al<sup>308</sup> conducted a five-year-long transition research programme focusing on improving transition for young people with long-term health conditions from CYP to adult healthcare services in the UK. They found improved outcomes were associated with appropriate parent involvement, promotion of young people's confidence in decision making and managing their health condition (health self-efficacy) and meeting the adult team before transfer. Colver et al.<sup>308</sup> identified several recommendations from their research which are applicable to all

areas of healthcare including those for CYP with ABI. These include a need for commissioners to fund transitional healthcare across CYP and adult services and ensure developmentally appropriate healthcare, healthcare providers to adopt an organisation-wide approach to the implementation of transitional healthcare, and joint early planning between adult and children's services, including personalisation of the transition process for the young person. Future research needs to build on the findings in this thesis, by exploring the views of older young adults and their families using qualitative methods to develop effective interventions focused on supporting them through the transition period.

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#### 7.4 Recommendations for practice and policy

From the findings in this thesis, the following recommendations are made for practice and policy:

- CYP with ABI should have long-term access to specialist neurorehabilitation services to ensure ongoing participation and well-being needs are identified and addressed.
- Neurorehabilitation services for CYP with ABI should be family-focused, with the needs of the whole family being assessed and addressed.
- Needs assessment and goal setting should be carried out by a healthcare professional who is knowledgeable in ABI in CYP and the potential visible and hidden impacts.

- CYP and their families should have long-term access to neurorehabilitation specialists for targeted participation-focused interventions, such as psychological support, neuropsychological rehabilitation, and skills-based training (e.g., independence skills, return to sports).
- Transition from CYP to adult services needs to be well planned and coordinated.
- Parents should have a single point of contact and access to practical, emotional and psychological support, training and education to support their health literacy and self-efficacy.
- Establishment of peer support networks for CYP with ABI, parents and siblings.
- Provision of training for education staff, community health teams and social care professionals on the hidden impacts of an ABI.
- Ensure professionals working with CYP with ABI from across health, education, social care and charities have access to information and sources of support.
- Develop cross-sector care pathways that are collaborative and coordinated, ensuring effective communication with all involved in supporting a CYP with ABI.
- Implementation of routine, meaningful, participation and well-being outcome measures into clinical practice to support data collection. This should align with the national core outcome set once it is developed.

## 7.5 Strengths and Limitations

The methodological approach taken in this thesis is a strength. A mixed-methods theoretical approach, defined at the outset, guided, and informed each component of the study methodology. This ensured a robust and methodical process to the research, analysis and intervention development with relevant theories and models incorporated throughout. The mixed-methods design ensured a comprehensive understanding of CYP with ABI, family and stakeholder needs, barriers, and facilitators. The ICF and BCW facilitated a biopsychosocial-ecological view of the findings, with needs being understood at individual, organisational and societal levels. The ICF and TDF provided a common language with which to identify and describe needs, barriers, and facilitators. As well as considering the individual needs, these also enabled organisational and societal barriers to be considered, and a focus on the context and system as a whole, across sectors. This was important as this is what families experience and the system within which the intervention will be delivered. The findings were integrated between each stage, with the previous findings informing the next. After primary data collection, all the findings were synthesised and triangulated using a framework matrix and consultation with participants at the co-design workshop. This ensured that the intervention development phase incorporated all the findings and participants views into the intervention and outcomes of the thesis. Additionally, following the BCW process facilitated the

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convergence of findings from different studies where the same framework was used, which gives the potential for increasing sample populations and increasing the generalisability of findings.

The second strength is the co-design/user involvement thread that runs throughout the thesis. As a clinician, CYP and their families have always been at the heart of everything I do and were naturally central to this thesis. PPI is vital in the evaluation of clinical services and academic research. Whilst participants were recruited via a regional specialist centre, all CYP with ABI were community dwelling and at least one year post discharge from hospital. This ensured that longer-term needs could be understood as well as the contextual barriers that families face in the years after ABI. I consulted with CYP with ABI and parents about the design of the whole study, including the outcome measures included in the survey. CYP with ABI and parents were participants in the survey, interviews and workshop and professional stakeholders participated in the focus groups and workshop. Throughout there has been PPI consultation, collaboration, and participation, informed by the National Institute of Health and Care Research PPI guidance <sup>309</sup>. Involving the population being studied is fundamental to the PBA, with co-design being an identified mechanism that enables the inclusion of shared wisdom when developing interventions and planning for successful implementation to best meet the needs of the local population <sup>135</sup>. The workshop brought together families with health, education, social care and charity professionals



and researchers. I was able to present the study findings to the participants and gain confirmation that what I had presented rang true for them. There was a shared understanding of the problem and a desire to work together to make a change. It also enabled us to explore solutions together that were acceptable to both families and professionals. This active engagement with all stakeholders in a collaborative environment, with open and clear communication across sectors, was invaluable both to me as a researcher and to them. Many reported how much they had personally gained from the workshop from speaking to others in similar situations.

Further [expert consultation and](#) co-design workshops could be held to explore some of the specific elements of the intervention in more detail and other solutions that emerged from the workshop (e.g., developing a digital resource) that remain to be addressed. Alongside this, further PPI consultation, involvement, and collaboration is required to support the intervention development, testing and implementation work that is to follow <sup>3</sup>. I also plan to consult experts from across the country and internationally through presenting the findings and intervention to the national paediatric neurorehabilitation network and at national and international conferences.

However, there are some limitations to the findings. The studies were conducted in one geographical region of the UK and therefore may not be representative of the needs nationally. Whilst equality, diversity and inclusion guidance was followed, and diverse representation was aimed

for, this varied. More families of CYP with brain tumours participated than other diagnoses. Participation of fathers was limited to the survey only, with none participating in the interviews or workshop. Generally, it was mothers that participated. This could be due to the maternal caring role and mothers taking on the majority of this. However, the views of fathers are lacking, particularly in the qualitative interview data. Whilst the survey and interviews had good representation from families of different ethnicities, only white British families attended the workshop. There was also greater representation from health and education amongst stakeholder participants and limited social care involvement throughout. Diverse representation is needed in future consultations regarding the intervention development and implementation, with targeted consultation at those under-represented within this thesis.

The complexity of the needs of CYP with ABI and their families is clear. When developing the intervention, the needs were considered at an individual, organisational and societal level and within the confines of this thesis prioritisation was necessary. This was done collaboratively, with users and stakeholders, to ensure the intervention developed within this thesis addressed the most pressing issues for CYP with ABI, their families and the stakeholders supporting them. It was clear within the workshop where the priorities were for them and whilst this thesis presents an intervention aimed at addressing several of their priorities, there are more still to be addressed.

Developing and evaluating complex interventions is difficult and the heterogeneity of ABI compounds this. Whilst there are many recommendations in the literature for the development of interventions to address the needs of this population, there are few intervention development studies or effectiveness trials due to the difficult nature of doing so in this population, resulting a lower level of effectiveness evidence<sup>280</sup>. There is also a lack of theoretical underpinning reported. This thesis has achieved its aim of developing a theoretically informed intervention. However, this further refinement is required prior to feasibility testing.

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#### **7.5.1 Impact of COVID-19 Pandemic**

This PhD commenced in October 2019 on a part time basis alongside my clinical role. In March 2020 the COVID-19 pandemic forced the UK into a series of national lockdowns – 26<sup>th</sup> March 2020 to 23<sup>rd</sup> June 2020, 5<sup>th</sup> November 2020 to 2<sup>nd</sup> December 2020 and 6<sup>th</sup> January 2020 to 8<sup>th</sup> March 2021. These impacted the NHS services in which I worked, my research and my family. I began studying at home alongside my children who were home-schooling, as well as continuing to work at the hospital. There was inevitably an impact not just on the study itself in terms of recruitment, data collection and timescales, but also on myself in terms of stress and managing multiple priorities.

Originally, face-to-face interviews and focus groups were planned for Study 1, however, in light of the pandemic restrictions, the protocol was

amended to conduct these using a virtual platform. Ethical approval was initially granted in November 2020, just as the UK went back into lockdown. As the survey was asking CYP and their families about participation, it was not appropriate to send the survey out when no-one was participating in activities outside the home. A substantial amendment was applied for, to adapt the protocol to delay and extend recruitment, and include additional questions regarding the impact of the pandemic. This was agreed and recruitment to the survey began in April 2021 as lockdown measures were being lifted.

Recruitment of families was slow and difficult. This had to be conducted via telephone, email, or letter, due to being unable to recruit face-to-face at hospital clinic appointments as the majority were being conducted virtually. Families were also dealing with the impact of the pandemic, as well as added pressures of caring for a CYP with ABI, on top of already busy family lives. Some families consented to participation but did not complete the survey, others simply said it was too much. The burden of research on busy families must be considered in further research. This is an under-served population who are isolated, marginalised and under-represented within research and society. There is a need to investigate how to best enable them to participate in research without it being too onerous or burdensome. One option would be including standardised tools and outcome measures in routine clinical practice, to ensure data is collected that can be retrospectively or prospectively analysed.

### **7.5.2 Reflexivity**

Whilst my role as a clinician gave me insight into the organisations and context, awareness of the needs of the population, and trust and rapport with the families and stakeholders, this potentially could have biased the findings. Participants may have not wanted to say things they thought I would not want to hear. However, my role is largely inpatient-based and as the research was about longer-term post discharge needs, interview and focus group questions were not related to the elements of the service I work within. I was therefore able to separate any comments or discussion regarding inpatient service provision from those relevant to the research.

Additionally, listening to the traumatic experiences of many of the families was at times emotional. As a clinician I am used to working with families in this situation and therefore have reasonably good coping strategies for managing and dealing with any emotions it invokes in me. I employed the same strategies in this context. However, during the course of conducting this research, my own son sustained a rare traumatic injury, and I found myself in a similar situation to many of the families I had interviewed, having to advocate for effective management, navigate complex care systems and support him in his recovery. This meant that I was acutely aware of the barriers and frustrations many of the families were experiencing. I was very mindful of this during the analysis of the findings, aiming to prevent biases or

interpretation errors, as well as ensuring I allowed myself space to deal with my own emotions away from the research.

As discussed in Chapter 5, having recognised the potential influence of my perspective, I ensured the research coding, themes and findings were regularly discussed within supervision and with the study steering group. I also maintained field notes and a reflective diary throughout the entire research process <sup>179,180</sup>.

## 7.6 Future Research Directions

This research has developed an intervention which is now ready for expert consultation to refine it prior to feasibility testing to assess its acceptability, practicability, sustainability, and effectiveness. The proposed intervention is complex and contains multiple components that would address specific needs, such as coaching, fatigue and psychological support interventions. The specifics of these components require further refinement and confirmation of the pre-existing interventions which will be included. Identification or development of a standardised needs assessment is required to aid needs assessment and data collection. Sources of education and training are required for families and professionals. This includes identifying existing sources and development of specific packages where required, and a central digital resource created to aid signposting.

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To facilitate this an expert consensus workshop will be held, including expert stakeholders and experts by experience (CYP with ABI and parents). The Nominal Group Technique (NGT) will be used to refine the intervention. NGT is a group facilitation technique that provides a structured method for gathering and prioritising ideas, and therefore lends itself well to intervention refinement<sup>311</sup>. Through individual idea generation, group sharing and discussion and independent ranking for prioritisation, this technique would help refine the intervention, specify its components, and consider the importance and feasibility of each and any implementation challenges<sup>311</sup>. This would inform the ongoing iterative development of the intervention and implementation plan for feasibility testing.

Given the variability in the needs of individual families, questions to be addressed at the feasibility testing stage concern the ability of the intervention to meet target population needs, whether it can be sufficiently individually tailored to the needs of the child with ABI and their family, whether the costs can be measured to inform future cost effectiveness evaluation and implementation and whether it can be delivered to CYP across wide geographical regions.

Additionally, the data regarding prevalence of need is incomplete. The clinical database maintained by the regional team only includes those CYP admitted to the regional centre and not those admitted to other district general hospitals who are not transferred to the regional centre, those who are discharged from Emergency Departments (ED) or who

never present at healthcare providers. Whilst the majority of moderate or severe ABI's will be included, the data regarding mild TBIs and concussions is lacking. A data linkage study is required to link up hospital, ED, and GP data to provide evidence of overall prevalence of need.

The desire for change has to be balanced against organisational constraints and any funding of new interventions or service developments relies on cost-effectiveness and economic benefit. There is a lack of evidence for the economic benefit of effective neurorehabilitation in paediatrics, however, there is in the adult population <sup>130</sup>. CYP have more years ahead of them and the impact on their future employment as well as their parents' health, well-being and employment need to also be taken into account. This is complex and hard to measure but does need addressing.

Vital for implementation success is stakeholder buy-in. The stakeholders involved in this study were invested and there is a strong desire for change. However, this is at a family and clinician level, and this now needs to be communicated to commissioners. Engaging with commissioners locally and nationally is key.



## **7.7 Impact**

My clinical role involves co-leading the children's inpatient neurorehabilitation service at the regional centre. This service is funded by NHS England who provide a service specification for paediatric neurorehabilitation. The service specification is in the process of being reviewed and updated and the project lead from NHS England has been consulting with all regional services regarding this. As a result of this engagement with the project lead, I was invited to become an affiliate member of the NHS England Clinical Reference Group for Paediatric Neurosciences to contribute to the updated service specification. The findings and recommendations from this research have been reviewed by the project lead and are informing discussions regarding the updated service specification and the commissioner's recommendations for service provision at regional centres across England.

Additionally, during the period of this PhD, I was appointed to the role of Topic Advisor for Children and Young People to the National Institute for Health and Care Excellence guideline committee currently developing guidelines for Rehabilitation for Chronic Neurological Disorders for CYP and adults. The training and knowledge I have gained through the course of this PhD have impacted on my confidence and ability to contribute to this guideline which I hope will greatly impact on the service provision for people with neurological disorders, including ABI, across the life course.

## 7.8 Conclusion

The studies within this thesis have illuminated the extensive long-term unmet participation and well-being needs of CYP with ABI and their families. Using a theory-, evidence-, person-based approach, incorporating a literature review, mixed methods research, and co-design intervention development, an intervention has been developed aimed at identifying and addressing the needs of this population. The findings are being disseminated through publication and presentation at conferences to begin translating knowledge into practice and provide a foundation for future research to build upon. Further research and consultation are required to refine this multi-faceted intervention, specify the components and develop the care pathway to support its effective implementation, prior to feasibility testing, to ensure acceptability, effectiveness, and sustainability.

Key to the success of this research has been the involvement of CYP with ABI, families, and multiple stakeholders. Future research must continue in this vein, maintaining a family-centred, collaborative, multi-disciplinary approach, drawing on the collective expertise of all those involved in supporting CYP with ABI and their families to improve their participation and well-being and enable them to achieve their potential.

