Co-designing an evidence-based intervention to support parent delivered physiotherapy to children after traumatic brain injury

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Abstract

Following paediatric traumatic brain injury, parental involvement in rehabilitation in the context of family-centred care is considered best practice. This includes parent-delivered physiotherapy exercises. However, little is currently known about how to best support parents to adhere to delivering physiotherapy exercises to their child. Patient and public consultation highlighted that parents would like a digital intervention to support them. The overall aim of this doctoral research was to develop a digital behaviour change intervention based on theory and evidence to support parents to adhere to delivering physiotherapy exercises.

The Capability, Opportunity, Motivation-Behaviour (COM-B) model was used to identify influences on behaviour with the intervention designed according to Behaviour Change Wheel guidance. To inform intervention design, a systematic review and three integrated research studies were conducted. Firstly, a systematic review sought to identify and analyse the active ingredients - behaviour change techniques - of interventions supporting parents to deliver physiotherapy. In total, 24 different behaviour change techniques were identified with an average of 11.67 per intervention. All interventions included elements of goal setting and action planning, plus instruction, demonstration and practice. Secondly, one-to-one semi-structured interviews with parents were conducted with automatic motivation, reflective motivation and psychological capability identified as key influences on adherence. Thirdly, paediatric physiotherapists participated in focus groups which identified that physiotherapists particularly influence parental adherence through automatic motivation, reflective motivation and psychological capability, with social opportunity being another key influence. Finally, a co-design study was conducted which sought to develop a detailed understanding of user requirements for the intervention using a generative co-design framework.

This thesis utilised the Behaviour Change Wheel together with the Medical Research Council’s guidance for developing complex interventions to co-design a prototype digital intervention. Future research will involve rounds of early user-testing and refinement of the intervention before undertaking a feasibility study.

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<u>Statement of authorship</u>

The research reported throughout this thesis is my own work which was carried out in collaboration with others as follows:

Chapter 1: Written by David Young

Chapter 2: David Young was the lead author of the following peer reviewed publication upon which the chapter is based:

Young, D., Cawood, S., Mares, K., Duschinsky, R. and Hardeman, W. (2024) ‘Strategies supporting parent-delivered rehabilitation exercises to improve motor function after paediatric traumatic brain injury: A systematic review’. *Developmental Medicine and Child Neurology*; 66: 836-848. DOI: 10.1111/dmcn.15773

DY led and designed the study with WH, KM and RD. DY wrote the study protocol with contributions from WH, KM and RD. DY registered the study protocol on PROSPERO. DY, WH, KM, RD and SC made substantial contributions to the conception and design of the review. DY and SC screened the papers. DY and SC completed quality appraisal of the accepted papers. DY extracted data from all the included papers, WH and KM validated data extraction. DY and WH independently coded interventions for Behaviour Change Techniques. DY prepared the manuscript. DY responded to peer review comments with advice from WH. All authors read, commented, contributed and approved the final manuscript.

Chapter 3: Written by David Young

Chapter 4: Written by David Young

Chapter 5: Written by David Young

Chapter 6: Written by David Young

Chapter 7: Written by David Young

David Young was the lead author of the following published paper which came from the research carried out in the chapter:

Young, D. and Gravett, K. (2025) ‘Evidence-based Reflective Commentary: When is a goal not a goal?’. *The Association of Paediatric Chartered Physiotherapists Journal*; 16: 3-6.

DY and KG jointly developed the initial idea for the paper. DY and KG both contributed to the preparation of the manuscript and responded to peer review comments. DY and KG read, commented, contributed and approved the final manuscript. The contributions of WH, KM and RD in the form of academic guidance and expertise have been acknowledged in the manuscript.

Chapter 8: Written by David Young

Chapter 9: Written by David Young

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List of abbreviations

AIS – Abbreviated Injury Scale

APCP – Association of Paediatric Chartered Physiotherapists

APEASE criteria - Affordability, Practicability, Effectiveness and cost-effectiveness, Acceptability, Side-effects and safety, and Equity

BCW – Behaviour Change Wheel

BCT – Behaviour change technique

BCTTv1 - Behaviour change technique taxonomy, version 1

COM-B – Capability, opportunity, motivation – behaviour model

CSP – Chartered Society of Physiotherapy

CYP – Child and young person (singular) or children and young people (pleural)

GCS – Glasgow Coma Scale

HCPC – Health and Care Professions Council

ICF – International Classification of Functioning, Disability and Health

ICF-CY – International Classification of Functioning, Disability and Health, Children and Youth Version

ISS – Injury Severity Score

MDT – Multi-Disciplinary Team

MRC – Medical Research Council

NICE – National Institute for Health and Care Excellence

NIHR – National Institute for Health and Care Research

NHS – National Health Service

NMTR – National Major Trauma Registry

pGCS – Paediatric Glasgow Coma Scale

PICU – Paediatric Intensive Care Unit

PPI – Patient and Public Involvement

pTBI – Paediatric traumatic brain injury

TARN – Trauma Audit and Research Network

TBI – Traumatic brain injury

WHO – World Health Organization

Chapter 1: Introduction to the thesis

1.1 A brief overview of the thesis

This thesis describes the development of a digital behaviour change intervention designed to support parents to adhere to the delivery of physiotherapy exercises to their child following a traumatic brain injury. Such an intervention is deemed complex in its nature due to the multiple components involved and the need for tailoring to individuals. The intervention focuses on supporting behaviour change in the form of promoting parental adherence to delivering physiotherapy exercises. Therefore, gaining a detailed understanding of existing evidence and influences on parental adherence is an essential element of the design process, and an important prerequisite to inform intervention development. As such, human behaviour change, and the endeavour to design an intervention to influence parental adherence in the desired direction, will be a common thread running throughout the entire thesis.

In this thesis, I will firstly provide a detailed background regarding paediatric traumatic brain injury, the importance of physiotherapy and the role of parents. Secondly, I will examine and synthesise evidence to identify active ingredients and components of existing interventions designed to support parents to deliver physiotherapy exercises following paediatric traumatic brain injury. Thirdly, I will explore the views and experiences of parents of children with traumatic brain injury and paediatric physiotherapists related to influences on parental adherence to delivering physiotherapy exercises. I will then detail the assimilation of existing and new evidence which inform the conceptual design of the intervention according to Behaviour Change Wheel guidance. Finally, I will present a co-design study involving parents, physiotherapists and other key stakeholders, followed by an overview of the prototype theory- and evidence-based digital intervention 'Physio Together'. The prototype is the first version of the intervention which I intend to develop further within post-doctoral research.

Patient and Public Involvement has been integral to the design, planning and delivery of this doctoral research. I will consider the important role that Patient and Public Involvement has played throughout this thesis.

1.2 My motivation behind developing this programme of research

In the summer of 2007, I qualified as a chartered physiotherapist. Throughout my training, I was always very interested in childhood development, brain injury and neurodisability, therefore the field of paediatric neurorehabilitation has always greatly appealed to me. Having taken every opportunity to gain experience of paediatrics, in 2014 I secured my first permanent role within the paediatric department at Addenbrooke's Hospital, part of Cambridge University Hospitals, England.

Later that year, I became a founding member of the national Neurodisability Group: a specialist interest group within the Association of Paediatric Chartered Physiotherapists (APCP) working across United Kingdom and Northern Ireland. This opportunity allowed me to broaden my understanding and knowledge of neurodisability and rehabilitation, whilst working with colleagues and experts in the field both nationally and internationally. In 2021, I co-authored a national guidance document for paediatric physiotherapists titled 'Guidance for Paediatric Physiotherapists Managing Children and Young People with Acquired Brain Injury' on behalf of the APCP (available online from https://apcp.csp.org.uk/publications/guidance-paediatric-physiotherapists-managing-children-young-people-acquired-brain). Writing this guidance coincided with me becoming the paediatric rehabilitation coordinator for major trauma at Addenbrooke's Hospital, focussing my interest on paediatric traumatic brain injury.

Whilst writing the national guidance document, I personally recommended that paediatric physiotherapists should engage with parents and involve them in physiotherapy, understanding this to be a key element of patient-centred care and best practice. When exploring the evidence base further, I identified references advocating the need for physiotherapists to engage parents in rehabilitation, however the key question of **how** to do this remained largely unanswered (Braga et al., 2005, Bray, 2015, Muscara et al., 2015). Moreover, I was able to reflect upon my own clinical practice of working with children and young people following paediatric traumatic brain injury and identify examples of varying degrees of parental engagement in physiotherapy. However, I was unable to clearly articulate why this was the case or how parental adherence to delivering physiotherapy exercises could be supported or influenced.

Therefore, the clinically grounded question of how to support parents to engage in physiotherapy and adhere to delivering recommended physiotherapy exercises emerged. The development of a theory- and evidence-based digital intervention to support this became the central focus of my PhD research.

1.3 An overview of paediatric traumatic brain injury, including primary and secondary injuries

The focus for my PhD thesis is paediatric traumatic brain injury, and the research question for my PhD is directly informed by my clinical work. At the time of commencing my PhD I was the paediatric major trauma rehabilitation coordinator at Addenbrooke's Hospital, a large teaching hospital and regional major trauma centre in the East of England. A large proportion of my clinical caseload within that role was traumatic brain injury. The inconsistent and variable level of support for parents provided a clinically rooted context for my research at the time that I sought grant funding and indeed commenced the research itself.

Traumatic brain injuries are characterised by the traumatic mechanism of injury being a sudden external force, or forces, resulting in damage to the brain and brain function (National Institute for Health and Care Excellence, 2023a, National Institute of Neurological Disorders and Stroke, 2024). During childhood, a traumatic brain injury is known as a paediatric traumatic brain injury - or pTBI - the acronym that I will consistently use throughout this thesis.

Damage to the brain can occur at different stages following the traumatic injury and are classified as primary and secondary injuries (Araki et al., 2017). Damage from the initial traumatic event is conceptualised as the primary injury occurring at the point of impact and can include a skull fracture, intra- or extra-parenchymal injuries, or vascular damage leading to cellular membrane disruption. This is followed by secondary injuries which evolve within the subsequent hours and days resulting from breakdown within the blood brain barrier and concurrent cellular, chemical, tissue or blood vessel changes (Goldman et al., 2022, Lui et al., 2022, Haydel et al., 2024, Johns Hopkins Medicine, 2025).

A pTBI can be classified as being either focal, meaning that the injury is confined to one area of the brain due to impact forces, or diffuse, meaning that damage is more widespread and often occurs due to rotational or acceleration-deceleration forces (Araki et al., 2017, Huh and Raghupathi, 2019). For more information about the primary and secondary phases of injury, please see Appendix 1.

Paediatric traumatic brain injury falls under the umbrella term of acquired brain injury which includes both traumatic and non-traumatic injuries (Allonsius et al., 2024). Examples of traumatic brain injuries include those suffered because of road traffic accidents or falls, and non-traumatic brain injuries include those caused by brain tumours, stroke or infections (Department of Health and Social Care, 2022, Goldman et al., 2022). Acquired brain injuries involve damage or injury to the brain which occurs in a non-degenerative fashion following a period of normal development, therefore making them distinct from other conditions of childhood such as genetic diseases or cerebral palsy (Forsyth et al., 2022, Goldman et al., 2022).

I will now consider the epidemiology, heterogeneity and management of pTBI before providing more background information about physiotherapy and the role of parents. Following that, I will introduce the importance of adherence to delivering physiotherapy exercises following pTBI.

1.4 The epidemiology and heterogeneity of paediatric traumatic brain injury

From an epidemiological perspective, the exact prevalence of pTBI is debated with reports that it results in the hospitalisation of between 47 and 280 per 100,000 children and young people (CYP) annually (Dewan et al., 2016, Thurman, 2016). National Institute for Health and Care Excellence (NICE) guidance on head injury assessment and early management published as recently as 2023 corroborate with these figures. The NICE guidance reports that amongst CYP aged 15 years and under in England and Wales alone, the annual incidence of pTBI in accident and emergency departments is as many as 500,000, equating to hospital admission rate of approximately 20,000 annually (National Institute for Health and Care Excellence, 2023b).