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## References

1. The United Kingdom Acquired Brain Injury Forum. *Life After Brain Injury - A Way Forward: Manifesto for Children and Young People with Acquired Brain Injury*. 2013. Accessed 26/07/17. <http://ukabif.org.uk/wp-content/uploads/2014/02/Manifesto-for-Children-and-Young-People-with-ABI.pdf>
2. de Kloet A, Hilberink S, Roebroek M, et al. Youth with acquired brain injury in The Netherlands: A multi-centre study. *Brain Injury*. 2013;27(7-8):843-849.
3. McKinlay A, Linden M, DePompei R, et al. Service provision for children and young people with acquired brain injury: Practice recommendations. *Brain Injury*. 2016;30(13-14):1656-1664. doi:10.1080/02699052.2016.1201592
4. Gmelig Meyling C, Verschuren O, Rentinck IR, Engelbert RHH, Gorter JW. Physical rehabilitation interventions in children with acquired brain injury: a scoping review. *Dev Med Child Neurol*. 2022;64:40-48. doi:10.1111/dmcn.14997
5. World Health Organization. Over 1 in 3 people affected by neurological conditions, the leading cause of illness and disability worldwide. World Health Organization. <https://www.who.int/news/item/14-03-2024-over-1-in-3-people-affected-by-neurological-conditions--the-leading-cause-of-illness-and-disability-worldwide>
6. Abdollahi M, Aboagye RG, Abu-Gharbieh E, et al. Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021. *Lancet neurology*. 2024;23(4):344-381. doi:10.1016/S1474-4422(24)00038-3
7. NHS England. *2013.2014 NHS Standard Contract for Paediatric Neurosciences: Neurorehabilitation Section B Part 1 - Service Specifications*. 2013.
8. Treadgold B, Kennedy C, Spoudeas H, Sugden E, Walker D, Bull K. Paediatric neuro-oncology rehabilitation in the UK: carer and provider perspectives. *BMJ Paediatrics Open*. 2019;3:e000567.
9. Bull K, Homsey S, CR. K, et al. Systematic review: Measurement properties of patient reported outcome measures evaluated with childhood brain tumor survivors or other acquired brain injury. *Neuro-Oncology Practice*. 2019;doi:DOI: 10.1093/nop/npz064
10. Royal College of Paediatrics and Child Health. *Stroke in Childhood: Clinical guideline for diagnosis, management and rehabilitation*. 2017.
11. NHS Digital. Cancer Survival in England. NHS Digital. Accessed 05.09.2023, 2023. <https://digital.nhs.uk/data-and-information/publications/statistical/cancer-survival-in-england/cancers-diagnosed-2016-to-2020-followed-up-to-2021>

12. Anderson V, Godfrey C, Rosenfeld J, Catroppa C. 10 years outcome from childhood traumatic brain injury. *International Journal of Developmental Neuroscience*. 2012;30:217-224.
13. Pozzi M, Galbiati S, Locatelli F, et al. Severe acquired brain injury aetiologies, early clinical factors, and rehabilitation outcomes: a retrospective study on pediatric patients in rehabilitation. *Brain Injury*. 2019;33(12):1522-1528. doi:10.1080/02699052.2019.1658128
14. Popernack M, Gray N, Reuter-Rice K. Moderate-to-Severe Traumatic Brain Injury in Children: Complications and Rehabilitation Strategies. *Journal of Pediatric Health Care*. 2015;29(3):e1-e7.
15. Stark D, Pujar S, Heyman I, Murphy T. An introduction to paediatric acquired brain injury. In: Jim J, Cole E, eds. *Psychological Therapy for Paediatric Acquired Brain Injury*. Routledge; 2020.
16. Gordon A, di Maggio A. Rehabilitation for Children After Acquired Brain Injury: Current and Emerging Approaches. *Pediatric Neurology*. 2012;46:339-344.
17. Andersson K, Bellon M, Walker R. Parents' experiences of their child's return to school following acquired brain injury (ABI): A systematic review of qualitative studies. *Brain Injury*. 2016;30(7):829-838.
18. Keetley R, Bennett E, Williams J, et al. Outcomes for children with acquired brain injury (ABI) admitted to acute neurorehabilitation. *Developmental Medicine & Child Neurology*. 2021;63:824-830. doi:DOI: 10.1111/dmcn.14846
19. de Kloet A, Gijzen R, Braga L, Meesters J, Schoones J, Vliet Vlieland T. Determinants of participation of youth with acquired brain injury: A systematic review. *Brain Injury*. 2015;29(10):1135-1145.
20. Gordon A. Functioning and disability after stroke in children: using the ICF-CY to classify health outcome and inform future clinical research priorities. *Developmental Medicine & Child Neurology*. 2014;56:434-444.
21. Forsyth R, Kirkham F. Predicting outcome of childhood brain injury. *Canadian Medical Association Journal*. 2012;184:1257.
22. Gagnon I, Swaine B, Champagne F, Lefebvre H. Perspectives of adolescents and their parents regarding service needs following a mild traumatic brain injury. Research Support, Non-U.S. Gov't. *Brain Injury*. Feb 2008;22(2):161-73. doi:https://dx.doi.org/10.1080/02699050701867381
23. Jones S, Davis N, Tyson S. A scoping review of the needs of children and other family members after a child's traumatic injury. *Clinical Rehabilitation*. 2018;32(4):501-511.
24. Slomine BS, McCarthy ML, Ding R, et al. Health care utilization and needs after pediatric traumatic brain injury. Research Support, U.S. Gov't, P.H.S. *Pediatrics*. Apr 2006;117(4):e663-74.
25. Greenspan A, MacKenzie E. Use and need for post-acute services following paediatric head injury. *Brain Injury*. 2000;14(5):417-429. doi: 10.1080/026990500120529

26. Towards a Common Language for Functioning, Disability and Health - ICF (WHO) (2002).
27. Imms C, Green D. *Participation: Optimising Outcomes in Childhood-Onset Neurodisability*. 1 ed. Clinics in Developmental Medicine. Mac Keith Press; 2020.
28. Vargus-Adams J, Majnemer A. International Classification of Functioning, Disability and Health (ICF) as a Framework for Change: Revolutionizing Rehabilitation. *Journal of Child Neurology*. 2014;29(8):1030-1035.
29. World Health Organisation. *How to use the ICF: A Practical Manual for using the International Classification of Functioning, Disability and Health (ICF)*. 2013. <http://www.who.int/classifications/drafticfpracticalmanual2.pdf?ua=1>
30. Ciccia A, Threats T. Role of contextual factors in the rehabilitation of adolescent survivors of traumatic brain injury: emerging concepts identified through modified narrative review. *International Journal of Language and Communication Disorders*. 2015;50(4):436-451.
31. World Health Organisation. Classifications: International Classification of Functioning, Disability and Health. World Health Organisation. Accessed 27/06/17, <http://www.who.int/classifications/icf/en/>
32. Fougeyrollas P, Lepage C, Boissière L, Deaudelin I, Doré L. Assessment of social participation in three measurement times in children with traumatic brain injuries (TBI) based on parental perceptions. *Open Journal of Therapy and Rehabilitation*. 2014;2:156-165.
33. Thompson M, Elliott C, Willis C, et al. Can, Want and Try: Parent's viewpoints regarding the participation of their child with an acquired brain injury. *PLoS ONE*. 2016;11(7):e0157951.
34. McDougall J, Wright V, Rosenbaum P. The ICF model of functioning and disability: Incorporating quality of life and human development. *Developmental neurorehabilitation*. 2010;13(3):204-211. doi:10.3109/17518421003620525
35. Hayes L, Shaw S, Pearce M, Forsyth R. Requirements for and current provision of rehabilitation services for children after severe acquired brain injury in the UK: a population-based study. *Arch Dis Child*. 2017;102:813-820.
36. Jim J, Costello G, Lowing V, Nash S, Scholes C, Perkins A. Hidden social inequalities in paediatric neurorehabilitation. In: Boakye N, Mwale A, eds. *Systemic Approaches to Brain Injury Treatment: Navigating Contemporary Practice*. Taylor & Francis; 2022.
37. Jim J, Liddiard H, Cole E. Our children do deserve better. In: Jim J, Cole E, eds. *Psychological Therapy for Paediatric Acquired Brain Injury*. Routledge; 2020.

38. Rohrer-Baumgarter N, Holthe I, Svendsen E, et al. Rehabilitation for children with chronic acquired brain injury in the Child in Context Intervention (CICI) study: study protocol for a randomised controlled trial. *Trials*. 2022;23(169)doi:10.1186/s13063-022-06048
39. Molteni E, Ranzini M, Beretta E, Modat M, Strazzer S. Individualised Prognostic Prediction of the Long-Term Functional Trajectory in Pediatric Acquired Brain Injury. *J Pers Med*. 2021;11doi:10.3390/jpm11070675
40. Sariaslan A, Sharp D, D'Onofrio B, Larsson H, Fazel S. Long-Term Outcomes Associated with Traumatic Brain Injury in Childhood and Adolescence: A Nationwide Swedish Cohort Study of a Wide Range of Medical and Social Outcomes. *PLoS Med*. 2016;13(8)doi:10.1371/journal.pmed.1002103
41. Holloway M, Orr D, Clark-Wilson J. Experiences of challenges and support among family members of people with acquired brain injury: a qualitative study in the UK. *Brain Injury*. 2019;33(4):401-411. doi:10.1080/02699052.2019.1566967
42. Lindsay S, Patel S, Ragnathan S, Fuentes K. Ableism among children and youth with acquired brain injuries and their caregivers: a systematic review. *Brain Injury*. 2023;doi:doi.org/10.1080/02699052.2023.2184869
43. Babikian T, Merkley T, Savage R, Giza C, Levin H. Chronic Aspects of Paediatric Traumatic Brain Injury: Review of the Literature. *Journal of Neurotrauma*. 2015;32:1849-1860. doi:10.1089/neu.2015.3971
44. Kuruvilla S, Sadana R, Montesinos EV, et al. A life-course approach to health: Synergy with sustainable development goals. *Bulletin of the World Health Organization*. 2018;96(1):42-50. doi:10.2471/BLT.17.198358
45. Forsyth R. Describing outcome after acquired brain injury: ending the quest for the holy grail. *Developmental Medicine & Child Neurology*. 2008;50:405.
46. Lambregts SAM, Van Markus-Doornbosch F, Catsman-Berrevoets CE, et al. Neurological outcome in children and youth with acquired brain injury 2-year post-injury. *Developmental neurorehabilitation*. 2018;21(7):465-474. doi:10.1080/17518423.2018.1460770
47. Hawley C, Ward A, Magnay A, Long J. Outcomes following childhood head injury: a population study. *J Neurol Neurosurg Psychiatry*. 2004;75:737-742.
48. Brandt AE, Rø TB, Finnanger TG, et al. Intelligence and executive function are associated with age at insult, time post-insult, and disability following chronic pediatric acquired brain injury. *Frontiers in neurology*. 2024;14:1192623-1192623. doi:10.3389/fneur.2023.1192623
49. Chapman S. Neurocognitive stall: a paradox in long term recovery from pediatric brain injury. *Brain Injury Professional*. 2006;3:10-13.

50. Imms C, Granlund M, Wilson P, Steenbergen B, Rosenbaum P, Gordon A. Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability. *Developmental Medicine & Child Neurology*. 2017;59:16-25.
51. Kolehmainen N, Marshall J, Hislop J, et al. Implementing participation-focused services: A study to develop the Method for using Audit and Feedback in Participation Implementation (MAPI). *Child Care Health Dev*. 2020;46:37-45. doi:10.1111/cch.12723
52. Adair B, Ullenhag A, Rosenbaum P, Granlund M, Keen D, Imms C. Measures used to quantify participation in childhood disability and their alignment with the family of participation-related constructs: a systematic review. *Developmental Medicine & Child Neurology*. 2018;60:1101-1116.
53. Darzins SW, Imms C, Di Stefano M. Measurement of activity limitations and participation restrictions: examination of ICF-linked content and scale properties of the FIM and PC-PART instruments. *Disability and Rehabilitation*. 2017;39(10):1025-1038. doi:10.3109/09638288.2016.1172670
54. World Health Organization. International classification of functioning, disability and health: children and youth version. Geneva: WHO Press; 2007.
55. Madden RH, Bundy A. The ICF has made a difference to functioning and disability measurement and statistics. *Disability and Rehabilitation*. 2019;41(12):1450-1462. doi:10.1080/09638288.2018.1431812
56. Chagas PSC, Magalhães EDD, Sousa Junior RR, et al. Development of children, adolescents, and young adults with cerebral palsy according to the ICF: A scoping review. *Developmental medicine and child neurology*. 2023;65(6):745-753. doi:10.1111/dmnc.15484
57. Bennett E, Fletcher A, Talbot E, Robinson L. Returning to education after childhood acquired brain injury: Learning from lived parental experience. *NeuroRehabilitation*. 2023-06-15 2023;52(4):625-640. doi:10.3233/nre-220205
58. Bedell GM, Dumas HM. Social participation of children and youth with acquired brain injuries discharged from inpatient rehabilitation: a follow-up study. *Brain Injury*. Jan 2004;18(1):65-82. doi:10.1080/0269905031000110517
59. Gfroerer SD, Wade SL, Wu M. Parent perceptions of school-based support for students with traumatic brain injuries. Research Support, N.I.H., Extramural Research Support, U.S. Gov't, P.H.S. *Brain Injury*. Aug 2008;22(9):649-56. doi:https://dx.doi.org/10.1080/02699050802227162
60. Glang A, Todis B, Thomas CW, Hood D, Bedell G, Cockrell J. Return to school following childhood TBI: who gets services? Research Support, U.S. Gov't, Non-P.H.S. *Neurorehabilitation*. 2008;23(6):477-86.

61. Hartman LR, Duncanson M, Farahat SM, Lindsay S. Clinician and educator experiences of facilitating students' transition back to school following acquired brain injury: A qualitative systematic review. Review. *Brain Injury*. Oct 2015;29(12):1387-1399. doi:10.3109/02699052.2015.1071431
62. Hawley C, Ward A, Magnay A, Mychalkiw W. Return to school after brain injury. *Arch Dis Child*. 2004;89:136-142.
63. Lindsay S, Hartman LR, Reed N, Gan C, Thomson N, Solomon B. A Systematic Review of Hospital-to-School Reintegration Interventions for Children and Youth with Acquired Brain Injury. *Plos One*. Apr 2015;10(4)e0124679. doi:10.1371/journal.pone.0124679
64. Mealings M, Douglas J, Olver J. Considering the student perspective in returning to school after TBI: A literature review. *Brain Injury*. 2012;26(10):1165-1176.
65. Roscigno CI, Fleig DK, Knafl KA. Parent management of the school reintegration needs of children and youth following moderate or severe traumatic brain injury. Research Support, N.I.H., Extramural Research Support, Non-U.S. Gov't. *Disability & Rehabilitation*. 2015;37(6):523-33. doi:https://dx.doi.org/10.3109/09638288.2014.933896
66. Hassett L, Moseley A, Harmer A. The Aetiology of Reduced Cardiorespiratory Fitness Among Adults with Severe Traumatic Brain Injury and the Relationship with Physical Activity: A Narrative Review. *Brain impairment*. 2016;17(1):43-54. doi:10.1017/Brlmp.2015.28
67. Baque E, Sakzewski L, Barber L, Boyd RN. Systematic review of physiotherapy interventions to improve gross motor capacity and performance in children and adolescents with an acquired brain injury. *Brain injury*. 2016;30(8):948-959. doi:10.3109/02699052.2016.1147079
68. Hawkey LC, Capitanio JP. Perceived social isolation, evolutionary fitness and health outcomes: a lifespan approach. *Philosophical Transactions of the Royal Society B: Biological Sciences*. 2015-05-26 2015;370(1669):20140114. doi:10.1098/rstb.2014.0114
69. Brooks R, Lambert C, Coulthard L, Pennington L, Kolehmainen N. Social participation to support good mental health in neurodisability. *Child: Care, Health and Development*. 2021-09-01 2021;47(5):675-684. doi:10.1111/cch.12876
70. Hendry K, Ownsworth T, Waters AM, Jackson M, Lloyd O. Investigation of children and adolescents' mood and self-concept after acquired brain injury. *Child Neuropsychology*. 2020-11-16 2020;26(8):1005-1025. doi:10.1080/09297049.2020.1750577
71. Williams H, Tonks J, Fox S. Psychotherapy for children and young people with brain injury in conflict with the law. In: Jim J, Cole E, eds. *Psychological Therapy for Paediatric Acquired Brain Injury*. Routledge; 2020.
72. United Nations General Assembly. Universal Declaration of Human Rights. In: Nations U, editor. 1948.



73. Galvin J, Froude E, McAleer J. Children's participation in home, school and community life after acquired brain injury. *Australian Occupational Therapy Journal*. 2010;57:118-126.
74. Kolehmainen N, Ramsey C, McKee L, Missiuna C, Owen C, Francis J. Participation in Physical Play and Leisure in Children with Motor Impairments: Mixed-Methods study to generate evidence for developing an intervention. *Physical Therapy*. 2015;95(10):1374-1386.
75. Allonsius F, de Kloet A, Bedell G, et al. Participation restrictions among children and young adults with acquired brain injury in a paediatric outpatient rehabilitation cohort: The patients' and parents' perspective. *International Journal of Environmental Research and Public Health*. 2021;18:1625. doi:10.3390/ijerph18041625
76. van Markus-Doornbosch F, van der Holst M, de Kloet A, Vliet Vlieland T, Meesters J. Fatigue, participation and quality of life in adolescents and young adults with acquired brain injury in an outpatient rehabilitation cohort. *Developmental Neurorehabilitation*. 2020;23(5):328-335.
77. Anaby D, Khetani M, Piskur B, et al. Towards a paradigm shift in paediatric rehabilitation: Accelerating the uptake of evidence on participation into routine clinical practice. *Disability and Rehabilitation*. 2021;doi:10.1080/09638288.2021.1903102
78. Eriksson L, Granlund M. Conceptions of participation in students with disabilities and persons in their close environment. *Journal of Developmental and Physical Disabilities*. 2004;16(3):229-245.
79. King G, Ziviani J, Imms C. Participation: Theoretical underpinnings to inform and guide interventions. In: Imms C, Green D, eds. *Participation: Optimising outcomes in childhood-onset neurodisability*. Mac Keith Press; 2020:15:chap 2.
80. Resch C, van Kruijsbergen M, Ketelaar M, et al. Assessing participation of children with acquired brain injury and cerebral palsy: a systematic review of measurement properties. *Developmental Medicine & Child Neurology*. 2020;
81. Geyh S, Schwegler U, Peter C, Müller R. Representing and organising information to describe the lived experience of health from a personal factors perspective in the light of the International Classification of Functioning, Disability and Health (ICF): a discussion paper. *Disability and Rehabilitation*. 2019;41(14):1727-1738.
82. Di Marino E, Tremblay S, Khetani M, Anaby D. The effect of child, family and environmental factors on the participation of young children with disabilities. *Disability and health journal*. 2018;11(1):36-42. doi:10.1016/j.dhjo.2017.05.005
83. Limond J, Adlam ALR, Cormack M. A Model for Pediatric Neurocognitive Interventions: Considering the Role of Development and Maturation in Rehabilitation Planning. *Clinical Neuropsychologist*. Feb 2014;28(2):181-198. doi:10.1080/13854046.2013.873083
84. Wharton A. Work and Family in the 21st Century: Four Research Domains. *Sociology Compass*. 2012;6(3):219-235.

85. Rashid M, Mabood N, Goetz H, Damanhoury S. The impact of pediatric traumatic brain injury (TBI) on family functioning: A systematic review. *Journal of Pediatric Rehabilitation Medicine: An interdisciplinary approach*. 2014;7:241-254.
86. Stenberg M, Stålnacke B-M, Saveman B-I. Family experiences up to seven years after a severe traumatic brain injury—family interviews. *Disability and Rehabilitation*. 2022-02-13 2022;44(4):608-616. doi:10.1080/09638288.2020.1774668
87. Kwan C, Gitimoghaddam M, Collet J-P. Effects of Social Isolation and Loneliness in Children with Neurodevelopmental Disabilities: A Scoping Review. *Brain Sciences*. 2020-10-28 2020;10(11):786. doi:10.3390/brainsci10110786
88. Aitken ME, McCarthy ML, Slomine BS, et al. Family burden after traumatic brain injury in children. Comparative Study Multicenter Study Research Support, N.I.H., Extramural. *Pediatrics*. Jan 2009;123(1):199-206. doi:https://dx.doi.org/10.1542/peds.2008-0607
89. Allonsius F, De Kloet A, Van Markus-Doornbosch F, et al. Parent-reported family impact in children and young adults with acquired brain injury in the outpatient rehabilitation setting. *Brain Injury*. 2021;35(5):563-573.
90. de Kloet A, Lambregts S, Berger M, van Markus F, Wolterbeek R, Vliet Vlieland T. Family impact of acquired brain injury in children and youth. *Journal of Developmental & Behavioral Pediatrics*. 2015;36(5):342-351.
91. Manning J, Hemingway P, Redsell S. Long-term psychosocial impact reported by childhood critical illness survivors: a systematic review. *Nursing in critical care*. 2014;19(3):145-156.
92. Lundine JP, Ciccio AH, Koterba C, Guernon A. Factors that Influence Follow-Up Care for Families of Children with Acquired Brain Injury: A Scoping Review. *Brain Injury*. 2022-03-21 2022;36(4):469-478. doi:10.1080/02699052.2022.2051741
93. Zonfrillo MR, Haarbauer-Krupa J, Wang J, et al. Effect of parental education and household poverty on recovery after traumatic brain injury in school-aged children. *Brain Injury*. 2021-09-19 2021;35(11):1371-1381. doi:10.1080/02699052.2021.1972141
94. Roscigno C, Swanson K. Parents' experiences following children's moderate to severe traumatic brain injury: A clash of cultures. *Qualitative Health Research*. 2011;21(10):1413-1426.
95. Kirk S, Fallon D, Fraser C, Robinson G, Vassallo G. Supporting parents following childhood traumatic brain injury: a qualitative study to examine information and emotional support needs across key care transitions. *Child Care Health and Development*. Mar 2015;41(2):303-313. doi:10.1111/cch.12173
96. Zaidman EA, Scott KM, Hahn D, Bennett P, Caldwell PH. Impact of parental health literacy on the health outcomes of children with chronic disease globally: A systematic review. *Journal of Paediatrics and Child Health*. 2023-01-01 2023;59(1):12-31. doi:10.1111/jpc.16297

97. Eller LS, Lev EL, Yuan C, Watkins AV. Describing Self - Care Self - Efficacy: Definition, Measurement, Outcomes, and Implications. *International Journal of Nursing Knowledge*. 2018-01-01 2018;29(1):38-48. doi:10.1111/2047-3095.12143
98. Emerson E, Giallo R. The wellbeing of siblings of children with disabilities. *Research in Developmental Disabilities*. 2014;35:2085 - 2092.
99. Hartling L, Milne A, Tjosvold L, Wrightson D, Gallivan J, Newton AS. A systematic review of interventions to support siblings of children with chronic illness or disability. *Journal of Paediatrics and Child Health*. 2014-10-01 2014;50(10):E26-E38. doi:10.1111/j.1440-1754.2010.01771.x
100. Montgomery V, Oliver R, A. R, Fallat M. The Effect of Severe Traumatic Brain Injury on the Family. *The Journal of Trauma, Injury, Infection and Critical Care*. 2002;52(1121-1124)
101. Manning J, Hemingway P, Redsell S. Survived so what? Identifying priorities for research with children and families post-paediatric intensive care unit. *Nursing in Critical Care*. 2017;doi:10.1111/nicc.12298
102. Luymes N, Fletcher P, Bryden P. Evaluating the Needs of Families Raising Children With and Without Disabilities: Focus on Physical Activity. *International Journal of Disability, Development and Education*. 2023-09-19 2023;70(6):911-929. doi:10.1080/1034912x.2021.1931816
103. Bloemen MAT, Backx FJG, Takken T, et al. Factors associated with physical activity in children and adolescents with a physical disability: a systematic review. *Developmental Medicine & Child Neurology*. 2015-02-01 2015;57(2):137-148. doi:10.1111/dmcn.12624
104. Shen J, Zhao S, Horn T, et al. Family matters: A systematic review and meta-analysis on the efficacy of family-oriented interventions for children with acquired brain injuries. *Clinical Psychology Review*. 2023;99doi:10.1016/j.cpr.2022.102218
105. Morelli M, Cattelino E, Baiocco R, et al. Parents and Children During the COVID-19 Lockdown: The Influence of Parenting Distress and Parenting Self-Efficacy on Children's Emotional Well-Being. *Frontiers in Psychology*. 2020-10-06 2020;11doi:10.3389/fpsyg.2020.584645
106. Toseeb U, Asbury K, Code A, Fox L, Deniz E. Supporting Families with Children with Special Educational Needs and Disabilities during COVID-19. PsyArXiv: University of York; 2020.
107. Masi A, Diaz A, Tully L, et al. Impact of the Covid-19 pandemic on the well-being of children with neurodevelopment disabilities and their parents. *Journal of Paediatrics and Child Health*. 2021;doi:10.1111/jpc.15285
108. Aishworiya R, Kang Y. Including children with developmental disabilities in the equation during this Covid-19 pandemic. *Journal of Autism and Developmental Disorders*. 2020;doi:doi.org/10.1007/s10803-020-04670-6

109. Bova S, Basso M, Bianchi M, et al. Impact of COVID-19 lockdown in children with neurological disorders in Italy. *Disability and Health Journal*. 2020;doi:doi.org/10.1016/j.dhjo.2020.101053
110. Dan B. Postmodern family-centred care for disability. *Developmental Medicine and Child Neurology*. 2021;63(7)doi:10.1111/dmcn.14905
111. Uniacke S, Browne T, Shields L. How should we understand family-centred care? *Journal of Child Health Care*. 2018;22(3):460-469.
112. Stucki G, Bickenbach J. Health, Functioning, and Well-being: Individual and Societal. *Archives of physical medicine and rehabilitation*. 2019;100(9):1788-1792. doi:10.1016/j.apmr.2019.03.004
113. Karimi M, Brazier J. Health, Health-Related Quality of Life, and Quality of Life: What is the Difference? *PharmacoEconomics*. 2016;34:645-649.
114. World Health Organization. WHOQOL User Manual. Geneva: WHO; 2012.
115. Healthy People 2020. Health-Related Quality of Life and Well-Being. Office of Disease Prevention and Health Promotion. <https://www.healthypeople.gov/2020/about/foundation-health-measures/Health-Related-Quality-of-Life-and-Well-Being>
116. Wu X, Han L, Zhang J, Luo S, Hu J, Sun K. The influence of physical activity, sedentary behaviour on health-related quality of life among the general population of children and adolescents: A systematic review. *PLoS ONE*. 2017;12(11):e0187668.
117. McCarron R, Watson S, Gracey F. What do Kids with Acquired Brain Injury Want? Mapping Neuropsychological Rehabilitation Goals to the International Classification of Functioning, Disability and Health. *Journal of the International Neuropsychological Society*. 2019;25:403-412.
118. The NHS Long Term Plan (NHS) (2019).
119. UK Parliament. Health and Care Bill. <https://www.legislation.gov.uk/ukpga/2022/31/contents/enacted>
120. Wade DT. What is rehabilitation? An empirical investigation leading to an evidence-based description. *Clinical rehabilitation*. 2020;34(5):571-583. doi:10.1177/0269215520905112
121. British Society of Rehabilitation Medicine. Specialist Neuro-Rehabilitation Services: Providing for Patients with Complex Rehabilitation Needs BSRM core standards for specialist rehabilitation. 2023. <https://www.bsprm.org.uk/resources/guideline-documents/>
122. Diener M, Kirby A, Sumsion F, Canary H, Green M. Community reintegration needs following paediatric brain injury: perspectives of caregivers and service providers. *Disability and Rehabilitation*. 2022;44(19):5592-5602.

123. Botchway-Commey E, Mascara F, Greenham M, et al. Rehabilitation models of care for children and youth with traumatic brain and/or spinal cord injuries: a focus on service structure, service organisation, and barriers and facilitators of rehabilitation service provision. *Neuropsychological rehabilitation*. 2022;doi:10.1080/09602011.2022.2147196
124. Haarbauer-Krupa J, Ciccio A, Dodd J, et al. Service delivery in the healthcare and educational systems for children following traumatic brain injury: gaps in care. *Journal of Head Trauma Rehabilitation*. 2017;32(6):367-377. doi:10.1097/HTR.0000000000000287
125. Regional Major Trauma Network. *Regional Major Trauma Network Peer Review Visit Report*. 2014.
126. House of Commons Committee of Public Accounts. *NHS specialised services: Tenth Report of Session 2016-17*. 2016. Accessed 15/03/17. <https://www.publications.parliament.uk/pa/cm201617/cmselect/cmpubacc/387/38702.htm>
127. Hamilton C, Maw A, Gill A, Brahmhatt M, Phaal R, Pickard J. Paediatric neurorehabilitation: finding and filling the gaps through the use of the Institute for Manufacturing strategic roadmapping method. *BMJ Innov*. 2017;doi:10.1136/bmjinniv-2017-000202
128. NHS England. *Commissioning Guidance for Rehabilitation*. 2016. Accessed 09/07/17. <https://www.england.nhs.uk/wp-content/uploads/2016/04/rehabilitation-comms-guid-16-17.pdf>
129. Department of Health. *The Government's mandate to NHS England for 2016-17*. 2017. Accessed 28/07/17. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/600604/NHSE\\_Mandate\\_2016-17.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/600604/NHSE_Mandate_2016-17.pdf)
130. Turner-Stokes L, Williams H, Bill A, Bassett P, Sephton K. Cost-efficiency of specialist inpatient rehabilitation for working-aged adults with complex neurological disabilities: a multicentre cohort analysis of a national clinical data set. *BMJ Open*. 2016;6(e010238) doi:10.1136/bmjopen-2015-010238
131. Turner-Stokes L. Evidence for the effectiveness of multi-disciplinary rehabilitation following acquired brain injury: a synthesis of two systematic approaches. *Journal of Rehabilitation Medicine*. 2008;40:691-701.
132. Badge H, Hancock J, Waugh M-C. Evaluating paediatric brain injury services in NSW. *Child: care, health and development*. 2009;36(1):54-62.
133. Skivington K, Matthews L, Simpson SA, et al. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. *BMJ*. Sep 30 2021;374:n2061. doi:10.1136/bmj.n2061
134. Nilsen P. Making sense of implementation theories, models and frameworks. *Implementation Science*. 2015;10(53)doi:10.1186/s13012-015-0242-0

135. Guyatt S, Ferguson M, Beckmann M, Wilkinson S. Using the Consolidated Framework for Implementation Research to design and implement a perinatal education program in a large maternity hospital. *BMC Health Services Research*. 2021;21doi:10.1186/s12913-021-07024-9
136. Atkins L, Francis J, Islam R, et al. A guide to using the Theoretical Domains Framework of behaviour change to investigate implementation problems. *Implementation Science*. 2017;12(77)doi:10.1186/s13012-017-0605-9
137. O'Cathain A, Croot L, Duncan E, et al. Guidance on how to develop complex interventions to improve health and healthcare. *BMJ Open*. 2019;9:e029954. doi:10.1136/bmjopen-2019-029954
138. Williams TS, Deotto A, Roberts SD, Ford MK, Désiré N, Cunningham S. COVID-19 mental health impact among children with early brain injury and associated conditions. *Child neuropsychology*. 2022;28(5):627-648. doi:10.1080/09297049.2021.1998407
139. Pollock A, D'Cruz K, Schoenberg A, et al. Family-centred care for children with traumatic brain injury and/or spinal cord injury: a qualitative study of service provider perspectives during the COVID-19 pandemic. *BMJ Open*. 2022;12(e059534)doi:10.1136/bmjopen-2021-059534
140. Levac D, DeMatteo C. Bridging the gap between theory and practice: Dynamic systems theory as a framework for understanding and promoting recovery of function in children and youth with acquired brain injuries. *Physiotherapy theory and practice*. 2009;25(8):544-554. doi:10.3109/09593980802667888
141. Colquhoun H, Levac D, O'Brien K, et al. Scoping reviews: time for clarity in definition, methods, and reporting. *Journal of Clinical Epidemiology*. 2014;67:1291-1294.
142. Munn Z, Peters MDJ, Stern C, Tufanaru C, McArthur A, Aromataris E. Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Medical Research Methodology*. 2018-12-01 2018;18(1)doi:10.1186/s12874-018-0611-x
143. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*. 2005-02-01 2005;8(1):19-32. doi:10.1080/1364557032000119616
144. Peters M, Godfrey C, McInerney P, Baldini Soares C, Khalil H, Parker D. Aromataris E, Munn Z, eds. *Chapter 11: Scoping Reviews*. In: *Joanna Briggs Institute Reviewer's Manual*. . The Joanna Briggs Institute; 2017. Accessed 2/5/18. Available from <https://reviewersmanual.joannabriggs.org>
145. Terry G, Hayfield N, Clarke V, Braun V. Thematic Analysis. In: Willig C, Stainton Rogers W, eds. *The SAGE Handbook of Qualitative Research in Psychology*. SAGE Publications Ltd; 2017.