Paediatric traumatic brain injury is widely acknowledged as being a leading cause of death and long-term disability in CYP both in the United Kingdom and worldwide (Kirk et al., 2014, Thurman, 2016, Araki et al., 2017, Hayes et al., 2017, Shen et al., 2020). The leading causes of pTBI are falls and road traffic collisions - either as an occupant of a vehicle or as a pedestrian - followed by abusive injuries, often referred to as non-accidental injuries, and sports related injuries (Dewan et al., 2016).

As a patient population, CYP affected by pTBI are heterogeneous with regards to the injury, its mechanism and management, plus the resultant impact on function (Goldman et al., 2022). Indeed, heterogeneity in these matters has been described as the hallmark of traumatic brain injury (Covington and Duff, 2021). A wide range of CYP may be managed in primary care settings and accident and emergency departments without the need to be admitted to hospital. These are typically referred to as mild pTBI – colloquially termed concussion (Schuchat et al., 2018, National Institute for Health and Care Excellence, 2023b). By contrast, those more severely affected have an increased likelihood of being admitted to hospital, as do those with a 'complicated mild pTBI', characterised by a classically mild pTBI presentation however with positive neuroimaging findings such as skull fracture or intracranial bleed (Araki et al., 2017, Schuchat et al., 2018). The way in which pTBI severity is classified will be outlined in detail in the following section: this thesis focuses on parent delivered physiotherapy to CYP that are admitted to hospital following their pTBI.

1.5 Severity assessment and hospital admission following paediatric traumatic brain injury

1.5.1 Assessing injury severity according to the Glasgow Coma Scale

Like traumatic brain injuries which affect adults, pTBI is broadly divided into three categories of severity: mild, moderate and severe.

Internationally, the Glasgow Coma Scale (GCS) is the most widely used measure to objectively assess responsiveness and the extent of altered consciousness following pTBI, as well as acute illness more broadly (Mattei and Teasdale, 2020, Aguilar-Fuentes et al., 2024). The GCS was originally developed in 1974 by Teasdale and Jennett and assesses responsiveness on a 15-point scale across three domains (Teasdale and Jennett, 1974). A score of between 3-15 is given comprising of eye-opening (range 1-4), verbal response (range 1-5) and motor response (range 1-6) (Aguilar-Fuentes et al., 2024).

When interpreting the GCS to inform severity, a score of 13-15 corresponds to a mild traumatic brain injury (TBI), a score of 9-12 corresponds to a moderate TBI and a score of 8 or below corresponds to a severe TBI (Schuchat et al., 2018). Adaptations to the scale have been made for the paediatric population below the age of five years due to known challenges of accurately assessing this age group (Royal College of Paediatrics and Child Health, 2015, Borgialli et al., 2016). The main differences relate to age-appropriate verbal and motor responses. The paediatric GCS includes babbling, cooing and saying words as a normal verbal response (score of 5), whereas, crying and moaning in response to pain are classed as abnormal responses. Normal spontaneous movement is acceptable for a typical response within the motor domain, as opposed to the ability to follow commands which is the standard requirement for a score of 6 amongst children over five years of age and adults (Borgialli et al., 2016, Caruana et al., 2024).

Depending on the circumstances and severity of the injury, diagnosis may involve a combination of both clinical assessment and neuroimaging, possibly including serial or diagnostic neuroimaging (Araki et al., 2017). The CYP that are admitted to hospital following pTBI will be considered to have suffered a major trauma, with severity being classified according to the specific assessments undertaken within hospital as outlined further below.

1.5.2 Hospital admission following paediatric traumatic brain injury

Since 1990, for CYP hospitalised in the United Kingdom following pTBI, and other forms of major trauma, criteria have been set by the Trauma Audit and Research Network (TARN) to assess injury severity. This has recently been replaced by the National Major Trauma Registry (NHS England, 2025b) which coordinates the collection and processing of data for all patients who have suffered major trauma.

Injury severity is classified according to the Abbreviated Injury Scale (AIS) and derived Injury Severity Score (ISS) which provide an anatomically based classification of injury severity considered ‘gold standard’ in scoring injury severity (Van Ditshuizen et al., 2021). Additional criteria are set for location of admission and duration of stay within the hospital. This includes a ward-based stay for at least three nights or direct admission to a paediatric intensive care unit (PICU) (NHS England, 2025b). Therefore, a CYP will meet the criteria for major trauma due the severity of their injury, the location of their admission and the duration of their stay in hospital. Within childhood and following a pTBI, parents play a vitally important role in their child’s life. This will be explored in further detail below.

1.6 Childhood development and paediatric traumatic brain injury in the context of family

1.6.1 The important role of parents in childhood development

Childhood is a period of human life spanning birth to 18 years of age. The environment in which a child grows and develops shapes their early experiences and ongoing development (UNICEF, 2025). This growth and development involves complex interactions of biological, physiological, psychological and social factors (Hyde et al., 2022).

Throughout childhood, it is widely accepted that key people which are involved in shaping and nurturing an individual's experiences are the child's parents and primary care givers, often within the context of family (Novak-Pavlic et al., 2023). Furthermore, parents have been described as the central 'contextual factor' in their child's lives, emphasising the predominant role that parents play in a child's life and development (Rosenbaum and Gorter, 2011).

For the sake of clarity, the following definition of a 'parent' will be used throughout this thesis: a parent is 'a mother or a father of a person…or someone that looks after a person in the same way that a parent does' (Cambridge University Press & Assessment, 2025). I have chosen this definition as it acknowledges that a parent can be either a biological parent or another person fulfilling the parenting role, such as a legal guardian or other primary care giver. For simplicity and consistency, the term 'parent' will be used throughout the thesis, with their role occurring within the context of a family unit.

1.6.2 Paediatric traumatic brain injury is a 'family affair'

When a CYP suffers a pTBI, it can have significant implications for parents and the entire family unit (Ylvisaker et al., 2005, Tyerman et al., 2017, Hickey et al., 2018). Parents and other family members may have witnessed the initial incident that caused the pTBI, they may also be present during the hyper acute, acute and long-term phases of recovery, which can alter the normal functioning of the affected family (Demellweek and Appleton, 2006). Such is the enormous impact of pTBI on parents and the wider family that it has been referred to as a 'family affair' (Lezak, 1988).

As outlined above, childhood is a critical period of human development which can be suddenly and dramatically disrupted because of a pTBI affecting the physical, social, emotional and psychological function of the individual involved (Wade et al., 2018). As parents are primary care givers for CYP affected by pTBI, there is a great deal of expectation placed on them following their child's injury (The Association of Paediatric Chartered

Physiotherapists, 2016, The Association of Paediatric Chartered Physiotherapists, 2018). This includes their involvement in, and delivery of, physiotherapy exercises with the aim of maintaining and improving physical skills and motor outcomes following pTBI.

1.7 The role of physiotherapy following paediatric traumatic brain injury

1.7.1 Physiotherapy and parent delivered physiotherapy exercises

For CYP who sustain movement impairments following admission to hospital with a pTBI, physiotherapy is a core element of neurorehabilitation which is considered essential within recommended best practice (Carr and Shepherd, 2010, Jones et al., 2018, National Institute for Health and Care Excellence, 2022, NHS England, 2025b). Physiotherapists work within multi-disciplinary teams (MDTs) which consist of professional groups such as Occupational Therapists, Speech and Language Therapists, Dieticians, Psychologists, Nurses and Doctors (Health and Care Professions Council, 2023). It is a core component of physiotherapy to work collaboratively within MDTs to develop and deliver comprehensive and integrated rehabilitation plans based on the needs and priorities of the child and family (Jones et al., 2018).

The aim of physiotherapy is to help the CYP to regain physical skills such as standing and walking, whilst learning new or modified ways of doing day-to-day activities through exercise, education and advice (Chartered Society of Physiotherapy, 2023). Alongside this, physiotherapists also focus on optimising the motor function of CYP which consists of complex interactions of physical, perceptual and cognitive components of movement (Hallemans et al., 2020).

It is important that the affected CYP receives regular opportunities to complete physiotherapy exercises to support them to regain physical skills and optimise motor function following the pTBI. This is because neural networks within the brain respond to environmental stimuli, experiences and challenges which lead to their adaptation and reorganisation following damage sustained because of the pTBI: a process known as neuroplasticity (Khan et al., 2017, Maier et al., 2019). For those affected by pTBI, neuroplasticity occurs alongside environmental adaptations, enabling a CYP to function within daily life (Forsyth and Basu, 2015, Maier et al., 2019).

A leading approach for improving functional skills and motor performance is motor learning which focuses on repetitive task-orientated training within activity-stimulating environments (Kleynen et al., 2020). This is where the role of parents in frequently delivering physiotherapy exercises which are stimulating and challenging becomes so important within neurorehabilitation. Parents return home from hospital with their injured child following a pTBI and are well placed to make environmental adaptations within day-to-day life and to deliver physiotherapy exercises as prescribed by a physiotherapist (The Association of Paediatric Chartered Physiotherapists, 2016, Kleynen et al., 2020). Furthermore, adherence to delivering physiotherapy exercises is vital as this supports the achievement of rehabilitation goals whilst providing greater dosage of physiotherapy to support neuroplasticity (Jenkin et al., 2022a, Ley and Putz, 2024).

Here, the World Health Organization's (WHO) definition of adherence helps to clarify the importance of behaviour, alongside the role of collaboration and a positive partnership between the parent and physiotherapist (Jones et al., 2020, Jenkin et al., 2022b). The WHO defines adherence as "the extent to which a person's behaviour…corresponds with agreed recommendations from a health care provider" (World Health Organization, 2003a, p.3). Within the context of rehabilitation, parents need to learn how to deliver physiotherapy exercises, prioritise them and ultimately make a choice to follow the relevant and collaboratively developed and agreed recommendations from physiotherapists. As such, in this thesis adherence is considered a positive behaviour based on collaborative working involving an active choice, which contrasts with compliance considered to be more passive behaviour whereby an individual is simply following instructions or doing as they are told (Mir, 2023).

Intuitively, given the rationale outlined in the above paragraphs, supporting parents to deliver physiotherapy exercises appears to be a very important thing to do, almost 'common sense'. That said, in 2018 the Chartered Society of Physiotherapy (CSP) together with the James Lind Alliance established the top ten research priorities for physiotherapy. Featured in the list were i) 'what approaches are effective for enabling parents…to support physiotherapy treatment?', and ii) 'what parts of physiotherapy treatments cause behaviour change?' (Chartered Society of Physiotherapy, 2018, James Lind Alliance, 2025). These research priorities highlight that far greater research is required within the field of parental adherence to delivering physiotherapy, and these priorities are of central importance in shaping this doctoral research.

1.7.2 Unpacking the complexity of parental adherence

The objective of ‘supporting parents to adhere to delivering physiotherapy exercises’ may initially seem simple, however when broken down, the underlying complexity is revealed. For example, a parent could understand what a particular physiotherapy exercise involves and why that physiotherapy exercise is required. However, this is quite different to being able to physically carry out the exercise itself with their child. In addition, this example does not provide any detail about underlying influences on parents adhering to repeatedly delivering the physiotherapy exercise on a daily basis or over time, for example, their motivation. Similarly, many existing healthcare interventions are described in broad terms, such as the use of education or training. However, a detailed behavioural analysis considering who needs to do what and when/where to achieve the desired outcomes is lacking (Michie et al., 2011, Michie et al., 2014).

This is where behavioural science with recognised theoretical models and frameworks can offer invaluable insights through in depth and detailed research, plus a behavioural analysis from which interventions can be developed (Ojo et al., 2019, Atkins et al., 2020). A detailed behavioural analysis reveals the different actors, behaviours which require consideration and their influences. It is from an in-depth behavioural analysis that complex interventions based on the best available theory and evidence can be developed (Sinnott et al., 2015, O'Cathain et al., 2019, Ojo et al., 2019). Further details about behavioural science and the behavioural frameworks which I will utilise within this thesis, namely the Behaviour Change Wheel (BCW) and COM-B model, are provided below in section ‘1.13 Key overarching frameworks’.