146. Limond J, Dorris L, McMillan T. Quality of life in children with acquired brain injury: Parent perspectives 1-5 years after injury. *Brain Injury*. 2009;23(7-8):617-622.
147. Chevignard M, Toure H, Brugel D, Poirier J, Laurent-Vannier A. A comprehensive model of care for rehabilitation of children with acquired brain injuries. *Child: care, health and development*. 2009;36(1):31-43.
148. French B, Leathley M, Radford K, et al. *UK Stroke Survivor Needs Survey Information Mapping Exercise: Report to the Stroke Association*. 2009.
149. Savage R, Depompei R, Tyler J, Lash M. Paediatric traumatic brain injury: A review of pertinent issues. *Pediatric Rehabilitation*. 2005;8(2):92-103.
150. Aukema EJ, Last BF, Nettek Schouten-van Meeteren AY, Grootenhuis MA. Explorative study on the aftercare of pediatric brain tumour survivors: a parents' perspective. *Support Care Cancer*. 2011;19:1637-1646.
151. Hermans E, Winkens I, Winkel-Witlox ST, van Iperen A. Caregiver reported problems of children and families 2-4 years following rehabilitation for pediatric brain injury. *Neurorehabilitation*. 2012;30(3):213-7. doi:<https://dx.doi.org/10.3233/NRE-2012-0747>
152. Jackson AC, Stewart H, O'Toole M, et al. Pediatric brain tumor patients: their parents' perceptions of the hospital experience. Research Support, Non-U.S. Gov't. *Journal of Pediatric Oncology Nursing*. Mar-Apr 2007;24(2):95-105.
153. Karver CL, Kurowski B, Semple EA, et al. Utilization of behavioral therapy services long-term after traumatic brain injury in young children. Research Support, N.I.H., Extramural Research Support, Non-U.S. Gov't. *Archives of Physical Medicine & Rehabilitation*. Aug 2014;95(8):1556-63. doi:<https://dx.doi.org/10.1016/j.apmr.2014.03.030>
154. Massey S, Fisher K, Croker A, Smith T. Collaboration across the health care and education interface: what is it like for teachers of children with traumatic brain injury? Research Support, Non-U.S. Gov't. *Australian Journal of Primary Health*. 2015;21(1):74-8. doi:<https://dx.doi.org/10.1071/PY13035>
155. Roscigno CI, Swanson KM, Vavilala MS, Solchany J. Longing for everydayness: life after traumatic brain injury in children. Research Support, N.I.H., Extramural Research Support, Non-U.S. Gov't. *Brain Injury*. 2011;25(9):882-894.
156. Soanes L, Hargrave D, Smith L, Gibson F. What are the experiences of the child with a brain tumour and their parents? *European Journal of Oncology Nursing*. Sep 2009;13(4):255-61. doi:<https://dx.doi.org/10.1016/j.ejon.2009.03.009>

157. Soo C, Tate RL, Williams L, Waddingham S, Waugh MC. Development and validation of the Paediatric Care and Needs Scale (PCANS) for assessing support needs of children and youth with acquired brain injury. Research Support, Non-U.S. Gov't Validation Studies. *Developmental neurorehabilitation*. Jul 2008;11(3):204-14. doi:<https://dx.doi.org/10.1080/17518420802259498>
158. Swaine BR, Gagnon I, Champagne F, et al. Identifying the specific needs of adolescents after a mild traumatic brain injury: a service provider perspective. Research Support, Non-U.S. Gov't. *Brain Injury*. Jul 2008;22(7-8):581-8. doi:<https://dx.doi.org/10.1080/02699050802189701>
159. Vilela T, Phillips M, Minnes P. A comparison of challenges faced by parents of children with ABI with and without access to third party funding. *Developmental Neurorehabilitation*. 2008;11(2):149-158. doi:10.1080/17518420701780115
160. McKinlay A, McLellan T, Daffue C. The invisible brain injury: the importance of identifying deficits following brain injury in children with intellectual disability. Case Reports Research Support, Non-U.S. Gov't. *Neurorehabilitation*. 2012;30(3):183-7. doi:<https://dx.doi.org/10.3233/NRE-2012-0743>
161. Gagnon A, Lin J, Stergiou-Kita M. Family members facilitating community re-integration and return to productivity following traumatic brain injury – motivations, roles and challenges. *Disability and Rehabilitation*. 2016-02-27 2016;38(5):433-441. doi:10.3109/09638288.2015.1044035
162. World Health Organisation. Adolescent Health. [http://www.who.int/topics/adolescent\\_health/en/](http://www.who.int/topics/adolescent_health/en/)
163. Boylan A, Linden M, Alderdice F. Interviewing children with Acquired Brain Injury (ABI). *Journal of early childhood research*. 2009;7(3):264-282.
164. O'Reilly M, Ronzoni P, Dogra N. *Research with Children: Theory and Practice*. SAGE Publications Ltd; 2013.
165. van Heugten C, Renaud I, Resch C. The role of early intervention in improving the level of activities and participation in youths after mild traumatic brain injury: a scoping review. *Concussion*. 2017;2(3)doi:<https://doi.org/10.2217/cnc-2016-0030>
166. Pearson A, White H, Bath-Hextall F, Apostolo J, Salmond S, Kirkpatrick P. *The Joanna Briggs Institute Reviewers' Manual 2014: Methodology for JBI Mixed Methods Systematic Reviews*. The Joanna Briggs Institute; 2014.
167. Huang X, O'Connor M, Ke L-S, Lee S. Ethical and methodological issues in qualitative health research involving children: A systematic review. *Nursing ethics*. 2016;23(3):339-356. doi:10.1177/0969733014564102
168. Mah K, Gladstone B, King G, Reed N, Hartman LR. Researching experiences of childhood brain injury: co-constructing knowledge with



- children through arts-based research methods. *Disability and rehabilitation*. 2020;42(20):2967-2976.  
doi:10.1080/09638288.2019.1574916
169. Health and Care Professions Council. Standards of Proficiency - Physiotherapists. London, UK: Health and Care Professions Council; 2023.
  170. Clark A, Flewitt R, Hammersley M, Robb M. *Understanding Research with Children and Young People*. SAGE Publications Ltd; 2014.
  171. NSPCC. Social media and online safety. NSPCC. Accessed 02.07.20, <https://learning.nspcc.org.uk/safeguarding-child-protection/social-media-and-online-safety>
  172. Angell C, Alexander J, Hunt JA. 'Draw, write and tell': A literature review and methodological development on the 'draw and write' research method. *Journal of Early Childhood Research*. 2015-02-01 2015;13(1):17-28. doi:10.1177/1476718x14538592
  173. Berger R. Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qualitative Research*. 2015;15(2):219-234.
  174. Call-Cummings M, Ross K. Re-positioning Power and Re-imagining Reflexivity: Examining Positionality and Building Validity Through Reconstructive Horizon Analysis. In: Strunk K, Locke L, eds. *Research methods for social justice and equity in education*. Palgrave MacMillan; 2019.
  175. Creswell J, Creswell J. *Research Design: Qualitative, Quantitative and Mixed Methods Approaches*. 5th edition ed. SAGE Publications Ltd.; 2018.
  176. Walker S, Read S, Priest H. Use of reflexivity in a mixed-methods study. *Nurse Res*. Jan 2013;20(3):38-43. doi:10.7748/nr2013.01.20.3.38.c9496
  177. Cain LK, MacDonald AL, Coker JM, Velasco JC, West GD. Ethics and Reflexivity in Mixed Methods Research: An Examination of Current Practices and a Call for Further Discussion. *International journal of multiple research approaches*. 2019;11(2):144-155. doi:10.29034/ijmra.v11n2a2
  178. Green J, Thorogood N. *Qualitative Methods for Health Research*. 2nd ed. SAGE Publications Ltd; 2009.
  179. Saldaña J. *The Coding Manual for Qualitative Researchers*. 3rd ed. SAGE Publications Ltd; 2016.
  180. Phillippi J, Lauderdale J. A Guide to Field Notes for Qualitative Research: Context and Conversation. *Qual Health Res*. Feb 2018;28(3):381-388. doi:10.1177/1049732317697102
  181. National Institute for Health and Care Research. Briefing notes for researchers - public involvement in NHS, health and social care research. NIHR. Accessed 09/02/24, <https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371>

182. Liabo K, Boddy K, Bortoli S, et al. Public involvement in health research: what does 'good' look like in practice? *Research Involvement and Engagement*. 2020-12-01 2020;6(1)doi:10.1186/s40900-020-0183-x
183. Doyle L, Brady A-M, Byrne G. An overview of mixed methods research - revisited. *Journal of Research in Nursing*. 2016;21(8):623-635.
184. Allemang B, Sitter K, Dimitropoulos G. Pragmatism as a paradigm for patient-oriented research. *Health Expect*. Feb 2022;25(1):38-47. doi:10.1111/hex.13384
185. French SD, Green SE, O'Connor DA, et al. Developing theory-informed behaviour change interventions to implement evidence into practice: a systematic approach using the Theoretical Domains Framework. *Implementation Science*. 2012-12-01 2012;7(1):38. doi:10.1186/1748-5908-7-38
186. Cox JS, Searle A, Thornton G, Hamilton-Shield JP, Hinton EC. Integrating COM-B and the person-based approach to develop an ACT based therapy programme to raise self-determination in adolescents with obesity. *BMC Health Services Research*. 2023-10-26 2023;23(1)doi:10.1186/s12913-023-09930-6
187. Easton S, Ainsworth B, Thomas M, et al. Planning a digital intervention for adolescents with asthma (BREATHE4T): A theory-, evidence- and Person-Based Approach to identify key behavioural issues. *Pediatric Pulmonology*. 2022-11-01 2022;57(11):2589-2602. doi:10.1002/ppul.26099
188. Band R, Bradbury K, Morton K, et al. Intervention planning for a digital intervention for self-management of hypertension: a theory-, evidence- and person-based approach. *Implementation Science*. 2017-12-01 2017;12(1)doi:10.1186/s13012-017-0553-4
189. Bradbury K, Morton K, Band R, et al. Using the Person-Based Approach to optimise a digital intervention for the management of hypertension. *PLOS ONE*. 2018-05-03 2018;13(5):e0196868. doi:10.1371/journal.pone.0196868
190. Yardley L, Morrison L, Bradbury K, Muller I. The person-based approach to intervention development: application to digital health-related behavior change interventions. *J Med Internet Res*. Jan 30 2015;17(1):e30. doi:10.2196/jmir.4055
191. Person-Based Approach. The Person-Based Approach for developing health interventions. Person-Based Approach. Accessed 01.06.23, [https://personbasedapproach.org/pba\\_diagram.html](https://personbasedapproach.org/pba_diagram.html)
192. Michie S, van Stralen M, West R. The behaviour change wheel: A new method characterising and designing behaviour change interventions. *Implementation Science*. 2011;6(42)
193. Michie S, Atkins L, West R. *The Behaviour Change Wheel: A guide to designing interventions*. Silverback Publishing; 2014.