As identified above, my focus on parent delivered physiotherapy and parental adherence is informed by identified research priorities within physiotherapy (Chartered Society of Physiotherapy, 2018, James Lind Alliance, 2025). The focus of my doctoral research has also been heavily informed by parents with lived experience of pTBI and the challenges that they face following their child’s brain injury. In the next section, I will provide an overview of the important role that parents and patient and public involvement (PPI) have played in shaping my research presented in this thesis.

1.8 The important role of Patient and Public Involvement in shaping this research

1.8.1 Considering the perspectives of parents

When applying for National Institute for Health and Care Research (NIHR) grant funding for my doctoral research, I greatly valued listening to the experiences of parents of CYP with pTBI. I intentionally and proactively listened to parents with lived experience so that my research questions reflected the experiences and identified needs of parents. Within these discussions, February to July 2019 and March 2020, I took the research priorities identified by the CSP and James Lind Alliance, as outlined above, to parents as part of initial PPI consultations.

I was able to hear directly from parents, who are experts by experience within initial PPI workshop discussions, which I co-hosted with the NIHR Brain Injury MedTech Cooperative (now the NIHR HealthTech Research Centre for Brain Injury). I also consulted with parents that I encountered through clinical practice. When speaking to parents, what immediately struck me was the overwhelming challenges that they faced following their child's pTBI from a combination of emotional, practical and logistical perspectives. It also became clear that parents experienced a bombardment of information when coming into hospital following their child's admission. Current methods of supporting and enabling parents to deliver physiotherapy were said to be insufficient and lack standardisation, at times leaving parents confused and unsure of how best to support their child through physiotherapy.

During these discussions the importance of context was raised. It became clear that parents encountered physiotherapists and were required to deliver physiotherapy across a range of different contexts following their child's pTBI. CYP and parents initially met and started working with physiotherapists in the acute hospital setting following the pTBI. They then often returned home either directly from hospital or via a specialist residential rehabilitation placement. At that point an injured CYP may be in receipt of additional input from a community physiotherapist, whereas others may not.

It was evident from discussions that support from physiotherapists which began in the acute hospital was an essential starting point in equipping parents to support their child thereafter. Focussing on home-based physiotherapy in isolation was not sufficient. Instead, consideration of the continuum of care from the acute hospital setting through the community was required.

1.8.2 The role of technology in supporting rehabilitation following paediatric traumatic brain injury

During PPI discussions, parents proposed that digital technology with accessible and tailored content could support parents to adhere to delivering physiotherapy exercises. An additional benefit of technology was said to be the ability for remote information transfer from physiotherapists to parents to support their child. These initial PPI discussions were held between February to July 2019 and March 2020, shortly prior to the global Covid-19 pandemic.

During the Covid-19 pandemic, the proposed benefits of a digital delivery mode were brought sharply into focus due to the ability for remote access by parents to support physiotherapy, including home-based physiotherapy (Wade et al., 2020). Additionally, the use of collaborative, patient and family-centred care and the roll out of technology to support rehabilitation were included in the National Health Service's (NHS) long term plan (National Health Service, 2019). The prominence of technology demonstrates the NHS' commitment to integrating technology to better support the self-management of long-term health conditions (National Health Service, 2019, National Institute for Health and Care Excellence, 2023b).

In conjunction with PPI discussions involving parents, I also consulted three experienced paediatric physiotherapists (May 2019). The physiotherapists agreed with parents, expressing that a tailored digital intervention would aid information transfer from physiotherapist to parent, streamline the process of supporting parents to deliver physiotherapy exercises and save time. They also commented that pictures or video tutorials may aid parents' recall of exercises at home and in the community.

1.9 Existing technologies designed to support rehabilitation

1.9.1 Health technologies for children and young people

Online resources and digital interventions for CYP and families following pTBI have been shown to support functional improvements across many domains in the pTBI population, including motor skills, language and communication functioning, and cognitive functioning (Wade et al., 2018). Increased engagement and adherence to treatment are just two of the important identified benefits of technology (Wade et al., 2018) with evidence to support high levels of feasibility and acceptability amongst parents, CYP and therapists alike (Wade et al., 2020).

Interventions orientated towards parents and families following pTBI exist and have been shown to be effective. One such intervention is Internet Interacting Together Everyday: Recovery after Childhood TBI (I-InTERACT) for parents of children aged nine and under. I-InTERACT provides online parent skills training to support behaviour problems following pTBI through online modules and remote sessions with a therapist. Intervention outcomes demonstrate reduced levels of parent stress and reduced behavioural problems amongst children following pTBI (Narad et al., 2017, Wade et al., 2020). Another intervention is online family problem-solving therapy, including Teen Online Problem Solving (TOPS, family and teen-only versions). Online family problem-solving therapy consists of seven to ten sessions with families around cognitive reframing, problem-solving, communication skills and behavioural management. Intervention outcomes demonstrate benefits for both the CYP with pTBI and family, with family composition found to be a consideration for optimal treatment delivery (Wade et al., 2017, Narad et al., 2019, Wade et al., 2019). Since existing interventions focus mainly on CYP behaviour and family problem solving following pTBI, digital interventions supporting physiotherapy also require consideration.

1.9.2 Digital platforms for physiotherapy

A leading digital platform to support physiotherapy through an online exercise prescription platform is Physitrack™, currently used across a range of NHS hospitals in the United Kingdom and health services further afield (Physitrack, 2024). Given the widespread adoption of the Physitrack™ platform across different age groups and health conditions, it is important to take note of the literature which relates specifically to childhood neurodisability and paediatric neurorehabilitation.

A recent single-blinded, parallel-groups, randomised controlled trial investigated the role of Physitrack™ in supporting adherence to home exercise programmes amongst children with cerebral palsy and other neurodevelopmental disabilities aged six to 17 years (Johnson et al., 2020). Children were randomised to either using the Physitrack™ platform or conventional paper-based methods for exercise prescription over an eight-week trial period.

The trial found no difference in adherence between groups, with adherence levels in both groups reaching approximately 60%. Moreover, results demonstrated that adherence reduced over time with a statistically significant downward weekly trend of -2.3% ($p<0.001$) for exercises performed and -2.0% ($p<0.001$) for repetitions completed (Johnson et al., 2020).

Considering the focus of this thesis, it is of value to note that parental involvement in supporting and delivering physiotherapy exercises was only implicit and assumed. Whilst the authors expressed the importance of positive parent-therapist relationships in successful home exercise programmes, there was an overt lack of scope to acknowledge and include parents in the process of exercise delivery (Johnson et al., 2020).

The authors did however identify the role of behaviour change and the need for theory- and evidence-based support to aid adherence moving forwards. They also expressed that there remains scope for a specifically designed intervention for CYP with neurodisability concluding that an opportunity remains for such an intervention to be developed (Johnson et al., 2020). This is where behavioural science and behaviour change frameworks have such an important role to play, by providing an explicit framework to determine who needs to do what, when and in what situation for the desired behaviour to occur (Michie et al., 2011).

1.10 The problem and how to address it

1.10.1 The problem

The factors outlined above provide a compelling background regarding the problem. The problem is that there is an identified gap in provision for parent supported physiotherapy as highlighted by PPI discussions. There is an identified absence of behavioural science insights informing the design of existing digital platforms used to prescribe physiotherapy exercises (Johnson et al., 2020, Chartered Society of Physiotherapy, 2018). Crucially, current platforms also overlook the key role that parents play in delivering physiotherapy exercises to their child (Johnson et al., 2020). The problem is further underpinned by the research priorities set out by the James Lind Alliance and Chartered Society of Physiotherapy (Chartered Society of Physiotherapy, 2018, James Lind Alliance, 2025). The research priorities clearly and specifically highlight the need for research into how best to facilitate parent involvement in physiotherapy and the need for greater understanding regarding the role of behaviour change in physiotherapy.

1.10.2 Addressing the problem

Due to the identified problem, I deemed it essential to design a new digital behaviour change intervention to support parental involvement and adherence to delivering physiotherapy exercises based on theory and research evidence (West and Michie, 2016, O'Cathain et al., 2019).

A range of different approaches and behaviour change frameworks are available. The essential drive to design a theory- and evidence-based digital behaviour change intervention guided my choice of overarching frameworks and research methods. Two complementary frameworks which support the design of theory- and evidence-based interventions are the Medical Research Council's (MRC) complex intervention development and evaluation framework and the Behaviour Change Wheel (Craig et al., 2008, Michie et al., 2014, O'Cathain et al., 2019, Ojo et al., 2019). Combined use of these frameworks to inform intervention development provides a robust and transparent process by determining key influences upon behaviour from which interventions are designed. An existing intervention which has been developed through combined use of the MRC framework and BCW is MultimorbiditY COllaborative Medication Review And DEcision Making - MY COMRADE (for full details, please see Sinnott et al., 2015).

An introduction to the key frameworks which I will utilise within this thesis to deliver on the research objectives is provided in section '1.13 Key overarching frameworks' below.

1.11 Research aim and objectives

The aim of this doctoral research is to co-design a digital behaviour change intervention to support parents to adhere to delivering physiotherapy exercises to their child following traumatic brain injury.

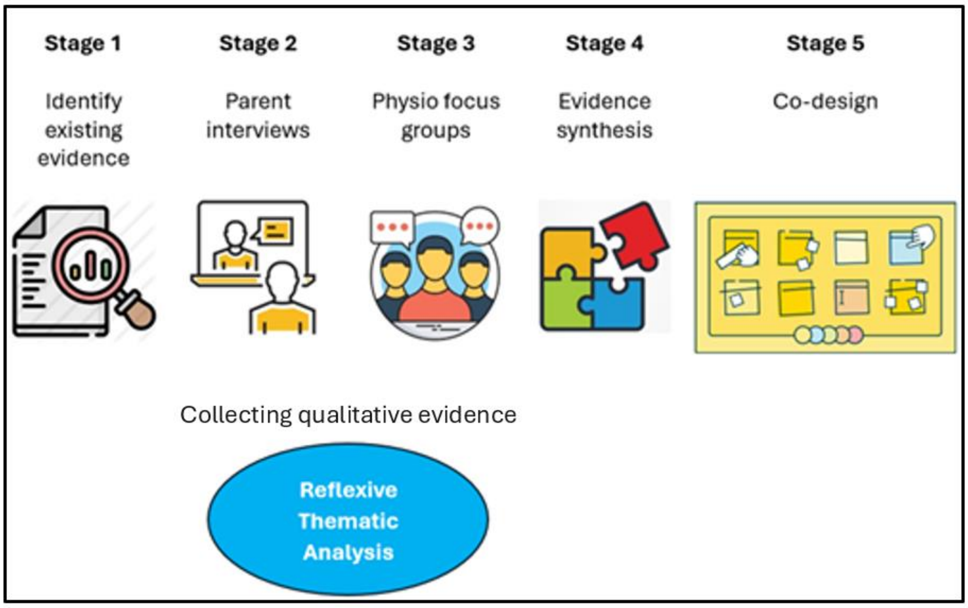
To deliver this research aim I have identified the following four objectives:

1. To identify the active ingredients of existing interventions designed to support parents to deliver physiotherapy exercises aimed at improving motor function of their child following a pTBI.
2. To explore first-hand experiences of delivering physiotherapy exercises and identify factors which influence parental adherence to the delivery of recommended physiotherapy, from the perspective of parents and physiotherapists.
3. To synthesise evidence and specify the conceptual design of a theory- and evidence-based intervention utilising Behaviour Change Wheel guidance.
4. To develop a detailed understanding of user requirements for the intervention, then co-design a prototype digital intervention.

1.12 Thesis structure

This thesis is divided into five stages which map on to the identified objectives. As a helpful aid to orientation of the thesis structure, I will utilise Figure 1.1 throughout the various chapters. Please note, parent interviews and physiotherapy focus groups (Stages 2 and 3 of the below figure) both relate to research objective 2 through collecting new qualitative evidence.

Figure 1.1 - Figure providing an overview to the thesis structure



In addition to Figure 1.1, Table 1.1 provides an overview of the various stages of the thesis together with the chapter titles.

Table 1.1 - An overview of the stages and chapters of the thesis

Chapter	**Title**
Chapter 1	Introduction to the thesis
Stage 1	Identify existing evidence

Chapter 2	Systematic review
Stages 2 and 3	Collecting new qualitative evidence
Chapter 3 Chapter 4 Chapter 5	An introduction to the qualitative studies Qualitative study involving parent interview Qualitative study involving physiotherapy focus groups
Stage 4	Evidence synthesis and conceptual design of the intervention
Chapter 6	The conceptual design of the intervention
Stage 5	Co-designing the prototype intervention
Chapter 7 Chapter 8	Developing a detailed understanding of user requirements for the intervention Prototype intervention development
Chapter 9	General discussion

1.13 Key overarching frameworks

Important priorities guiding intervention development are the need for the intervention to be based on the best available evidence which is underpinned by theory. I therefore intend to develop a theory- and evidence-based intervention designed with parents of CYP with pTBI as the target end-users (O'Cathain et al., 2019). To achieve this, a complex intervention informed by a sound understanding of the influences on parental adherence will be required. I will utilise the MRC framework for developing and evaluating complex interventions (Craig et al., 2008). I will also utilise a complimentary behaviour change framework, the Behaviour Change Wheel, which has been designed primarily for use within the intervention development phase (Michie et al., 2011, Michie et al., 2014).

1.13.1 The Medical Research Council's framework for developing and evaluating complex interventions

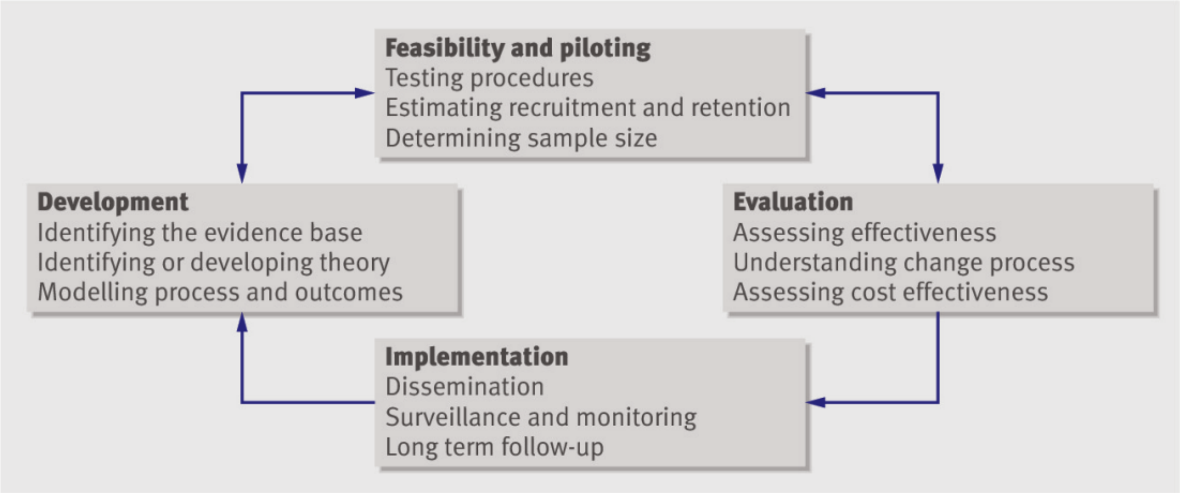
My proposed intervention is deemed complex due to the number of components involved and the proposed flexibility of the intervention for tailoring to individuals (Craig et al., 2008)

(Craig et al., 2008). As a result, the MRC framework for developing and evaluating complex interventions will be used to guide the intervention development process (Craig et al., 2008, Dunford et al., 2016, O'Cathain et al., 2019).

It is acknowledged that multiple versions of the MRC framework exist. When designing this programme of research, the 2008 version of the MRC guidance was the latest available and was therefore used to guide intervention development (Craig et al., 2008). The 2008 framework has since been superseded by the 2021 version published by Skivington and colleagues (Skivington et al., 2021).

The 2008 MRC framework is divided into four phases: development, feasibility and piloting, evaluation and implementation phases (Craig et al., 2008). Each phase has a defined focus, although it is acknowledged by the authors that moving an intervention from development through to implementation is not a linear process, but rather it is an iterative one. Please see the below figure for further details.

Figure 1.2 – Medical Research Council's framework for developing and evaluating complex interventions (Craig et al., 2008)



As no intervention currently exists which specifically focuses on parent delivered physiotherapy following pTBI, the focus of this doctoral thesis is the 'development' of a new intervention to support parent delivered physiotherapy. Involved in this process is gathering appropriate evidence to feed into the intervention development process (Craig et al., 2008, Sinnott et al., 2015). The development phase is divided into the following three sub-phases, as outlined below.

Identifying the evidence base

The first step in developing a new complex intervention is to identify similar interventions and what is already known about them. It is recommended that this should be completed as a high-quality systematic review if a recent one has not been undertaken (Craig et al., 2008).

Identifying or developing theory

A key component of designing a complex intervention is to develop a detailed understanding of the process of change which is proposed to occur for those that utilise the intervention. This is achieved through drawing on theory and existing evidence, plus the contribution of new primary research where required (Craig et al., 2008).

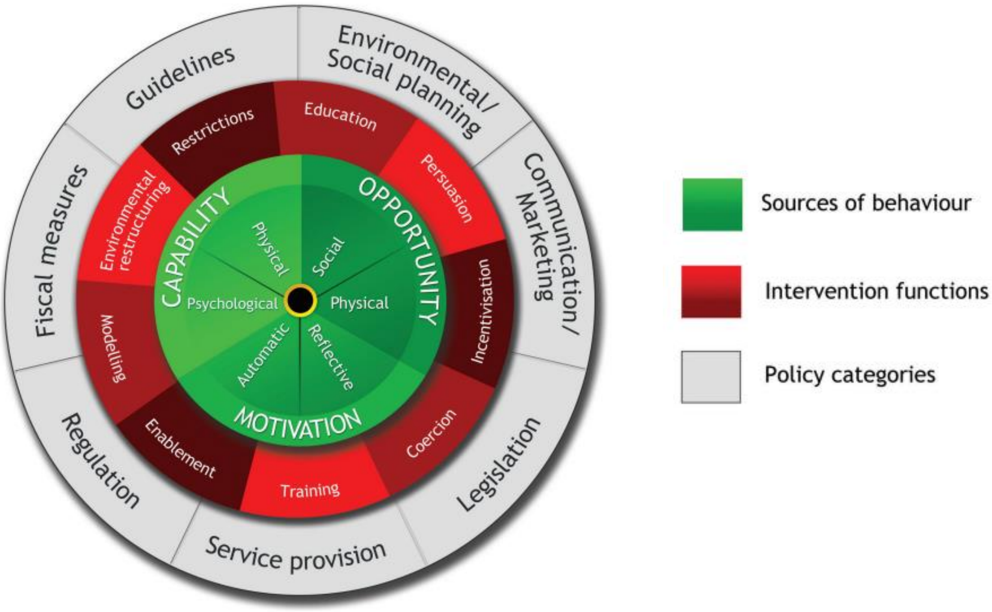
Modelling process and outcomes

It is said that modelling the intervention together with iterative refinement of the intervention is important prior to carrying out a full-scale evaluation (Craig et al., 2008). This can be important for both informing the design of the intervention and planning its evaluation. In *Chapter 8: Prototype intervention development* I will provide a detailed logic model (Figure 8.2) of how the intervention is proposed to work, including the short-, medium- and long-term outcomes. However, beyond the prototype intervention and detailed logic model, this stage sits largely outside the scope of this doctoral research which focuses on the initial development of the intervention. The evidence gathered through the systematic review and new primary research will inform a theoretical understanding of parental adherence to delivering physiotherapy and help guide intervention development.

1.13.2 The Behaviour Change Wheel

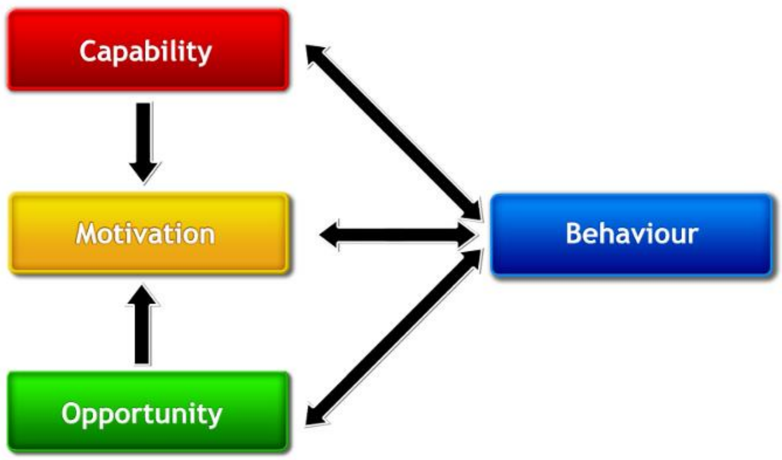
The Behaviour Change Wheel has been developed through the assimilation of 19 different behaviour change frameworks which have been coherently brought together via synthesising common features to form a broad model of behaviour (Michie et al., 2011, Michie et al., 2014). The Behaviour Change Wheel consists of three different layers as illustrated in Figure 1.3 below, and at the centre of the Behaviour Change Wheel is the Capability, Opportunity, Motivation-Behaviour (COM-B) model (Figure 1.4).

Figure 1.3 - The Behaviour Change Wheel (Michie et al., 2014)



The COM-B model identifies the source of a behaviour as well as important influences on the behaviour (identified in green in Figure 1.3). The COM-B model considers the role of capability, referring to ‘the person or people concerned must have the physical strength, knowledge, skills, stamina etc. to perform the behaviour’ (Michie et al., 2014, p.59). It also considers the role of opportunity relating to requirement for ‘opportunity for the behaviour to occur in terms of a conducive physical and social environment’ (Michie et al., 2014, p.59). It additionally considers the role of motivation relating to the need for the person to ‘be more highly motivated to do the behaviour at the relevant time than not to do the behaviour, or to engage in a competing behaviour’ (Michie et al., 2014, p.59). Each component of the COM-B model is further sub-divided into two types. Capability is subdivided into physical and psychological; opportunity is subdivided into physical and social; and motivation is subdivided into automatic and reflective (Michie et al., 2014).

Figure 1.4 - Capability, Opportunity, Motivation-Behaviour (COM-B) model (Michie et al., 2011)



The COM-B model is surrounded by nine intervention functions which are broad categories of approaches through which behaviour change can occur, for example, education or training (identified in red in Figure 1.3). The intervention functions are selected based on the findings of the behavioural analysis using COM-B. Finally, the third and outer layer includes seven policy categories which can be utilised to enable the intervention to occur (identified in grey in Figure 1.3).

Utilising the Behaviour Change Wheel supports the in-depth understanding of a selected behaviour through defining the problem in behavioural terms: who needs to do what, when and in what context for the desired behaviour to occur? I will utilise the Behaviour Change Wheel to ascertain a clear understanding of influences on parental adherence in a systematic, rigorous and transparent way to inform intervention design and content. The Behaviour Change Wheel will facilitate the selection of intervention functions, active ingredients for the intervention - called behaviour change techniques - and policy changes (Michie et al., 2011, Michie et al., 2014).