194. Reid H, Smith R, Williamson W, et al. Use of the behaviour change wheel to improve everyday person-centred conversations on physical activity across healthcare. *BMC Public Health*. Sep 20 2022;22(1):1784. doi:10.1186/s12889-022-14178-6
195. Cane J, O'Connor D & Michie S. Validation of the theoretical domains framework for use in behaviour change and implementation research. *Implementation science* : 2012;7, 37-37.
196. Kettlewell J, Phillips J, Radford KA. & Das Nair R. Informing evaluation of a smartphone application for people with acquired brain injury: a stakeholder engagement study. *BMC Medical Informatics and Decision Making*. 2018;18:33 doi.org/10.1186/s12911-018-0611-0
197. Ojo SO, Bailey DP, Brierley ML, Hewson DJ & Chater AM. Breaking barriers: Using the behavior change wheel to develop a tailored intervention to overcome workplace inhibitors to breaking up sitting time. *BMC public health*, 2019;19, 1126-17.
198. Murtagh EM, Barnes AT, McMullen J, Morgan PJ. Mothers and teenage daughters walking to health: using the behaviour change wheel to develop an intervention to improve adolescent girls' physical activity. *Public Health*. May 2018;158:37-46. doi:10.1016/j.puhe.2018.01.012
199. Truelove S, Vanderloo LM, Tucker P, Di Sebastiano KM, Faulkner G. The use of the behaviour change wheel in the development of ParticipACTION's physical activity app. *Prev Med Rep*. Dec 2020;20:101224. doi:10.1016/j.pmedr.2020.101224
200. Brown MC, Podmore M, Araújo-Soares V, Skinner R, Sharp L. Childhood cancer survivors' perceptions of the barriers and facilitators to physical activity: a systematic review and thematic synthesis of qualitative evidence using the theoretical domains framework. *Health psychology review*, 2023;17, 277-300.
201. Gingrich N, Bosancich J, Schmidt J, Sakakibara BM. Capability, opportunity, motivation, and social participation after stroke. *Top Stroke Rehabil*. Jul 2023;30(5):423-435. doi:10.1080/10749357.2022.2070358
202. Christie LJ, Rendell R, McCluskey, A, Fearn, N, Hunter, A, Lovarini, M. Adult experiences of constraint-induced movement therapy programmes: a qualitative study using the Theoretical Domains Framework and Capability, Opportunity, Motivation – Behaviour system. *Brain impairment*, 2023;24, 274-289.
203. Cantwell M, Walsh D, Furlong B, Moyna N, McCaffrey N, Woods C. The Development of the MedEx IMPACT Intervention: A Patient-Centred, Evidenced-Based and Theoretically-Informed Physical Activity Behaviour Change Intervention for Individuals Living With and Beyond Cancer. *Cancer Control*. 2020;27:1-14. doi:10.1177/1073274820906124
204. Richardson M, Khouja CL, Sutcliffe K, Thomas J. Using the theoretical domains framework and the behavioural change wheel in an overarching synthesis of systematic reviews. *BMJ open*. 2019;9(6):e024950-e024950. doi:10.1136/bmjopen-2018-024950

205. Fajja CL, Gellatly J, Barkham M, et al. Enhancing the Behaviour Change Wheel with synthesis, stakeholder involvement and decision-making: a case example using the 'Enhancing the Quality of Psychological Interventions Delivered by Telephone' (EQUITY) research programme. *Implementation science* : IS. 2021;16(1):53-53. doi:10.1186/s13012-021-01122-2
206. Feters MD, Curry LA, Creswell JW. Achieving integration in mixed methods designs-principles and practices. *Health Serv Res*. Dec 2013;48(6 Pt 2):2134-56. doi:10.1111/1475-6773.12117
207. Regnault A, Willgoss T, Barbic S, (SIG) ISfQoLRIMMSIG. Towards the use of mixed methods inquiry as best practice in health outcomes research. *J Patient Rep Outcomes*. 2017;2(1):19. doi:10.1186/s41687-018-0043-8
208. Glogowska M. Paradigms, pragmatism and possibilities: mixed-methods research in speech and language therapy. *Int J Lang Commun Disord*. 2011;46(3):251-60. doi:10.3109/13682822.2010.507614
209. Creswell JW, Hirose M. Mixed methods and survey research in family medicine and community health. *Family Medicine and Community Health*. 2019-03-01 2019;7(2):e000086. doi:10.1136/fmch-2018-000086
210. Bowling A. *Research Methods in Health: Investigating health and health services*. McGraw-Hill Education; 2014.
211. McCauley SR, Wilde EA, Anderson VA, et al. Recommendations for the Use of Common Outcome Measures in Pediatric Traumatic Brain Injury Research. *Journal of neurotrauma*. 2012;29(4):678-705. doi:10.1089/neu.2011.1838
212. Gibson JE. Interviews and Focus Groups With Children: Methods That Match Children's Developing Competencies. *Journal of family theory & review*. 2012;4(2):148-159. doi:10.1111/j.1756-2589.2012.00119.x
213. Ritchie J, Lewis J, McNaughton Nicholls C, Ormiston R. *Qualitative Research: A guide for social science students and researchers*. 2nd ed. SAGE Publications Ltd; 2014.
214. Health Research Authority. Information Governance. <https://www.hra.nhs.uk/about-us/governance/information-governance/>
215. Gale N, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*. 2013;13
216. Lawton R, Heyhoe J, Louch G, et al. Using the Theoretical Domains Framework (TDF) to understand adherence to multiple evidence-based indicators in primary care: a qualitative study. *Implementation Science*. 2016;11doi:10.1186/s13012-016-0479-2
217. Muller I, Santer M, Morrison L, et al. Combining qualitative research with PPI: reflections on using the person-based approach for developing behavioural interventions. *Research Involvement and Engagement*. 2019-12-01 2019;5(1)doi:10.1186/s40900-019-0169-8

218. Santillo M, Morton K, Velthoven MHV, et al. Improving intervention development and implementation using the Person-Based Approach (PBA) to co-participatory stakeholder engagement: a worked example of a behavioural intervention to improve asthma reviews in primary care. *Research Square Platform LLC*; 2023.
219. Haines ER, Dopp A, Lyon AR, et al. Harmonizing evidence-based practice, implementation context, and implementation strategies with user-centered design: a case example in young adult cancer care. *Implementation science communications*. 2021;2(1):45-45. doi:10.1186/s43058-021-00147-4
220. Greenwell K, Ghio D, Sivyer K, et al. Eczema Care Online: development and qualitative optimisation of an online behavioural intervention to support self-management in young people with eczema. *BMJ open*. 2022;12(4):e056867-e056867. doi:10.1136/bmjopen-2021-056867
221. Keetley R, Radford K, Manning JC. A scoping review of the needs of children and young people with acquired brain injuries and their families. *Brain injury*. 2019;33(9):1117-1128. doi:10.1080/02699052.2019.1637542
222. Jenkin T, Anderson V, D'Cruz K, Scheinberg A, Knight S. Family-centred service in paediatric acquired brain injury rehabilitation: Bridging the gaps. *Frontiers in Rehabilitation Sciences*. 2022;3(1085967)doi:10.3389/fresc.2022.1085967
223. World Health Organisation. *Draft Intersectional Global Action Plan on Epilepsy and the Neurological Disorders 2022-2031, Seventy-Fifth World Health Assembly*. 2022. Accessed 21/07/22. [https://apps.who.int/gb/ebwha/pdf\\_files/WHA75/A75\\_10Add4-en.pdf](https://apps.who.int/gb/ebwha/pdf_files/WHA75/A75_10Add4-en.pdf)
224. Jones B, Woolfenden S, Pengilly S, et al. COVID-19 pandemic: The impact on vulnerable children and young people in Australia. *Journal of Paediatrics and Child Health*. 2020;56:1851-1855.
225. Pye V, Taylor N, Clay-Williams R, Braithwaite J. When is enough, enough? Understanding and solving your sample size problems in health services research. *BMC Res Notes*. 2016;9(90):1-7. doi:10.1186/s13104-016-1893-x
226. Bedell G. The Child and Adolescent Scale of Participation - Youth Version. Tufts University. <http://sites.tufts.edu/garybedell/measurement-tools/>
227. Varni J. Pediatric Quality of Life Inventory. PedsQL. Accessed 31.01.20, [http://www.pedsq.org/about\\_pedsq.html](http://www.pedsq.org/about_pedsq.html)
228. Kroenke K, Spitzer R, Williams JB, Löwe B. An ultra-brief screening scale for anxiety and depression: the PHQ-4. *Psychosomatics*. 2009;50:613-621.
229. De Bock F, Bosle C, Graef C, Oepen J, Phillippi H, Urschitz M. Measuring social participation in children with chronic health conditions: validation and reference values of the child and adolescent scale of participation (CASP) in the German context. *BMC Pediatrics*. 2019;19(125):1-13. doi:10.1186/s12887-019-1495-6

230. Upton P, Eiser C, Cheung I, et al. Measurement properties of the UK-English version of the Pediatric Quality of Life Inventory™ 4.0 (PedsQL™) generic core scales. *Health and Quality of Life Outcomes*. 2005;3(22)doi:10.1186/1477-7525-3-22
231. Medrano G, Berlin K, Davies H. Utility of the PedsQL™ family impact module: assessing the psychometric properties in a community sample. *Quality of Life Research*. 2013;22(10):2899-2907.
232. Löwe B, Wahl I, Rose M, et al. A 4-item measure of depression and anxiety: Validation and standardisation of the Patient Health Questionnaire-4 (PHQ-4) in the general population. *Journal of Affective Disorders*. 2010;122:86-95.
233. McCarthy M, MacKenzie E, Durbin D, et al. The Pediatric Quality of Life Inventory: An evaluation of its reliability and validity for children with traumatic brain injury. *Arch Phys Med Rehabil*. 2005;86:1901-1909.
234. Câmara-Costa H, Francillette L, Opatowski M, et al. Participation seven years after severe childhood traumatic brain injury. *Disability and Rehabilitation*. 2020;42(17):2402-2411.
235. Jenkin T, D'Cruz K, Anderson V, Scheinberg A, Knight S. Family-centred service in paediatric acquired brain injury rehabilitation: perspectives of children and adolescents and their families. *Disability and Rehabilitation*. 2022;doi:10.1080/09638288.2022.2121864
236. Green L, Godfrey C, Soo C, Anderson V, Catroppa C. A preliminary investigation into psychosocial outcome and quality-of-life in adolescents following childhood traumatic brain injury. *Brain Injury*. 2013;27(7-8):872-877. doi:10.3109/02699052.2013.775506
237. Tremblay S, Lal S, Xiang L, Ferro M, Anaby D. Organisation of rehabilitation services for youth with physical disabilities and mental health problems: a scoping review. *Frontiers in Rehabilitation Sciences*. 2023;4:1085827. doi:10.3389/fresc.2023.1085827
238. Hickey L, Anderson V, Jordan B. Australian parent and sibling perspectives on the impact of paediatric acquired brain injury on family relationships during the first 6 weeks at home. *Health & Social Care in the Community*. 2022;00:1-9. doi:https://doi.org/10.1111/hsc.13938
239. Analytis P, Warren N, Crichton A, Knight S, Ponsford J. Coping and wellbeing in families with a child with acquired brain injury compared with families in the community. *Disability and Rehabilitation*. 2022;44(25):7993-8000. doi:10.1080/09638288.2021.2008522
240. Teel E, Caron J, Gagnon I. Higher parental stress is significantly related to longer clinical recovery times in concussed children: A mixed-methods study. *Journal of Science and Medicine in Sport*. 2022:108-114. doi:10.1016/j.jsams.2021.08.014
241. Vallee M, Chevignard M, Boissel A. The impact of childhood acquired brain injury on siblings: a scoping review. *Brain Injury*. 2023;doi:10.1080/02699052.2023.2184870
242. Jenkin T, Anderson V, D-Cruz K, et al. Engaging children and adolescents with acquired brain injury and their families in goal setting:

- The clinician perspective. *Neuropsychological Rehabilitation*. 2022;32(1):104-130. doi:10.1080/09602011.2020.1801470
243. Janssens A, Williams J, Tomlinson R, Logan S, Morris C. Health outcomes for children with neurodisability: what do professionals regard as primary targets? *Arch Dis Child*. 2014;99:927-932. doi:10.1136/archdischild-2013-305803
  244. Kelly G, Dunford C, Forsyth R, Kavčič A. Using child- and family-centred goal setting as an outcome measure in residential rehabilitation for children and youth with acquired brain injuries: the challenge of predicting expected levels of achievement. *Child Care Health Dev*. 2019;45:286-291.
  245. Lester A, Leach P, Zaben M. The impact of the COVID-19 pandemic on traumatic brain injury management: Lessons learned over the first year. *World Neurosurgery*. 2021;156:28-32. doi:10.1016/j.wneu.2021.09.030
  246. Toomey S, Elliott M, Zaslavsky A, et al. Improving response rates and representation of hard-to-reach groups in family experience surveys. *Academic Pediatrics*. 2019;19(4):446-453.
  247. Dewan M, Mummareddy N, Wellons III J, Bonfield C. Epidemiology of Global Pediatric Traumatic Brain Injury: Qualitative Review. *World Neurosurgery*. 2016;91:497-509. doi:10.1016/j.wneu.2016.03.045
  248. Anaby D, Law M, Hanna S, Dematteo C. Predictors of change in participation rates following acquired brain injury: results of a longitudinal study. *Developmental Medicine and Child Neurology*. Apr 2012;54(4):339-346. doi:10.1111/j.1469-8749.2011.04204.x
  249. Wales L, Davis K, Kelly G, Lynott H. Long term participation outcomes for severe acquired brain injury in childhood - an expanded scoping review. *Developmental Neurorehabilitation*. 2021;24(6):379-387. doi:10.1080/175184423.2021.1886191
  250. Keetley R, Manning J, Williams J, Stewart I, Radford K. Child and family health-related quality of life and participation outcomes and goals after acquired brain injury: a cross-sectional survey. *Brain Injury*. 2024;doi:10.1080/02699052.2024.2309244
  251. McLaughlin J, Coleman-Fountain E. The unfinished body: the medical and social reshaping of disabled young bodies. *Soc Sci Med*. 2014;120(76-84)
  252. King G, Imms C, Stewart D, Freeman M, Nguyen T. A transactional framework for pediatric rehabilitation: shifting the focus to situated contexts, transactional processes, and adaptive developmental outcomes. *Disability and Rehabilitation*. 2018;40(15):1829-1841.
  253. Batorowicz B, King G, Mishra L, Mission C. An integrated model of social environment and social context for paediatric rehabilitation. *Disability and Rehabilitation*. 2016;38(12):1204-1215.
  254. Wade D. Measurement in neurological rehabilitation. *Curr Opin Neurol Neurosurg*. 1992;5(5):682-686.

255. Botchway E, Knight S, Muscara F, et al. Rehabilitation models of care for children and youth with traumatic brain and/or spinal cord injuries: A focus on family-centred care, psychosocial wellbeing, and transitions. *Neuropsychological Rehabilitation*. 2022;32(4):537-559.
256. Vasileiou K, Barnett J, Thorpe S, Young T. Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Med Res Methodol*. Nov 21 2018;18(1):148. doi:10.1186/s12874-018-0594-7
257. Crouchman M, Rossiter L, Colaco T, Forsyth R. A practical outcome scale for paediatric head injury. *Archives of Disease in Childhood*. 2001;84:120-124.
258. Ministry of Housing Communities and Local Government. National statistics: English indices of deprivation 2019. Accessed 11/02/21, 2021. <https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019>
259. Hudon C, Chouinard MC, Pluye P, et al. Characteristics of Case Management in Primary Care Associated With Positive Outcomes for Frequent Users of Health Care: A Systematic Review. *Ann Fam Med*. Sep 2019;17(5):448-458. doi:10.1370/afm.2419
260. Glang AE, McCart M, Slocumb J, et al. Preliminary Efficacy of Online Traumatic Brain Injury Professional Development for Educators: An Exploratory Randomized Clinical Trial. *J Head Trauma Rehabil*. 2019;34(2):77-86. doi:10.1097/HTR.0000000000000447
261. Holthe IL, Rohrer-Baumgartner N, Svendsen EJ, et al. Feasibility and Acceptability of a Complex Telerehabilitation Intervention for Pediatric Acquired Brain Injury: The Child in Context Intervention (CICI). *J Clin Med*. May 03 2022;11(9)doi:10.3390/jcm11092564
262. Kettlewell J, Lindley R, Radford K, et al. Factors Affecting the Delivery and Acceptability of the ROWTATE Telehealth Vocational Rehabilitation Intervention for Traumatic Injury Survivors: A Mixed-Methods Study. *Int J Environ Res Public Health*. Sep 16 2021;18(18)doi:10.3390/ijerph18189744
263. Alderwick H, Hutchings A, Briggs A, Mays N. The impacts of collaboration between local health care and non-health care organizations and factors shaping how they work: a systematic review of reviews. *BMC Public Health*. Apr 19 2021;21(1):753. doi:10.1186/s12889-021-10630-1
264. Fisher R, Russell L, Riley-Bennett F, Cameron T, Walker M, Sackley C. Barriers and facilitators in providing home-based rehabilitation for stroke survivors with severe disability in the UK: an online focus group study with multidisciplinary rehabilitation teams. *BMJ Open*. 2023;13:e071217. doi:10.1136/bmjopen-2022-071217
265. Gan C, Gargaro J, Kreutzer JS, Boschen KA, Wright FV. Development and preliminary evaluation of a structured family system intervention for adolescents with brain injury and their families. *Brain Injury*. 2010;24(4):651-663. doi:10.3109/02699051003692142