1.13.3 The Theoretical Domains Framework

Alongside the COM-B model, another theoretically informed tool is the Theoretical Domains Framework (TDF) which can be used to identify influences on behaviour in greater detail than the COM-B model (Atkins et al., 2020). The TDF consists of 14 domains of behaviour, each of which map onto one or more of the COM-B model components (Cane et al., 2012). The COM-B model and TDF are therefore complementary and have been used in conjunction to explore behavioural influences (Atkins et al., 2020). I will incorporate the TDF alongside COM-B to structure deductive analysis of qualitative data within the parent interview study and physiotherapy focus group study (chapters 4 and 5, respectively).

Below, Table 1.2 summarises the mapping of the COM-B model against the domains of the TDF, recreated based on Table 3 as presented in Cane et al. (Cane et al., 2012, p.15).

Table 1.2 - Mapping components of the COM-B model against the Theoretical Domains Framework (Cane et al., 2012)

COM-B component		**TDF domain**
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

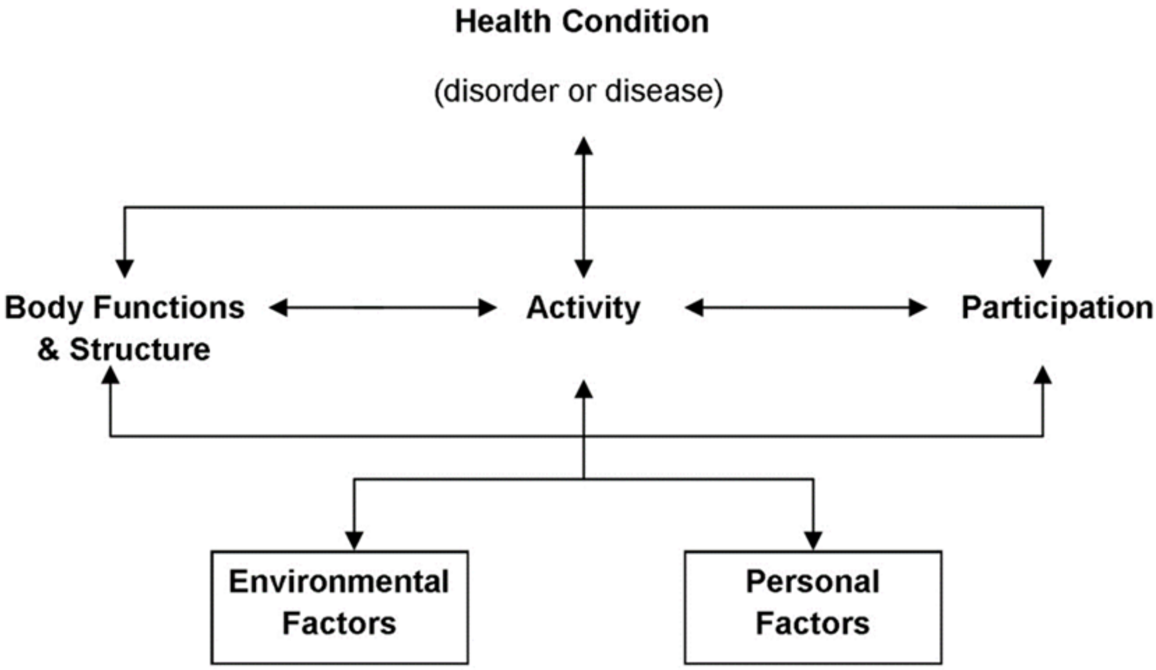
COM-B = Capability, Opportunity, Motivation-Behaviour model; TDF = Theoretical Domains Framework.

Whilst the MRC framework and Behaviour Change Wheel are widely applicable across a broad range of clinical and behavioural settings, there are also specific frameworks which relate to disability and rehabilitation which I will draw upon within the thesis. These will be considered in further detail below.

1.13.4 The International Classification of Functioning, Disability and Health

The impact of a health condition on human function can be conceptualised using the common language of The International Classification of Functioning, Disability and Health, commonly referred to as the ICF (World Health Organization, 2001). There is also a children and youth version of the ICF: the ICF-CY (World Health Organization, 2007). This framework considers the impact of a health condition on human functioning according to the structures and functions of the body, activity and activity limitations, and participation, whilst also considering the impact of an individual's personal and environmental factors.

Figure 1.5 - The World Health Organization's International Classification of Functioning, Disability and Health (World Health Organization, 2001)



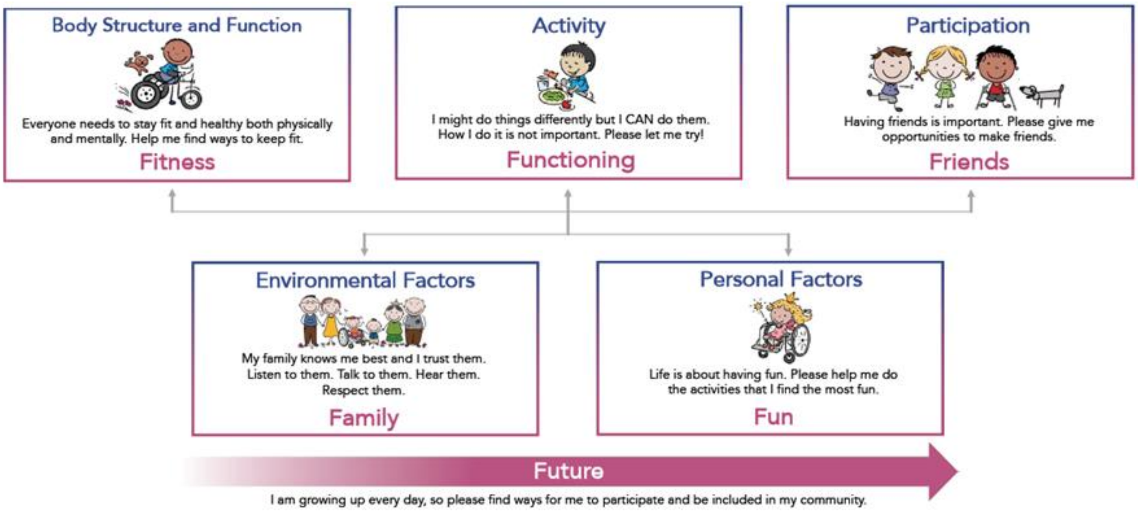
Where the ICF is applicable across all health conditions, a more recent framework derived from the ICF focusses specifically on childhood development and disability: the F-words for child development (Rosenbaum and Gorter, 2011, Rosenbaum, 2022).

1.13.5 The F-words for childhood development

The F-words for childhood development, originally referred to as the F-words in childhood disability, is a framework which embeds the words Functioning, Family, Fitness, Fun, Friends, and Future into the ICF (Rosenbaum and Gorter, 2011, Rosenbaum, 2022). The F-words for child development is a child, adolescent and family-friendly way to think about development, function and the consequences of disability in childhood. The F-words support an inclusive and accessible way to think about child development and childhood disability, whilst providing a common language which assists clinicians in embracing a more holistic approach that should form the basis for rehabilitation (Rosenbaum and Gorter, 2011).

Within the context of pTBI, functioning refers to how a CYP does an activity, such as walking, and how this may need to be adapted because of their physical impairment. Family refers to the family members around the CYP and represents the essential environment for that young person; collaborating with the family within rehabilitation is essential for meaningful rehabilitation. Fitness refers to the activities that CYP engage in to remain physically active and promote fitness within everyday life, and consideration needs to be given to how CYP can be supported to remain physically active. Fun refers to what CYP enjoy doing and, importantly, how activities may need to be adapted to support those with pTBI to meaningfully engage in them. Friends refers to the important peer relationships that CYP may have and how they can be supported to nurture and invest in these following the pTBI. Finally, future considers what the CYP, family and service providers are working towards within their rehabilitation efforts (Rosenbaum and Gorter, 2011).

Figure 1.6 - The F-words for child development embedded within the International Classification of Functioning, Disability and Health (Rosenbaum and Gorter, 2011)



1.14 Chapter summary and next steps

In this introduction to the thesis, I have provided a background to pTBI and the important role that parents play in delivering physiotherapy exercises to their child. I have contextualised the problem and outlined four research objectives which I use to structure the various stages and chapters of my thesis, as per Figure 1.1 above.

Next, I will proceed to Stage 1 of the design process whereby I will identify the existing evidence presented using a systematic review.

Stage 1 – Identify existing evidence

Chapter 2: Systematic review

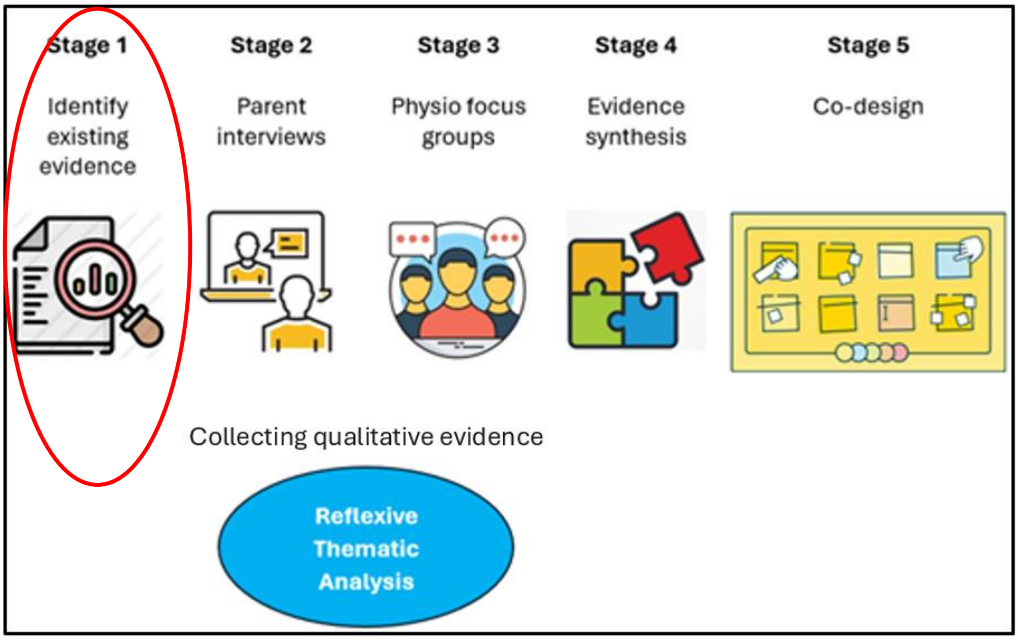
2.1 A brief overview of this chapter

In 'Chapter 1: Introduction to the thesis', I provided a background to pTBI and established that CYP who suffer complicated mild, moderate or severe injuries may need a period of hospitalisation and rehabilitation. I also established that physiotherapy is a key element of rehabilitation following pTBI and parents play an important role in delivering physiotherapy exercises.

The focus of my programme of research is to co-design a digital intervention based on behaviour change theory together with the integration of existing and new evidence. To date, no systematic reviews have specifically sought to identify and synthesise evidence from interventions supporting parent delivered physiotherapy following pTBI. Furthermore, no systematic reviews have sought to identify the active ingredients (behaviour change techniques) of such interventions to provide a fine-grained understanding of intervention content.

The focus of this chapter will be to address Stage 1 of the development process, as identified in the Figure 1.1 below. This chapter presents a systematic review aimed at identifying and synthesising the behavioural components and active ingredients of existing interventions. To achieve this, a detailed and fine-grained method of coding intervention components has been utilised which will be detailed further within the chapter.

Figure 1.1 - Figure providing an overview to the thesis structure



Please note, within this chapter I refer to the specific roles of colleagues and supervisors within the conduct of the systematic review, for example within title and abstract screening phase of the review. For simplicity, individuals will be referred to by their initials throughout this chapter as was the case within the following peer-reviewed publication:

Young, D., Cawood, S., Mares, K., Duschinsky, R. and Hardeman, W. (2023) 'Strategies supporting parent-delivered rehabilitation exercises to improve motor function after paediatric traumatic brain injury: A systematic review'. Developmental Medicine and Child Neurology; 00: 1-13 (online).

For the sake of transparency, SC refers to Ms Sarah Cawood (highly specialist physiotherapist and major trauma rehabilitation coordinator within the NHS), WH refers to Prof Wendy Hardeman (academic lead supervisor), RD refers to Prof Robbie Duschinsky (academic co-supervisor), and KM refers to Dr Kath Mares (academic co-supervisor).

2.2 Introduction

Paediatric traumatic brain injury occurs very suddenly and can have significant and prolonged impacts on the CYP affected, as well as the parents, family and support network around that person (Jones et al., 2018, Wade et al., 2018). The underlying mechanisms and impacts of pTBI are outlined in detail in *Chapter 1: Introduction to the thesis*.

In line with the MRC's detailed complex intervention guidance, a pre cursor to designing an intervention is a comprehensive review of the existing literature, for example through a systematic review (Craig et al., 2008). The process of undertaking a systematic review involves the identification and review of all relevant evidence related to a clearly formulated research question (Wright et al., 2007, Cumpston et al., 2023). Inherent to this process is the systematic implementation of explicit methods required for the identification, selection and critical appraisal of primary research, combined with the extraction and analysis of data from included studies (Lasserson et al., 2023).

The strength of a systematic review is that the means of identifying, selecting, analysing and synthesising evidence from primary studies are documented *a priori*, minimising reviewer bias (Wright et al., 2007, Lasserson et al., 2023). Systematic reviews are also a means of supporting clinical decision making and exist within the field of evidence-based medicine. Gold-standard guidance has been developed and implemented by the Cochrane Collaboration which was founded in the United Kingdom in 1993 (Cumpston et al., 2023, Cochrane, 2024).

It is acknowledged that systematic reviews have traditionally focused on randomised controlled trials with the aim of producing unbiased evaluations about the effects of alternative interventions on a health condition (Reeves et al., 2023). That being said, the purpose of the current systematic review was to identify and analyse the active ingredients of existing interventions supporting parent delivered physiotherapy following pTBI, not to estimate the effects of alternative interventions. Examples of active ingredients of interventions, referred to as behaviour change techniques, include providing 'instructions on how to perform the behaviour', giving a 'demonstration of the behaviour' and offering 'information about health consequences'. In such systematic reviews, the research method employed within studies is not an exclusion criterion; rather a broad range of study designs, including randomised controlled trials and non-randomised studies of interventions, are to be included (Reeves et al., 2023).

Related to the broad inclusion criteria for study designs, consideration was given to whether a scoping review would be an alternative method for completing this work. A scoping review can be broader, enabling mapping of the nature, range and extent of evidence within a given field, whilst identifying potential evidence gaps (Mak and Thomas, 2022). Based on specific guidance about this, I concluded that a systematic review was the most appropriate approach, as the ultimate aim of this review was to uncover all available evidence related to a specific research question and to inform practice (Aromataris and Pearson, 2014, Munn et al., 2018).

2.2.1 Family-centred care following paediatric traumatic brain injury

Outcomes for CYP and families have been shown to be bi-directional with the child's outcomes being closely aligned with family's functioning and ability to meet the child's needs (Jenkin et al., 2022b). Therefore, support for the CYP *and their family* is crucial, with patient and family-centred care being widely considered as best practice (Kokorelias et al., 2019). In such cases, parents are often supported to deliver rehabilitation exercises to their injured child (Ylvisaker et al., 2005, Gmelig Meyling et al., 2022).

It is the role of healthcare professionals, namely physiotherapists, to support parents to deliver physiotherapy exercises and empower them to be able to continue their child's rehabilitation exercises at home. This may be with support from community services to optimise the safety and success of the transition from hospital to home, to aid reengagement with meaningful tasks for that person and improve long-term outcomes (The Association of Paediatric Chartered Physiotherapists, 2016). In this way, rehabilitation following pTBI considers the CYP's participation in everyday life, defined as their 'involvement in a life situation' (World Health Organization, 2007) which has been shown to be reduced following head injury (Keetley et al., 2020). This type of support is likely to be complex and multi-faceted, involving elements of behaviour change on the part of parents to learn, prioritise and follow relevant recommendations from physiotherapists (World Health Organization, 2003a, Meade et al., 2019, Skivington et al., 2021, Mir, 2023).

For many decades parental involvement has been considered an important element of rehabilitation for children following pTBI (Neuhaeuser, 1974b, Beaulieu, 2002a, Ylvisaker et al., 2005). That said, little is known about how parents are supported to deliver physiotherapy exercises.

To illuminate how parents are supported to deliver rehabilitation, an approach is required which moves beyond descriptions of interventions to understand their component parts and active ingredients. To achieve this, I propose that behaviour change theory and the framework of the Behaviour Change Wheel provides an accessible and appropriate method for doing this (Michie et al., 2014).

2.2.2 Importance of behaviour change to support delivery of rehabilitation

To enhance understanding of how interventions propose to achieve behaviour change, analysis beyond the basic description of their delivery is required. To understand the active ingredients of interventions (e.g., goal setting) and identify promising strategies for future interventions, Michie and colleagues developed the Behaviour Change Technique Taxonomy v1 (BCTTv1) (Michie et al., 2013). A behaviour change technique (BCT) is an "observable, replicable, and irreducible component of an intervention" (Michie et al., 2013, p.82). Furthermore, the Behaviour Change Wheel (Michie et al., 2014) provides a broader framework which can be applied to unpack complex, multi-faceted interventions supporting parents to deliver rehabilitation to their child following pTBI. Interventions can be characterised in terms of intervention functions: broad categories of means through which behaviour change may be achieved (e.g., education). Finally, in terms of the respective targets of the interventions (e.g., motivation) and how interventions achieve their effects (mechanisms of action), the Capability Opportunity Motivation-Behaviour (COM-B) model (Michie et al., 2014) and Theory and Techniques Tool (Theory and Techniques Tool, 2018, Carey et al., 2019) can be utilised to aid understanding. For further details about the Behaviour Change Wheel and COM-B model, please see *Chapter 1: Introduction to the thesis*.

2.2.3 Systematic review aim

This systematic review aims to identify existing interventions designed to support parents to deliver rehabilitation exercises aimed at improving motor function of their child following a pTBI. The means by which support for parents is delivered, conceptualised as strategies, will be identified from intervention descriptions, followed by a fine-grained analysis of component behaviour change techniques (BCTs), intervention functions and mechanisms of action.

2.3 Methods

This systematic review has been reported according to the latest Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Page et al., 2021a). In keeping with the best practice guidelines from PRISMA, this systematic review was carried out in accordance with the protocol published with PROSPERO (CRD42021290183).

Initial scoping searches were completed in Medline (EBSCo) which identified small numbers of studies that met the inclusion criteria. To capture the breadth of available evidence for analysis of active ingredients, studies using qualitative, quantitative or mixed methods were included. For the same reason, studies written and published in languages other than English were included if they met the inclusion criteria. In such cases, support was sought for translation from colleagues with appropriate and relevant expertise and who were fluent in the required language to enable translation and assess eligibility of the study against inclusion criteria.

Moreover, a wide range of search terms were included to ensure that the search was sufficiently broad and sensitive to capture all relevant literature, as opposed to missing relevant literature by being overly specific (Pimental, 2005). See 'Search strategy' below for further details.

2.3.1 Study inclusion criteria

Types of studies

To capture the breadth of available evidence, studies utilising quantitative, qualitative or mixed methods approaches were included if they were published in peer-reviewed journals. This included studies describing intervention development or evaluation of interventions through randomised controlled trials, pilot or feasibility studies or observational studies. Study protocols were included if they met the inclusion criteria.

In addition, in order to capture all relevant literature, grey literature including unpublished and ongoing studies, conference papers, committee reports, dissertations and theses were included provided they met the inclusion criteria (Paez, 2017).

Participant / population inclusion criteria

Due consideration was given to the description and role played by parents within included interventions, with two clear criteria set out for their involvement. Firstly, parents were participants if they were the recipient of an intervention, provided their child was below the age of 18 years at the time of their injury and had a diagnosed pTBI. Secondly, studies where the CYP with pTBI was the recipient of the intervention were included, provided that explicit reference was made to parent involvement in the description of the participants or the intervention itself. Studies which included no reference to parents in the description of the participants or the intervention were excluded.

Studies describing patient groups other than pTBI – for example those affected by acquired brain injury - were included if they made explicit reference to the inclusion of CYP with pTBI. Studies which made no reference to pTBI were excluded.

Types of interventions

Included studies reported interventions which referred to the delivery of rehabilitation exercises aimed at improving the motor functioning of CYP following a pTBI. Included interventions could additionally target other areas of human functioning, for example, cognitive functioning or communication, provided that the intervention also explicitly targeted motor functioning.

Types of outcomes

The main outcome of interest was the motor function of the CYP, including gross and fine motor function. Intervention development work and feasibility studies did not need to make explicit reference to outcomes.

2.3.2 Search strategy

An in-depth systematic search strategy was iteratively developed according to the PICO (population, intervention, control, outcome) acronym (McKenzie et al., 2023), in consultation with the academic supervisory team and a specialist librarian. Search terms comprised of different variations of keywords. This included combinations of 1) population (child* OR teen* OR youth) AND (mother* OR father* OR parent* OR famil*); 2) intervention (physiotherp* OR physical therap* OR PT OR rehabilitation), and; 3) outcome (motor* OR movement* OR physical function*). There was no requirement for studies to include a control group given the broad range of included study designs within this review (see Table 2.1 for the PICO criteria).

Keywords were combined using Boolean logic (AND, OR, NOT) and advanced search techniques, such as truncation, proximity searching, phrase searching and the use of Medical Subject Headings, were employed where relevant (King's College London, 2024). For the complete search strategies employed in each database, see Appendix 2.

Table 2.1 – PICO criteria to inform the search strategy

PICO	Inclusion	Exclusion
Population	• Children and young people (<18 years) with traumatic brain injury • Parents of injured children and young people	• Parents not included • Not relating to children (recipient of rehabilitation >18 years) • Population not affected by traumatic brain injury
Intervention	• Rehabilitation exercises aiming to improve motor functioning • Parents or parent delivered rehabilitation must be: i) referred to as part of a stated aim; ii) included in the methods section; iii) in the description of participants; iv) within the description of an intervention	• Rehabilitation exercises not delivered by parents • Not focussing of motor function of children with traumatic brain injury
Control	N/A	N/A
Outcome	• Measures of functioning relating to motor recovery (including strength, power, gross and fine motor skills, balance, mobility, movement, dexterity), or more broadly improved motor function of limbs, trunk, neck • Specified measures of motor functioning	• No measurement of motor function or outcomes related to motor functioning

2.3.3 Sources of data

Online database search

Systematic searches were conducted in seven online databases, including Medline (EBSCo), AMED (EBSCo), CINAHL (EBSCo), PsycINFO (EBSCo), Embase (Ovid), Scopus and the Cochrane Library including the Cochrane Central Register of Controlled Trials (CENTRAL) from inception to 2nd November 2021. The rationale for choosing these databases relate to their evidence specific to allied health professional research (Medline, AMED, CINAHL), behavioural science research (PsycINFO) and high-quality literature spanning medicine, social and life sciences (Scopus, CENTRAL, Embase).

Searches were conducted with no geographical location or language restriction to reflect the sensitivity of the search (Pimental, 2005). To make the searches more comprehensive, hand searching reference lists and reverse citation searching of studies meeting the inclusion criteria was completed (Lefebvre et al., 2023).

Grey literature searches

Additional systematic searches were conducted in three grey literature databases including Ethos, Open Grey and ProQuest from inception to 26th November 2021. Search terms were based around the PICO criteria as outlined above and modified for each database.

2.3.4 Identification of studies

All identified studies were exported to EndNote x9 (Clarivate, Philadelphia, USA) and deduplicated. I personally reviewed all titles and abstracts against the inclusion criteria. Following formal PRISMA guidance for the assessment of records by more than one reviewer, a random sample of 20% of studies was double-screened by a second reviewer (SC) at the title and abstract screening phase (Page et al., 2021b).