266. Forsyth R, Waugh MC. Paediatric brain injury – getting there from here. *Child: Care, Health and Development*. 2010-01-01 2010;36(1):1-2. doi:10.1111/j.1365-2214.2009.01044.x
267. Ogourtsova T, O'Donnell M, De Souza Silva W, Majnemer A. Health coaching for parents of children with developmental disabilities: a systematic review. *Developmental Medicine & Child Neurology*. 2019-11-01 2019;61(11):1259-1265. doi:10.1111/dmnc.14206
268. Anaby DR, Avery L, Palisano RJ, et al. Environment - based approaches to improve participation of young people with physical disabilities during COVID-19. *Developmental Medicine & Child Neurology*. 2023-12-22 2023;doi:10.1111/dmnc.15822
269. Rodriguez A, Smith J, Barrett D. Research made simple: developing complex interventions. *Evidence-based nursing*. 2020;23(2):35-37. doi:10.1136/ebnurs-2020-103261
270. Yardley L, Ainsworth B, Arden-Close E, Muller I. The person-based approach to enhancing the acceptability and feasibility of interventions. *Pilot Feasibility Stud*. 2015;1:37. doi:10.1186/s40814-015-0033-z
271. Duncan E, O'Cathain A, Rousseau N, et al. Guidance for reporting intervention development studies in health research (GUIDED): an evidence-based consensus study. *BMJ open*. 2020;10(4):e033516-e033516. doi:10.1136/bmjopen-2019-033516
272. Keetley R, Manning J, Williams J, Bennett E, Westlake M, Radford K. Understanding barriers and facilitators to long-term participation needs in children and young people following acquired brain injury: A qualitative multi-stakeholder study. *Brain Impairment*. 2024; 25, IB23100. <https://doi.org/10.1071/IB23100>
273. Hoffmann T, Glasziou P, Boutron I, et al. Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. *BMJ*. 2014;348(g1687)
274. Fadyl JK, Mcpherson KM. Approaches to vocational rehabilitation after traumatic brain injury: A review of the evidence. *The journal of head trauma rehabilitation*, 2009;24, 195-212.
275. Gardiner E, Wong V, Lin G, Miller A. Terminology and descriptions of navigation and related practices for children with neurodisability and their families: a scoping review. *BMC Health Services Research*. 2022;22doi:10.1186/s12913-022-07617-y
276. Braaf S, Ameratunga S, Christie N, et al. Care coordination experiences of people with traumatic brain injury and their family members in the 4-years after injury: a qualitative analysis. *Brain Injury*. 2019-04-16 2019;33(5):574-583. doi:10.1080/02699052.2019.1566835
277. Budde H, Williams G, Scarpetti G, Kroezen M, Maier C. *What are patient navigators and how can they improve integration of care?* 2022. <https://eurohealthobservatory.who.int/publications/i/what-are-patient-navigators-and-how-can-they-improve-integration-of-care#:~:text=The%20patient%20navigator%20role%20originated,overcome%20barriers%20to%20accessing%20services>.

278. Palisano RJ, Chiarello LA, King GA, Novak I, Stoner T, Fiss A. Participation-based therapy for children with physical disabilities. *Disability and Rehabilitation*. 2012-06-01 2012;34(12):1041-1052. doi:10.3109/09638288.2011.628740
279. Olsen JM. Health Coaching: A Concept Analysis. *Nursing Forum*. 2014-01-01 2014;49(1):18-29. doi:10.1111/nuf.12042
280. Novak I, Morgan C, Fahey M, et al. State of the Evidence Traffic Lights 2019: Systematic Review of Interventions for Preventing and Treating Children with Cerebral Palsy. *Current Neurology and Neuroscience Reports*. 2020-02-01 2020;20(2)doi:10.1007/s11910-020-1022-z
281. Anaby DR, Law M, Feldman D, Majnemer A, Avery L. The effectiveness of the Pathways and Resources for Engagement and Participation (PREP) intervention: improving participation of adolescents with physical disabilities. *Developmental medicine and child neurology*, 2018;60, 513-519.
282. Lebrault H, Martini R, Manolov R, Chavanne C, Krasny-Pacini A, Chevignard M. Cognitive Orientation to daily Occupational Performance to improve occupational performance goals for children with executive function deficits after acquired brain injury. *Developmental medicine and child neurology*, 2024;66, 501-513.
283. Bedell G, Coster W, Law M, et al. Community Participation, Supports, and Barriers of School-Age Children With and Without Disabilities. *Archives of Physical Medicine and Rehabilitation*. Feb 2013;94(2):315-323. doi:10.1016/j.apmr.2012.09.024
284. Woods D, Catroppa C, Godfrey C, Anderson V. Long-term maintenance of treatment effects following intervention for families with children who have acquired brain injury. *Social care and neurodisability*. 2014;5(2):70-82.
285. Salvador Á, Crespo C, Barros L. The Benefits of Family-Centered Care for Parental Self-Efficacy and Psychological Well-being in Parents of Children with Cancer. *Journal of Child and Family Studies*. 2019-07-01 2019;28(7):1926-1936. doi:10.1007/s10826-019-01418-4
286. Minney MJ, Roberts RM, Mathias JL, Raftos J, Kochar A. Service and support needs following pediatric brain injury: perspectives of children with mild traumatic brain injury and their parents. *Brain Injury*. 2019-01-28 2019;33(2):168-182. doi:10.1080/02699052.2018.1540794
287. Morrison A, Glick A, Yin S. Health Literacy: Implications for Child Health. *Pediatrics in Review*. 2019;40(6):263-277.
288. Morley E, Bennett E, Costello G. Acquired brain injury: Providing support in schools. *British Journal of Child Health*. 2023;3(6)
289. Bennett E, Thomas S, Woolf E. Childhood acquired brain injury: the knowledge and training needs of special educational needs coordinators. *Support for Learning*. 2022;37(2):209-224.
290. Carroll L, Roberts E, Costello G. The road to transition: a SHARED model. In: Jim J, Cole E, eds. *Psychological Therapy for Paediatric Acquired Brain Injury*. Routledge; 2020.

291. Dunn P, Fraser C, Williamson S, Alderwick H. *Integrated care systems: what do they look like?* 2022.
292. Levesque J-F, Harris MF, Russell G. Patient-centred access to health care: conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health*. 2013-01-01 2013;12(1):18. doi:10.1186/1475-9276-12-18
293. Davidson L, Scott J, Forster N. Patient experiences of integrated care within the United Kingdom: A systematic review. *International Journal of Care Coordination*. 2021;24(2):39-56.
294. Mukherjee D. Looking Ahead: Traumatic Brain Injury, Ethics, and Discharge Planning. *The journal of head trauma rehabilitation*. 2022;37(2):125-129. doi:10.1097/HTR.0000000000000731
295. McNeilly P, Macdonald G, Kelly B. The participation of disabled children and young people: a social justice perspective. *Child Care in Practice*. 2015;21(3):266-286.
296. NHS England. Integrated Care Systems. [www.england.nhs.uk/integratedcare](http://www.england.nhs.uk/integratedcare)
297. The Neurological Alliance. What is specialised commissioning? <https://www.neural.org.uk/what-is-specialised-commissioning/>
298. Sirosis K, Tousignant B, Boucher N, et al. The contribution of social cognition in predicting social participation following moderate and severe TBI in youth. *Neuropsychological rehabilitation*. 2019;29(9):1383-1398. doi:10.1080/09602011.2017.1413987
299. Lambregts SAM, Smetsers JEM, Verhoeven IMAJ, et al. Cognitive function and participation in children and youth with mild traumatic brain injury two years after injury. *Brain injury*. 2018;32(2):230-241. doi:10.1080/02699052.2017.1406990
300. Byard K, Gosling S. Reflections on outcome measurement in child neuropsychological rehabilitation: a child-centred approach. In: Jim J, Cole E, eds. *Psychological Therapy for Paediatric Acquired Brain Injury*. Routledge; 2020.
301. Shakespeare T, Watson N. The social model of disability: an outdated ideology? *Research in Social Science and Disability*. 2002;2:9-28.
302. United Kingdom Acquired Brain Injury Forum. *Acquired Brain Injury and Neurorehabilitation: Time for Change - All-Party Parliamentary Group on Acquired Brain Injury Report*. 2018. [https://cdn.ymaws.com/ukabif.org.uk/resource/resmgr/campaigns/appg-abi\\_report\\_time-for-cha.pdf](https://cdn.ymaws.com/ukabif.org.uk/resource/resmgr/campaigns/appg-abi_report_time-for-cha.pdf)
303. Anwar F, Mee H, Allanson J, Mendis E, Hamilton C. Pattern of injuries and management of adolescent trauma in a combined adult and paediatric major trauma centre in United Kingdom. *Trauma (London, England)*. 2021;23(1):44-50. doi:10.1177/1460408620921709
304. Lindsay SP, Proulx MMA, Maxwell JM, et al. Gender and Transition From Pediatric to Adult Health Care Among Youth With Acquired Brain

- Injury: Experiences in a Transition Model. *Archives of physical medicine and rehabilitation*. 2016;97(2):S33-S39. doi:10.1016/j.apmr.2014.04.032
305. Willis ER, McDonagh JE. Transition from children's to adults' services for young people using health or social care services (NICE Guideline NG43). *Archives of disease in childhood Education and practice edition*. 2018;103(5):253-256. doi:10.1136/archdischild-2017-313208
  306. Shankar J, Nicholas D, Mrazik M, et al. Transition From Pediatric to Adult Services: Challenges for Family Caregivers of Young Adults With Traumatic Brain Injury. *SAGE Open*. 2018-10-01 2018;8(4):215824401880795. doi:10.1177/2158244018807954
  307. Royal College of Paediatrics and Child Health. Health Transition Resources. <https://www.rcpch.ac.uk/resources/health-transition-resources>
  308. Colver A, Rapley T, Parr JR, et al. Facilitating transition of young people with long-term health conditions from children's to adults' healthcare services – implications of a 5-year research programme. *Clinical Medicine*. 2020-01-01 2020;20(1):74-80. doi:10.7861/clinmed.2019-0077
  309. INVOLVE. Briefing notes for researchers. National Institute for Health Research. Accessed 12/08/17, <http://www.invo.org.uk/resource-centre/resource-for-researchers/>
  310. Greenhalgh T, Hinton L, Finlay T, et al. Frameworks for supporting patient and public involvement in research: Systematic review and co - design pilot. *Health expectations : an international journal of public participation in health care and health policy*. 2019;22(4):785-801. doi:10.1111/hex.12888
  311. Backhouse MR, Parker DJ, Morison SC, Anderson J, Cockayne S, Adamson JA. Using a modified nominal group technique to develop complex interventions for a randomised controlled trial in children with symptomatic pes planus. *Current controlled trials in cardiovascular medicine*, 2022;23, 286-286.

## 8 Appendices

### 8.1 Appendix 1

Topic Guide for Interviews

Questions	Theoretical frameworks
I know a bit about your brain injury, how does it affect you day to day? - What problems do you have? - What does it stop you doing? - How do you think you're doing at the moment?	TDF/BCW – all domains ICF – all domains
Tell me about what rehab you had? - Are you still having rehab? How do you think you are doing? (Experience of rehab/view on progress)	TDF/BCW – all domains ICF – all domains
Tell me about what you do day to day – activities, sports, things at home? How often? Which do you enjoy doing?	ICF domains - activity, participation TDF/BCW - motivation ICF – personal factors
Is there anything that you'd like to do that you don't currently do?	TDF/BCW – motivation/goals ICF – personal factors
What helps you do these things?	TDF/BCW – all domains ICF – Environmental factors, personal factors
What stops you from being able to do the things you want to	TDF/BCW – all domains ICF – all domains
Identified goals – why are these important?	TDF/BCW – all domains ICF – all domains
Goal setting – Does it happen as part of services you receive? Part of goal setting or HCP led? Relevant to CYP? Do CYP goals match parent and HCP goals?	TDF/BCW – all domains ICF – all domains
System issues – Have you had issues accessing help and support or services? Usually? During pandemic?	TDF/BCW – all domains

Topic Guide for Focus Groups

Questions	Theoretical frameworks
Describe experience of working with CYP-ABI <ul style="list-style-type: none"> <li>- What part of patient pathway</li> </ul>	
Thinking about participation specifically <ul style="list-style-type: none"> <li>- What participation needs do CYP-ABI and their families have?</li> <li>- - what helps CYP-ABI to be able to participate in activities at home, school and in community? (facilitators)</li> <li>- What barriers are there? - what stops CYP-ABI from participating?</li> </ul>	TDF – all domains ICF – all domains BCW – Capability, Opportunity Motivation, Intervention functions
What affects family well-being?	TDF – all domains ICF – all domains
What service do you provide to CYP with ABI? <ul style="list-style-type: none"> <li>- What works well</li> <li>- Even better if</li> </ul>	TDF – all domains BCW – Capability, Opportunity Motivation, Intervention functions
Is there anything that would help you in your role supporting CYP-ABI?	TDF – all domains BCW – Capability, Opportunity Motivation, Intervention functions

## 8.2 Appendix 2

Supplementary material provided online for Keetley, R., Manning, J.C., Williams, J., Stewart, I., Radford, K. (2024) Child and family health-related quality of life and participation outcomes and goals after acquired brain injury: a cross-sectional survey, *Brain Injury*, DOI: [10.1080/02699052.2024.2309244](https://doi.org/10.1080/02699052.2024.2309244)

Supplementary Table 1 – Statistical comparisons of demographic variables and outcome measure scores – Spearman's rho with Bonferroni correction. \*statistical significance

	Age	Time since injury	PedsQL (total score)	CASP (total score)	PHQ-4 (total score)	PedsQL-FIM (total score)
Diagnosis						
Age	1.0000					
Time since injury	0.1558 0.3184	1.0000				
Severity (KOSCHI score)	-0.0756 0.6298	0.0956 0.5418				
IMD	0.0750 0.6328	0.2058 0.1855				
PedsQL (total score)	-0.0630 0.6883	0.3443 0.0238 *	1.0000			
CASP (total score)	0.1306 0.4040	0.2467 0.1107	0.7454 0.0000 *	1.0000		
PHQ-4 (total score)	-0.0785 0.6170	-0.1368 0.3819	-0.4425 0.0030 *	-0.463 0.0018 *	1.0000	
PedsQL-FIM (total score)	0.1472 0.3463	0.3350 0.0281 *	0.6252 0.0000 *	0.5635 0.0001 *	-0.7541 0.0000 *	1.0000

Supplementary Table 2: Respondents v Non-respondents analysis

		Respondents	Non-respondents	p=
Total number		51	119	
Age (median (IQR))		13 (8-16)	11 (7-15)	0.0595 (Wilcoxon Rank Sum)
Sex	Female	15 (29%)	35 (29%)	1.000 (Chi <sup>2</sup> )
	Male	36 (71%)	84 (71%)	
Diagnosis	Brain Tumour	23 (45%)	27 (23%)	0.027 (Chi <sup>2</sup> ) *
	Trauma	12 (23%)	52 (44%)	
	Infection/Inflammation	6 (12%)	18 (15%)	
	Stroke/Bleed	6 (12%)	13 (11%)	
	Other	4 (8%)	9 (7%)	
Severity (KOSCHI, median (IQR))		3b (3a-4b)	4b (3a-5a)	0.233 (Chi <sup>2</sup> )
Time since injury (median (IQR))		2.92 (1.92-3.57)	2.86 (2.02-3.5)	0.9851 (Wilcoxon Rank Sum)



### **8.3 Appendix 3**

Supplementary material provided online for Keetley R, Manning JC, Williams J, Bennett E, Westlake M, Radford K. (2024) Understanding barriers and facilitators to long-term participation needs in children and young people following acquired brain injuries: a qualitative multi-stakeholder study. *Brain Impairment* 25, IB23100.