The approach of double-screening a random sample was chosen due to the resources available considering the sensitive database searches undertaken. Supporting the robustness of this process, inter-rater reliability of paper selection using the Cohen kappa statistic was calculated to assess the accuracy and precision of the dual-screening process as it takes chance agreement into account (Bland, 2015, Belur et al., 2018).

I downloaded and screened full texts of retained studies, with a random sample of 20% double-screened by a second reviewer (SC). Inter-rater reliability was again assessed using the Cohen kappa statistic (Bland, 2015, Belur et al., 2018). A third reviewer (WH) was on hand to facilitate discussion about disagreements between reviewers; however, the reviewer's input was not required within this stage of the screening process.

I additionally screened the eligibility of identified theses from the grey literature searches against the inclusion criteria at title and abstract plus full text screening phases.

2.3.5 Data extraction

The primary purpose for the systematic review was to identify strategies used to support parents to deliver rehabilitation exercises: this informed the data extraction and synthesis processes. Data extraction included numerical data related to the effectiveness of interventions, however this was not the primary purpose of the review.

I completed data extraction from accepted papers using a specifically designed data extraction template. All extracted data relating to intervention descriptions and strategies was checked for accuracy by two other reviewers (KM and WH, see below for further details). The template was developed in agreement with the supervisory team and initially piloted with an included study. I completed the data extraction using the template then discussed the data extracted with an academic supervisor (KM). Based on this process, the template was deemed to be appropriate and therefore was used for all included studies within the review.

Extracted data included general content: study title, lead author's name, country, year and journal of publication; study characteristics: design, number of groups, study aims, recruitment method, number of participants; and participant baseline characteristics: age, gender, ethnicity, type of injury. Outcome measurement and study outcomes using numerical data were also extracted, although this was not the primary purpose of the review.

2.3.6 Identification of intervention content

Intervention descriptions from included studies were independently reviewed by two reviewers (myself and KM) to identify strategies. Where a published research protocol was identified and accepted alongside a published study, data were extracted from both. Identified strategies were discussed and where discrepancies existed a third reviewer (WH) supported discussion until agreement was reached.

Intervention strategies were reviewed and component BCTs independently coded by two reviewers (myself and WH) using the BCTTv1 (Michie et al., 2013). The BCTTv1 is a taxonomy of 93 hierarchically structured BCTs divided into 16 groups through expert consensus, and applied extensively within behavioural science (Michie et al., 2013).

Prior to coding, I completed the accredited online BCT training course (BCT Taxonomy v1: Online training, 2023). Additionally, the second coder and my lead supervisor, Professor Hardeman, co-authored the BCTTv1 (Michie et al., 2013). BCTs were coded each time they appeared in intervention and control conditions to provide insight into both their presence and intensity. As outlined in the formal guidance, the level of certainty with which each BCT was present was also assigned (BCT Taxonomy v1: Online training, 2023). This was achieved by assigning a '+' symbol when the BCT was thought to be present in all probability and '++' assigned when the BCT was deemed present beyond all reasonable doubt. The two coders discussed any discrepancies until agreement was reached.

Subsequently, for each BCT all the corresponding intervention function(s) were coded using Table 3.3 (p.151-155) of the Behaviour Change Wheel book (Michie et al., 2014). Reviewers (myself and WH) included all intervention functions related to each BCT and did not make judgements about their relevance. They also coded relevant mechanism(s) of action using the Theory and Techniques Tool (Theory and Techniques Tool, 2018): a tool which triangulates evidence from published literature and expert consensus of 26 mechanisms of action with 74 BCTs (Theory and Techniques Tool, 2018). Finally, tables 2.2 (p.113-115) and 2.3 (p.116) of the Behaviour Change Wheel book (Michie et al., 2014) guided coding of intervention function(s) and mechanism(s) of action against the COM-B model to describe the behavioural targets of BCTs.

2.3.7 Data synthesis

I synthesised patterns between intervention content (including BCTs, intervention function, mechanisms of action and COM-B behavioural targets) and outcomes in a narrative way, in accordance with guidance from Popay and colleagues (Popay et al., 2006).

2.3.8 Quality assessment

Studies were categorised based on their methodology for quality and risk of bias assessments. The tools selected for assessment were based on gold standard recommendations for assessing risk of bias within systematic reviews (Reeves et al., 2023).

For included randomised controlled trials, quality assessment and risk of bias were assessed using the Revised Cochrane risk-of-bias tool for randomized trials (RoB-2) (Higgins et al., 2019). The RoB-2 tool offers a framework to consider the risk of bias of findings from any form of randomised trial (Higgins et al., 2019). Overall risk of bias ranges from low to high with 'some concerns' providing an intermediate rating.

For non-randomized studies of interventions, the The Risk Of Bias In Non-randomized Studies–of Interventions (ROBINS-I) assessment tool was used (Sterne et al., 2016). The ROBINS-I tool supports consideration of risk of bias from non-randomised studies of the effects of interventions which compare the effects of two or more interventions (Sterne et al., 2016). Overall risk of bias ratings ranges from low to critical with 'lack of information' used where there is no clear indication for risk of bias.

Two reviewers (myself and SC) independently applied the relevant tool and assessed risk of bias for included studies. Reviewers compared findings and discussed discrepancies until agreement was reached, with a third reviewer supporting discussions where needed (WH).

2.4 Results

2.4.1 Database searches

Online database searches identified a total of 8,355 studies: Medline (1,569), AMED (123), CINAHL (761), PsycINFO (2,403), Embase (1,886), Scopus (1,085) and the Cochrane Library (528). One thousand eight hundred and eighty-five duplicates were removed which left 6,470 studies for screening. Supplementary grey literature searching identified a total of 879 theses: Ethos (20), Open Grey (4) and ProQuest (855).

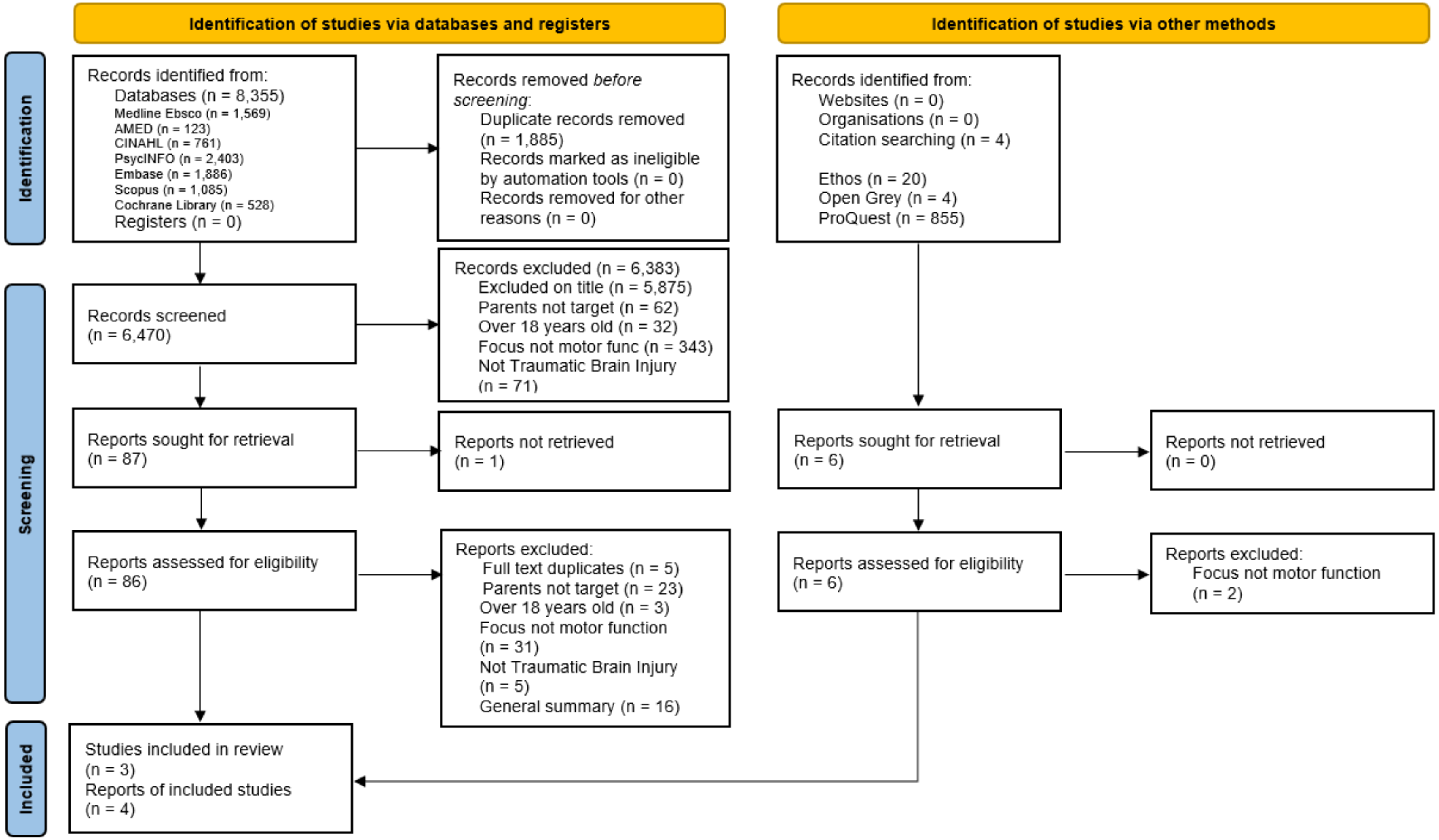
2.4.2 Selection process

There was substantial agreement between two reviewers for title and abstract screening (k=0.62 from 1,294 studies; overall agreement of 99%) (Bland, 2015). Following initial screening, 86 full texts were taken forward with almost perfect agreement between reviewers (k=0.82 from 18 studies; total agreement 94%). The full text for one study could not be located despite multiple attempts with support from specialist librarians and contacting the authors directly (Watkins, 2004). The main reasons for study exclusion were that studies made no reference to parents in intervention descriptions, participants were over the age of 18 years at the time of their injury or were not affected by pTBI (see Appendix 3 for full details).

As inter-rater reliability of study title and abstract screening had substantial agreement (k=0.62) and full text screening had almost perfect agreement (k=0.82), I reviewed all of the identified theses from the grey literature searches myself. A total of 877 theses were removed after title and abstract screening. Two theses were taken forward to full text review, but neither met the inclusion criteria due to the outcome under investigation not being motor function. A breakdown of the reasons for all exclusions of studies at the full text screening phase, including grey literature, are provided in Appendix 3.

In total, two peer-reviewed and published studies (Braga et al., 2005, Katz-Leurer et al., 2009b) and one study protocol (Boyd et al., 2015) met inclusion criteria following full-text screening. Four additional studies (Karman et al., 2003, Katz-Leurer et al., 2008, Cimolin et al., 2011, Sakzewski et al., 2016) were identified through hand searching of reference lists and included as they met the conclusion criteria, as reported in the PRISMA flow diagram below: see Figure 2.1 for details.

Figure 2.1 – PRISMA flow diagram



2.4.3 Summary of studies

Study and participant characteristics

In total, six studies evaluating six different interventions and one study protocol met the inclusion criteria (Karman et al., 2003, Braga et al., 2005, Katz-Leurer et al., 2008, Katz-Leurer et al., 2009b, Cimolin et al., 2011, Boyd et al., 2015, Sakzewski et al., 2016) with full details provided in Table 2.2. Studies were published over a 13-year period between 2003 to 2016 and were all written in English. Studies were conducted in Australia (Sakzewski et al., 2016), Brazil (Braga et al., 2005), Italy (Cimolin et al., 2011), Israel (Katz-Leurer et al., 2008, Katz-Leurer et al., 2009b) and the United States of America (Karman et al., 2003), none were conducted in the United Kingdom.