<https://doi.org/10.1071/IB23100>

Supplementary Table 1: Additional Quotes for Identified barriers mapped to Behaviour Change Wheel - Theoretical Domain Framework				
	TDF domain	TDF Construct	Theme	Quotes
Capability	Knowledge	Knowledge (about condition)	Lack of awareness and understanding	<p><i>'It's a bit of a battle with the school. Now that he's changed [school] trying to get them to actually understand more about the acquired brain injury.'</i> (Robert's Mother)</p> <p><i>'They've never had to deal with any of this before and I think there's a complete lack of understanding out there from other professionals that aren't necessarily specialists that they have all this to cope with on a daily basis.'</i> (Nurse-2)</p> <p><i>'We or they may not know at the outset, you as clinicians may not know at the outset what the impact of this is in long term. And so as they're going through the education process... you may hit a particular aspect of the curriculum or a cognitive step that you want them to take, and suddenly you find that they have lost that knowledge or they can't bridge that gap, or they've lost that function. But you and they don't know that until they reach that benchmark, milestone, challenge what, whatever it might be, so it's a really unpredictable kind of future for them with lots of unknowns. And for those people supporting them...things can suddenly happen out of the blue that you might have assumed were still there. And yet it's a loss that they have had somewhere.'</i> (EPS-1)</p> <p><i>'It's just really difficult to get a consistent kind of agreement and understanding between everybody. I find that's more difficult in secondary schools than primary schools, where they've usually got just one or two teachers. Yes, fatigue is a big one that comes up as a problem. I hear the word 'lazy' quite a lot.'</i> (AHPN-2)</p> <p><i>'It is a bit of an information overload when you're in a crisis situation though, because you don't want to accept that your child's got something really serious, it's a really difficult mental place that you're in. So there is a bit of an information overload because you're coming to terms with a lot of things.'</i> (Megan's Mother)</p>

		Procedural knowledge	Lack of knowledge regarding system navigation	<p><i>'That's you guys in specialist roles in a tertiary centre, you know, not knowing where to go. Then you've got community professionals struggling to also find that support and then we're expecting families who've got even less understanding to kind of be able to access, haven't we?'</i> (Nurse-2)</p> <p><i>'I mean they say then, oh go on and look at the local offer, and that's how you're left, go and have a look at the local offer, and you go on there and you're just bamboozled, and I think to myself, why don't they make it really simple, why don't they do a flow diagram saying, and pointing you to all the services... and make it all, because it's almost like they don't want you to find the services.'</i> (Megan's Mother)</p>
	<b>Skills</b>	Skill assessment	Lack of recognition or assessment of needs	<p><i>'I don't know if it's the [diagnosis] that's affected anything but I suppose his organisational skills sometimes don't come naturally to him and I don't know if that's in himself or it's a result of anything....I think there are some subtle things and you think, is that that or is that just how he would be anyway?' (Oscar's Mother)</i></p> <p><i>'No one may know what the impact of this might be long-term, you don't find the problem until they reach the benchmark/milestone/challenge'</i> (EPS-1)</p> <p><i>'They've never had to deal with any of this before and I think there's a complete lack of understanding out there from other professionals that aren't necessarily specialists that they have all this to cope with on a daily basis.'</i> (Nurse-2)</p> <p><i>'the understanding perhaps within a school environment....understanding about what they need and the hidden disability of ABI with our more mobile children.'</i> (AHPN-7)</p> <p><i>'So it's about very much what the family and the child's goals are, isn't it, and about trying to establish what they are and then this assessment of need, isn't it? So like X was saying, it relies on them knowing what their needs are and then whether those needs are being met, whether they're unmet or even unrecognised, in that they don't actually even recognise that it's a need.'</i> (AHPN-7)</p>

			<p><i>'I think as health professionals, we almost sometimes dismiss that sort of stuff, don't we, as like the cherry on the top of the cake because you're still alive. What are you moaning about? Get on with it, sort of thing... We almost don't even think of any of that extended stuff because we're so focused on okay, do whatever treatment we need to do, let's keep you alive, let's get you sorted, let's get you home.'</i> (Nurse-1)</p> <p><i>'So for a child who has an injury in primary school, actually you might not see some of the impact in terms of the executive skills... till secondary school and then that's a whole bigger challenge that hits sort of a second wave of it.'</i> (AHPN-7)</p> <p><i>'The impact can be subtly changing as they grow, or improving as they grow, or indeed deteriorating...'</i> (EPS-3)</p>
	Ability/Skill development	Lack of ongoing rehabilitation access to address impairments	<p><i>'...so every day since I've had that I've struggled and my whole left side a lot weaker, my whole body's weaker in general but more my left side's weaker, so I will struggle with mobility and balance and stuff.'</i> (Jack)</p> <p><i>'...we've both seen that Elijah struggles a bit with his memory and sometimes he struggles with trying to find the right words to say so he'll take a while to answer something to try and get the right word but, it's not major, but it is different to what it he was.'</i> (Elijah's Mother)</p> <p><i>'Banter sometimes can be a bit tricky. The filter's not on and he says what he's thinking out loud, and sometimes that can be, oh my gosh, should he have said that? I mean, the people around him know but, in the future, not everyone's going to know that.'</i> (Hamza's Mother)</p> <p><i>'Now, he can get a bit emotional about things and he does have some organisational...maybe he just needs to get into the habit of organising, but he can react in some - Just very, very subtle, just ticks a few little boxes, and you just need to understand him.'</i> (Oscar's Mother)</p>

				<i>'Everyone has helped within their speciality, but then you're discharged from that and there's lots of little things that happen all the time that you need advice on and you don't have it. You don't have any point of contact, you don't have one person who can help you with all these things'(Megan's Mother)</i>
	<b>Memory, attention, and decision processes</b>	Cognitive overload/tiredness	Impact of Fatigue	<p><i>'Fatigue is huge, and it plays a massive role' (Charlotte's Mother).</i></p> <p><i>'Much more tired, after school and stuff' (Elijah).</i></p> <p><i>'If you've got a child who's very, very fatigued and is really struggling, the parent's priority might be school and getting them to do the best at school and anything outside that might just seem too much to ask for, almost, because I think for a lot of families, the focus is on education and if a child is too tired to manage in school, then they're not even thinking about anything outside of that.'</i> (Nurse-1)</p> <p><i>'Managing their fatigue - I don't know if anybody has, that's such an under researched area and actually for schools to manage children and for children themselves actually. I don't know what it's like in the primary sector, I would imagine difficult, but for children to learn how to pace themselves and to manage their fatigues extremely difficult in the school context because of the way that the day works.'</i> (EPS-1)</p>

Opportunity	<b>Social influences</b>	Social support	Social isolation/Lack of CYP peer relationships	<p><i>'Not really, no, don't really have any really.... Yeah you can say I sit with them at lunchtime, but you can also say they're not my friends, .... just because I'm sitting with them doesn't mean I'm friends with them.'</i> (Megan)</p> <p><i>Amelia: 'Yeah, so I've been playing out with my friends.</i></p> <p><i>Amelia's Mother: 'That one can be a bit tricky, can't it, because I don't like you to go too far, do I? ...Like yesterday when her friends wanted to go off like round the block, you know, that is more challenging obviously for Amelia and for me to let her do that.'</i></p> <p><i>'He's become a bit of a recluse, to be fair. He spends a lot of time indoors.'</i> (Barney's Mother)</p> <p><i>'But that, no contact with other children...there's no groups or social groups I can take her to where – she's in that in between stage, you know what I mean...there's just nothing there as far as I can see.'</i> (Megan's Mother)</p> <p><i>'Yeah, that junction thing, that one road that terrifies you.'</i> (Hamza)</p> <p><i>'I think it actually contributes to that isolation because she... needs meeting and taking to lessons, so...she's wobbly on her feet, she's already looking vulnerable and she's feeling like she's more singled out, so it's actually having that social impact on her as well.'</i> (EPS-4)</p> <p><i>'it's all about the socialisation, being able to integrate with his peers, particularly at school, and that being a challenge for many, many reasons. Mobility, emotions, you know, the physical side of things, endurance, all of those types of things, but that being – his biggest need and wish and desire is that socialisation.'</i> (AHPN-1)</p>
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			<p>Lack of peer support for parents/families</p>	<p><i>'I think, if there's something for people with common experiences that give their tips, I don't know, or professionals that can advise, I think that would be useful' (Oscar's Mother)</i></p> <p><i>'I suppose maybe speaking to people that actually understand what you're talking about rather than just, "well, you know, he looks fine". He is fine, but it is quite isolating and lonely really'. (Robert's Mother)</i></p> <p><i>'I know a lot of parents that I see actually don't feel massively supported and they will seek their own sort of parental support, so they might just access support groups through Facebook, initially, if it's not well known to the charities or, like you guys were saying, actually charities are going under and it is harder and harder for parents to seek that kind of support.'</i> (AHPN-5)</p> <p><i>But it's kind of, perhaps it's asking too much for a hospital to be a social...but the hospital is the pinnacle of this isn't it, it's the only place that we've all, one thing we've got in common is the hospital.... there's lots of other women and children and whatever out there, that could do with the morale support and it's just a tremendous thing to get that support from somebody else going through the same thing.'</i> (Megan's Mother)</p> <p><i>'You know if the child in question has got siblings, you know, there's a lot of attention for that period of time, maybe on their sibling and then everything should be back to normal and it's not and there's still a lot of attention on that child. And actually...there's not an awful lot of support for the siblings of children with brain injuries, or you know cancer treatments, it's not there, and actually they've gone through a massive emotional turmoil as well. And then that can affect the relationship between the two siblings, or, however, many siblings there are.'</i> (EPS-2)</p>
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	<b>Environmental context and resources</b>	Environmental stressors	Substantial parent care and advocacy role	<p><i>'We're in a very fortunate position because I didn't work before, although I would've liked to have gone back to work to be fair, but yeah, full-time carer and my husband...he's retired. So in that way we're really, really fortunate, because we don't leave her unattended....so we just like swap and we manage to work it that way....And then I thought about the personal payment, and I thought...how am I going to get somebody to do this, I can't just get anybody and it's so unpredictable.'</i> (Megan's Mother)</p> <p><i>'...it was such a battle'</i> (Charlotte's Mother)</p> <p><i>'something I've pushed very hard for'</i> (Amelia's Mother)</p> <p><i>'nothing happens at all unless as a parent you're finding you're way with it'</i> (Megan's Mother)</p> <p><i>'I think in terms of brain injury I think there's no consistency of support, the consistency's not there...Everyone has helped within their speciality, but then you're discharged from that and there's lots of little things that happen all the time that you need advice on and you don't have it. You don't have any point of contact, you don't have one person who can help you with all these things'</i> (Megan's Mother)</p> <p><i>'I think there's a complete lack of awareness of actually how much the parents have to do and how much they have to manage and how much, on that discharge, is actually handed over to them...All those little tasks that, in hospital, are just done and then they have to then start all that and build all that back up as normal at home, on top of having to manage the whole NHS, which is ridiculously complicated.'</i>(Nurse-2)</p> <p><i>'I think the families and the young people I worry about more are perhaps those who can't express those things [needs and views] in the same way, or who perhaps don't have that support. And I think that's where, perhaps we need to be thinking about how</i></p>
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				<p><i>we put that support in around them a little bit more kind of thoroughly, I suppose, so that there are, there does feel like there is perhaps big gaps?' (AHPN-7)</i></p>
			<p>Lack of clear pathways/systems (health/social care/education)</p>	<p><i>'Again, you've got to understand how systems work to know who to go to, which parents often don't.' (Nurse-1)</i></p> <p><i>'I think the downside was just education, from, as soon as she was poorly, you know, and when things started to decline, you know, mainstream it was such a battle...you know, I can take a step back and go, actually they're sort of batting her away, but the reason is because they are frightened because, you know, she's quite complex...I think in comparison to medical, education has been extremely hard, like I say, now she's got it but in one year she literally had three hours in a school with education, in a whole twelve months and it was just so frustrating.'</i> (Charlotte's Mother)</p> <p><i>'I think the recognition that ABI is often long term/lifelong and that children are developing and that there's changing needs across developments and that transitions matter and that all of those other things matter, is just lost in commissioning.'</i> (AHPN-7)</p> <p><i>'I think most challenges extend into education and other settings as well, because you think about that sudden change of needs of an ABI and the education system is not set up to deal with that. So you know, you've often got kids going back in where they can't get any EHCP [Education Health Care Plan]. They probably won't even meet the criteria for an EHCP in a lot of our counties now, but also they've missed the funding pots because it's not the start of term when they had their brain injury. They're trying to get them back into school to get them participating, to get them seeing friends, to get them doing all those things we want them to do but they can't because they've not got a TA [Teaching Assistant] or they've not got the support and they're having to just juggle things within education because the system is not fit for purpose when you've got that change in needs.'</i> (AHPN-7)</p>

		Impact of Covid-19 pandemic	<p><i>'He'd only just sort of started with his whole time one-to-one when we went into lockdown, so he sort of fell even further behind.'</i> (Robert's Mother)</p> <p><i>'Well, it started really before Covid hit. Physio stopped. Occupational therapy, he had one visit while he was still in hospital, and that never took place again, which was promised. Speech and language. It's almost as if [county] just washed their hands of him. There's no support there.'</i> (Hamza's Mother)</p>
	Resources/material resources	Lack of resources (adaptation delays, lack of accessible activities, services and support, socio-economic factors)	<p><i>'Because he's struggling with buttons and his tie and laces and what have you, [specialist] did refer him to the OT [occupational therapy] around here. She did go into school and see him, but she said, because he's not physically disabled, if you like, and that's what they specialise in, so it was just sort of- She sent me some stuff through the post to try with him in regards to buttons and things, but I think it would be quite handy if he could see somebody, if it was still within the team sort of thing.... Because they [OT] sort of help with day-to-day stuff as well, don't they?'</i> (Robert's Mother)</p> <p><i>'She is interested in doing something but how do I, how do I do that.... what can I do for her and I don't know what I can do for her, I don't know where I can go to get help for her....I find it really difficult, really, really difficult, because there's no help with it at all, so [specialist nurse] has pointed me to the, you know, where I can get the information and I've gone on looking at the list of groups and trying to work out and I just give up in the end, because I just, I can't see anything that meets her needs.'</i> (Megan's Mother)</p> <p><i>'I think from my perspective, there is certainly a frustration around not being able to offer as much as one might like to. So we're very much based on episodes of care in the community....We set the goal, we do it, we discharge and then we might reopen again if there is another need, but that very much relies on the families and/or the schools being able to communicate that to you and if they're not identifying that as a need...they perhaps won't put that referral through. So it is hard to – certainly, it is difficult.'</i> (AHPN-1)</p>

				<p><i>'I think in terms of brain injury I think there's no consistency of support, the consistency's not there...Everyone has helped within their speciality, but then you're discharged from that and there's lots of little things that happen all the time that you need advice on and you don't have it. You don't have any point of contact, you don't have one person who can help you with all these things.'</i> (Megan's Mother)</p> <p><i>Much as we all want to, I think it is an endless frustration that we think oh, it would be brilliant for an OT to get involved at that point and to be able to help out with X, Y and Z, but can we find an OT in the community that we can make a referral to or that the child meets their threshold to get involved? No, not really. Same with speech and language. I mean, we have endless challenges getting speech and language therapy involved to support our patients and you can see those gaps, can't you, so clearly.'</i> (AHPN-7)</p>
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<b>Motivation</b>	<b>Social/professional role &amp; identity</b>	Social identity	'New normal'	<p><i>'Get them back into a proper [football] team' (Elijah's Mother)</i></p> <p><i>'I hate it when they're holding my arms when I'm walking, I was like so annoyed. I really just want them to stop doing that.'</i> (Megan's Mother)</p> <p><i>'Feels more singled out...she's more comfortable with students who knew her before and know this is not what she's really like....'it's a real barrier in her, she doesn't want to be seen as special, you know that's like how she phrases it'' (EPS-4)</i></p> <p><i>'Yes, there's something about being the same as your peers, isn't there, doing the same things, being the same, not standing out.'</i> (Nurse-1)</p> <p><i>"Yes, I think that's for children and parents. Everybody compares, don't they, to what natural development is and what children should be doing.'</i> (SCP-1)</p> <p><i>'I think there's a few things in primary [school] where it's a rite of passage to be able to go on a residential, but whether you feel like you can be, you know some of the things with brain injuries is it leaves you maybe having fits now and then, so could you go?' (EPS-2)</i></p> <p><i>'So sometimes it's about that acceptance, it's about the adjustment to kind of changes in identity and other issues where we're thinking, but it would be brilliant if people just knew and knew how to help, cos they all want to help, but it's not always in keeping with what young person wants.'</i> (AHPN-7)</p> <p><i>'All those stages that we sort of take for granted can be major sort of hurdles and blocking points, unless there's either a prompt or actually some physical assistance and it's that sort of – I don't know what the sort of either naivety or vulnerability, that we take a lot of that for granted or accept it as normal development stages and that, to an ABI can be quite a challenge.'</i> (AHPN-4)</p>
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		Professional role/boundaries	Professional roles and boundaries	<p><i>'We only advocate when we're open to them...and is it our role to advocate?' (AHPN-4)</i></p> <p><i>'I was always getting criticised in my role for molly coddling families and doing everything for them but, like you say, some families need that and actually sometimes, or most of the time, they only need it for a couple of months, just while they're getting themselves back on their feet and to...You know, it's giving them that understanding and that perspective, that they won't know what's more important and what isn't because why would they?'</i> (Nurse-2)</p>
<b>Beliefs about capabilities and consequences</b>		Self-confidence	Lack of parental or CYP confidence	<p><i>'she's lost all her confidence completely now talking to other people. She's looking to me all the time....'</i> (Megan's Mother)</p> <p><i>'Parents have a hard time having confidence and letting teenagers get out'</i> (SCP-1)</p> <p><i>'Children are just not necessarily confident enough to access those higher cognitive demand type groups.'</i> (AHPN-5)</p>
		Perceived competence	Lack of insight	<p><i>'It's not the actual journey of knowing the direction that you're going to walk to and from, it's the actual crossings, being aware of whose right is where and being aware of give-ways, being aware of three-way junctions..'</i> (Hamza's Mother)</p>
		Beliefs	Safety concerns	<p><i>'The bike was more because he'd still got the [condition] and I think I was too scared to take the stabilisers off and let him go for it.'</i> (Robert's Mother)</p> <p><i>'So for many of ours, they feel that the seizures rule their lives, so it's about trying to change that mental attitude. You can do anything with seizures, absolutely anything...It's just a case of adjusting that mindset to say you can do this, we just need to take a few extra precautions.'</i> (Nurse-3)</p>

	<b>Goals</b>	Goals (distal/proximal)	Lack of support to achieve longer-term goals	<p><i>'I think we're really good at thinking about the short-term aims and what our short-term goals are for these young people who've had ABI, but actually thinking long term, actually much more thinking about long term and how do we support these children long term because that's often what they are going to have to experience, is long term input for them.'</i> (AHPN-5)</p> <p><i>'We set the goal, we do it, we discharge and then we might reopen again if there is another need, but that very much relies on the families and/or the schools being able to communicate that to you and if they're not identifying that as a need.'</i> (AHPN-1)</p> <p><i>'She's got targets set, ...but it's all in fluffy educational language isn't it...well it's not happened...it's a complete waste of time'</i> (Megan's Mother)</p> <p><i>'I had a child that did have an EHCP...we were presented with his old EHCP to go through what his new one was and basically they just literally scored out everything they couldn't do, so the parents were presented with this document that literally had everything just crossed out....I don't know whether it was a legal thing...but I found that really poorly managed... Actually, we're better off starting again from scratch, rather than, actually let's rule out what they couldn't do. To me, it was almost criminal.'</i> (AHPN-4)</p>
	<b>Emotion</b>	Affect	CYP emotional impact	<p><i>'But I can't go swimming...because of my epilepsy....I'd drown really.'</i> (Megan)</p> <p><i>'I think quite a few of our children find frustration that they're not able to do the things that they were able to do before and want to do.'</i> (AHPN-6)</p> <p><i>'There's also an element of grief experienced by these children for what they've lost in terms of their capacity or their cognition or even time that they may have spent in hospital that they've lost socially.'</i> (EPS-1)</p> <p><i>'And there's therefore almost denial that she's not in the situation in the reality she's in'</i> (EPS-4)</p>

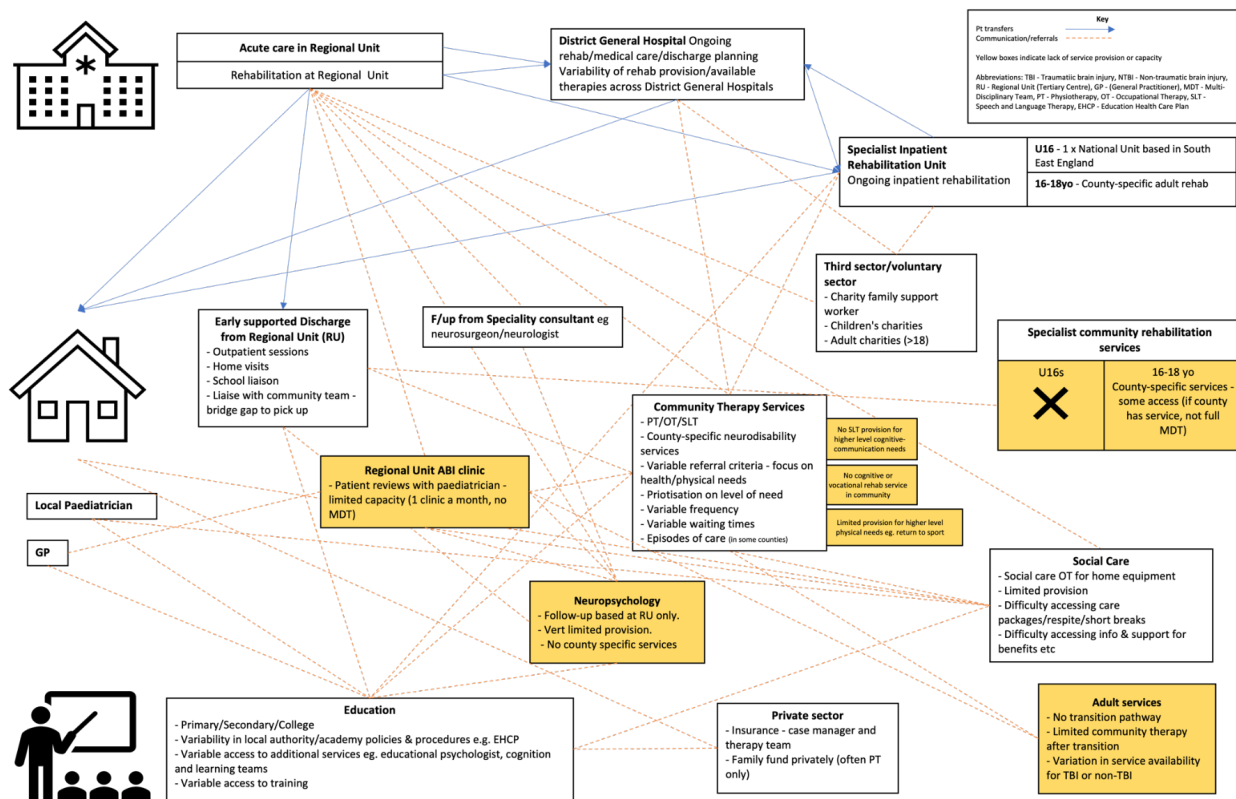
			<p><i>'The fear of what will happen because of the gag, the choking, and the gag reflex with my student. And that's why partly she doesn't eat anything in school. She really, really doesn't want to.'</i> (EPS-4)</p> <p><i>'A lot of them feel anxious because they perhaps weren't doing anything wrong, they were going about a normal activity and then something terrible happened to them or they feel anxiety for the future concerning their health. They feel personal anxiety about their families, their friends, all of that.'</i> (EPS-1)</p>
		Parental emotional impact	<p><i>'It cuts quite deep when you're comparing, when you see what all her friends are doing now and that she can't do any of that.'</i> (Megan's Mother)</p> <p><i>'I think it was such a traumatic time in our lives, it was so awful, and I was at such a low ebb and it was all.....because you're dealing with your own trauma... and it's like you've got a bit of post-traumatic stress disorder, I think after, I bet a lot of parents feel like this...when they've had a child that's in hospital with a serious illness, you feel really traumatised afterwards'</i> (Megan's Mother)</p> <p><i>'I really wanted to put him in a bubble wrap suit, I won't lie'</i> (Fred's Mother)</p> <p><i>'They want to but then they're scared. They're worried about them going out'</i> (SCP-1)</p> <p><i>'Parents fully expect their child to be the same as they were pre-diagnosis and it's that shock as they go through months and years and they just want their child to be the same as they were before, but you know they're not going to be the same and it's adapting to the child's needs for now'</i> (EPS-5)</p> <p><i>'it's almost as if those parents then tend to not be able to have that time to grieve properly and deal with trauma, what they've been through, because all of a sudden their whole life has changed and I find that a lot of my families, there can be relationship breakdowns as well and quite often, it tends to be the mum within the</i></p>

				<i>family that feels that she needs to take all of this on and then that breaks down relationships. It's a really hard time for them. It's almost like the devastating effects once you're home because you are in that bubble in hospital.'</i> (SCP-1)
			Family impact	<p><i>'I think they've found it quite tough actually...They did [have support] at the beginning with a psychiatrist, she did a really valuable session with, well it ended up being me and the boys actually at that point and they found it really helpful and a lot came out of that about how they were feeling and how difficult they were finding things, which I hadn't appreciated at that point.'</i> (Megan's Mother)</p> <p><i>'It is about balance...there's some things like when we've been to cinema...we can all do that together, but it is things like swimming that I feel we are, we're limited on things like that....so I feel like sometimes the boys miss out. But it is about compromise.'</i> (Charlotte's Mother)</p>



#### **8.4 Appendix 4**

Supplementary material provided for Keetley, R., Manning, JC., Kettlewell, J., Williams, J., Bennett, E., Lyon, V., Radford, K. Enabling participation in children and young people with acquired brain injuries and their families – a theory-, evidence- and person-based approach to intervention development. Submitted to *BMJ Open*.



Supplementary Figure 1 – Mapping of service provision and pathways

Supplementary Table 1: COM-B Behavioural Diagnosis				
Define the problem	CYP-ABI and their families experience restrictions in participation in activities at home, school and in the community due to multiple barriers, which impacts on their well-being.			
Target behaviour	Increasing participation of CYP-ABI and their families in activities at home, school and in the community.			
Barriers and facilitators				
COM-B/TDF Domain	TDF Construct	Barrier/Facilitator	Theme	
Capability	Knowledge	Knowledge (about a condition)	Barrier	Lack of awareness and understanding
			Facilitator	Education and training for families and professionals
		Procedural knowledge	Barrier	Lack of knowledge regarding system navigation
			Facilitator	Support and upskill parents
	Skills	Skill assessment	Barrier	Lack of recognition or assessment of needs
			Facilitator	Access to specialist assessment and review
		Ability/skill development	Barrier	Lack of ongoing rehabilitation access to address impairments
			Facilitator	Access to specialist rehabilitation support
	Memory, attention, and decision processes	Cognitive overload/tiredness	Barrier	Impact of fatigue
			Facilitator	Education and training regarding managing fatigue Support with learning
Opportunity	Social influences	Social support	Barriers	Social isolation/lack of CYP peer relationships Lack of peer support for parents/families
			Facilitator	Peer support for whole family
	Environmental context and resources	Environmental stressors	Barriers	Substantial parent care and advocacy role Lack of clear pathways/systems (health/social care/education) Impact of Covid-19 pandemic
			Facilitators	Point of contact/support for parents Care pathway/policies
		Resources/material resources	Barrier	Lack of resources (adaptation delays, lack of accessible activities, services and support, socio-economic factors)
			Facilitator	Information resources
Motivation	Social/professional role & identity	Social identity	Barrier	'New normal'
			Facilitator	CYP motivation
		Professional role/boundaries	Barrier	Professional roles and boundaries
			Facilitator	Collaborative cross-sector working
	Beliefs about capabilities and consequences	Self-confidence/perceived competence	Barriers	Lack of parental or CYP confidence Lack of insight Safety concerns
			Facilitator	Access to rehabilitation support
	Goals	Goals (distal/proximal)	Barrier	Lack of support to achieve longer-term goals
			Facilitator	CYP motivation/goals
	Emotion	Affect	Barriers	CYP, parental and family emotional impact
			Facilitators	Resilience/bravery Support for families

Supplementary Table 2 and 3 – BCW Intervention planning tables

		Identification of BCW intervention types									
COM-B		TDF	Education	Persuasion	Incentivisation	Coercion	Training	Restriction	Environmental Restructuring	Modelling	Enablement
Capability	Physical capability	Skills					*				*
	Psychological Capability	Knowledge	*				*				*
		Skills									*
		Memory, Attention, Decision-Making processes	*				*				*
Opportunity	Physical opportunity	Environmental Context & Resources					*				*
	Social opportunity	Social Influences							*		*
Motivation	Automatic motivation	Social/professional role & identity					*				*
		Emotion									*
	Reflective motivation	Beliefs about capability and consequences	*								
		Goals	*	*	*						*
		Social/professional role & identity	*								*

Shaded squares are BCW suggested links. \* indicates links relevant to key objectives of intervention

Identification of BCW Policy Options							
	Communication/ marketing	Guidelines	Fiscal measures	Regulation	Legislation	Environmental/ social planning	Service provision
Education	*	*					*
Persuasion							
Incentivisation							
Coercion							
Training		*					*
Restriction							
Environmental restructuring							
Modelling							*
Enablement		*					*

Shaded squares are BCW suggested links. \* indicates links relevant to key objectives of intervention