Studies included a total of 211 participants (ranging from seven to 87), and all included a mixture of males and females. Participant age range varied between studies, however, all participants were between the ages of five and 17 years. Two studies exclusively included participants that had sustained a pTBI (Braga et al., 2005, Cimolin et al., 2011), three included participants diagnosed with acquired brain injury, with a proportion having sustained a pTBI (ranging between 38-53% of the sample) (Karman et al., 2003, Katz-Leurer et al., 2008, Sakzewski et al., 2016), and one study had equal proportions of participants diagnosed with pTBI and cerebral palsy (Katz-Leurer et al., 2009b). Intervention duration lasted between two weeks and one year.

Summary of study designs

Studies utilised a range of designs: randomised controlled trial (Braga et al., 2005), pilot randomised trial (Sakzewski et al., 2016), feasibility study involving randomisation (Katz-Leurer et al., 2009b), feasibility study involving multiple case studies (Karman et al., 2003), non-randomised, self-control study with control and intervention periods (Katz-Leurer et al., 2008), and pre-post comparison study (Cimolin et al., 2011). Four studies included a control group which either received no care (Cimolin et al., 2011), received usual care in an out-patient clinic environment (Braga et al., 2005) or usual care in the community (Katz-Leurer et al., 2009b, Sakzewski et al., 2016).

Outcome measures

A range of 19 different outcome measures were used to assess changes in participants' motor function across the six studies. Only three outcome measures were common to more than one study – the ten-metre walking test, two-minute walk test and the energy expenditure index. These three outcome measures all relate to walking performance and both studies were conducted by the same lead researcher (Katz-Leurer et al., 2008, Katz-Leurer et al., 2009b). Upper limb dexterity and function were assessed using the highest number of different outcome measures (seven in total) as described in Appendix 4. Due to the heterogeneous array of outcome measures, meta-analysis was not possible.

Table 2.2 below summarises the accepted studies, including the outcome data. Within a randomised controlled trial, informal family supported rehabilitation led to a statistically significant improvement in motor function compared to direct clinician delivered rehabilitation (p=0.018) according to the SARAH scale (Braga et al., 2005). In a pre-post study, constraint-induced movement therapy led to a small effect size (Cohen's d = 0.48) according to the Gross Motor Function Measure (Cimolin et al., 2011). In a feasibility study, constraint-induced movement therapy led to large effect sizes according to the actual amount of use test: Cohen's d = 0.64 for amount of use, and Cohen's d = 0.97 for quality of movement subscales (Karman et al., 2003). In a different feasibility study, a home-based exercise programme led to significant improvements in walking speed (p=0.01) and 2-minute walking distance (p=0.02) following the intervention (Katz-Leurer et al., 2008). A further feasibility study demonstrated that home-based exercises led to a statistically significant reduction in the Timed Up and Go Test (p=<0.01) (Katz-Leurer et al., 2009b). Finally, in a pilot randomised trial, a web-based home intervention led to a statistically significant between-group difference (p=0.03) according to The Test of Visual Perceptual Skills Figure Ground when compared to usual care (Sakzewski et al., 2016).

Parent involvement in rehabilitation

In this section, I report the varying roles that parents played in their child's rehabilitation across studies, from active delivery of rehabilitation exercises to supervising their child.

All studies included an initial training period whereby the recipient of the intervention was trained to deliver/practice the rehabilitation exercises. In one study, parents were the primary focus of training and delivery of rehabilitation exercises to their child with pTBI

(Braga et al., 2005). Within this study, parents observed qualified professionals perform the intervention and assumed increasing responsibility as their competence increased. Parent involvement in their child's rehabilitation was somewhat different in the remaining studies.

Two studies included some parent delivered rehabilitation whereby a parent received training from therapists to deliver rehabilitation exercises alongside therapists or other hospital staff (Karman et al., 2003, Cimolin et al., 2011). Both studies implemented constrained induced movement therapy interventions whereby a parent co-delivered the rehabilitation. Three studies involved a therapist training the child how to complete the rehabilitation exercises at home (Katz-Leurer et al., 2008, Katz-Leurer et al., 2009b, Sakzewski et al., 2016) with parents also present during the training session. In these studies, parents were required to supervise the child completing rehabilitation exercises within the home environment.

Training in most studies included a description and demonstration of how to perform the exercises with an element of tailoring to the participant, for example, individualised goal setting or agreeing dosage based on baseline assessment measures. Some interventions included regular contact from therapists or the research team to review progress, trouble-shoot problems or update goals and plans. In all cases, a parent was present with the child at the time of these follow up contacts. In addition, some interventions also included diaries and reward charts to support monitoring of progress.

Context of rehabilitation delivery

Rehabilitation exercises were delivered within the home environment in four of the studies (Braga et al., 2005, Katz-Leurer et al., 2008, Katz-Leurer et al., 2009b, Sakzewski et al., 2016). In one study, rehabilitation exercises were delivered in a specialist rehabilitation unit (Karman et al., 2003) and in the other study, rehabilitation exercises were delivered in a combination of the home environment and a specialist rehabilitation unit (Cimolin et al., 2011).

Adherence to rehabilitation

Adherence is the extent to which an individual's behaviour aligns with a health professional's recommendation (World Health Organization, 2003a, Mir, 2023). No studies specifically reported parental adherence to the delivery of rehabilitation exercise at home. Three studies retrospectively assessed and reported child adherence to recommended rehabilitation exercises with parental supervision. In two studies, adherence data was extracted from self-reported records using paper-based exercise diaries (Katz-Leurer et al., 2008, Katz-Leurer et al., 2009b). Another study captured and analysed adherence data electronically (Sakzewski et al., 2016); see Table 2.2 for details.

Table 2.2 – Study and participant characteristics

Author, year of publication and country of study	**Study design, study duration, sample size**	**Population, study setting, recruitment method**	**Intervention group**		**Control group**		**Study / intervention retention, outcome and reported adherence**
			Sample size and participant characteristics	**Content and description of the intervention**	**Sample size and participant characteristics**	**Content of control**	
Braga et al. (2005), Brazil	Randomised controlled trial. One year, N=87	Children and young people aged 5-12 years, history of moderate to severe pTBI sustained 6-30 months prior to beginning the study. Home environment (intervention group) or clinic (control group). Recruited from admission records at specialist paediatric rehabilitation clinic.	N = 44. Age M(SD) = 97.66 (29.61) months. 47% female.	Parents delivered rehabilitation intervention. Parents underwent initial two-week block of training with therapists, goal setting and bi-weekly follow up in clinic. Intervention included individualised paper-based manuals with illustrations of exercises which parents delivered to their child at home.	N = 43 Age M(SD) = 96.95 (30.30) months. 44% female. Other characteristics not reported.	Parents received initial education and support. Children received daily out-patient clinic-based rehabilitation.	The intervention group retained 38 participants (86%) at follow up. The control group retained 34 participants (79%). Authors report that “the greater loss in the DCD [control] group was due largely to difficulties transporting the child to the clinic daily” (p.823). Between group comparison of outcome data for SARAH scale: IFS = 3.1 (0.8) and DCD 2.6 (1.1), p = 0.018. Adherence data not reported.
Cimolin et al. (2011), Italy	Pre-post study	Children and young people diagnosed with hemiplegia following pTBI with documented loss of	N = 10 Age range 8.8 – 12.9 years.	Constraint-Induced Movement Therapy (CIMT) intervention. Children wore mitt for	N = 10 Age range 7.3 – 13.6 years.	No intervention delivered	No reported loss to follow up.

	10 weeks, N=20	consciousness for 24 hours or more and a baseline IQ ≥60 (intervention group), compared to healthy subjects (control group). Inpatient brain injury unit of a rehabilitation hospital and home environment. Recruitment completed amongst inpatients in the brain injury unit.	Six had right (dominant)-sided and four had left (nondominant)-sided impairment. On average the participants commenced the intervention 0.7 years post injury (range 0.2-1.4 years).	three consecutive hours per day. Three days per week in hospital, therapists led unimanual activities for 1.5 hours and parent led unimanual activities for 1.5 hours. Four days per week at home parents led three hour sessions of unimanual activities.			Motor outcome according to the Gross Motor Function Measure increased from 88.1 (SD = 9.9) pre intervention to 92.6 (SD = 8.7) post intervention indicating a small effect size (Cohen's d = 0.48). Adherence data not reported.
Karman et al. (2003), USA	Feasibility study using multiple case studies. Two weeks, N=7	Children and young people with Acquired Brain Injury admitted to an inpatient rehabilitation unit. Intervention commenced between 25 days and 2 years post injury. Inpatient facility.	N = 7, pTBI = 43%. Age between 7-17 years old. 28.67% female	Two-week intensive block of Constraint-Induced Movement Therapy (CIMT). Posey mitt worn for all waking hours. Six hours of shaping activities daily (on weekdays) with graded difficulty of tasks to accommodate patient's limitations. At least four hours of therapy was delivered daily by therapy staff, all other shaping practice	No control group		All seven participants completed the intervention and post-intervention assessment. Amount of use (AOU) increased from 0.67 (SD = 0.87) pre intervention to 1.23 (SD = 0.92) post intervention indicating a large effect size (Cohen's d = .64) Quality of movement (QOM) increased from 0.96 (SD = 1.08) to 1.96 (SD = 1.63) with a large effect size (Cohen's d = .97).

				carried out by other staff and parents.			Adherence data not reported.
Katz-Leurer et al. (2008), Israel	Feasibility study. Non-randomised, self-control study. Four weeks, N=19	Children and young people with Acquired Brain Injury, aged five to 15 years at time of injury. Must be at least 1 year post onset of injury. Home environment.	N = 19, pTBI = 53%. Age M(SD) 12.5 (3.1) years. 53% female.	Child completed rehabilitation under supervision of a parent. Introduced to exercise protocol in a clinic environment and required to complete exercises at home under parental supervision (three sets of sit-to-stands, three sets of step-ups with each leg daily for at least three days per week). Intensity - 60% of individual max for first two weeks then up to 80% individual max for final two weeks.	No control group		High dropout rate of 53% (N=10) Authors report that “Logistics were cited most as the most significant factor [for withdrawal]” (p.74). Significant improvements were found in walking speed (baseline − pre-training difference = −0.06 metres/s and pretraining − post-training difference = 0.31 metres/s; P = 0.01) and in the 2-minute walking distance (baseline − pre-training difference = −1 metre and pre-training − post-training difference = 26 metres; P = 0.02). Exercise recommendations based on baseline results; it is not possible to determine participant adherence.

Katz-Leurer et al. (2009), Israel	Feasibility study. Randomised study. Six weeks, N=20	Children and young people aged 7-13 years, history of Cerebral Palsy or severe Traumatic Brain Injury Home environment. Recruited as outpatients or former patients of a Children's Rehabilitation Hospital.	N = 10, pTBI = 50%. Age M(SD) 8.2 (3.8) years. 30% female.	Child completed rehabilitation under the supervision of a parent. Completed sit-to-stand and step-up exercises on each leg daily, one minute rest between sets. Exercises five days per week, increased from 50% maximum for two weeks to 75% maximum thereafter. Intervention period was six weeks with follow up for a further 12 weeks.	N = 10 pTBI = 50%. Age M(SD) 9.2 (2.7) years. 30% female.	Told to continue with regular daily activities, including school and sports.	Nine participants in the intervention group completed the intervention. Eight participants were followed up at 12 weeks. Participants completed the exercises five times per week as recommended and were deemed to have adhered to the intervention. Post intervention the experimental group mean Functional Reach Test increased by 3-4cm with a reduction in Timed Up and Go Test of 1.6 +/- 2.1 seconds ($p=<0.01$). No changes found in the control group. No influences on adherence were reported.
Sakzewski et al. (2016)	Pilot randomised trial.	Children and young people aged 8-16 years with history of Acquired Brain Injury. Home environment.	N = 29, pTBI = 38%. Age M(SD) 11 years 10 months (2 years 6 months).	Child completed rehabilitation under the supervision of a parent.	N = 29, pTBI = 28%. Age M(SD) 11 years 11 months	Received usual care, determined by questionnaire completed	Participant retention to follow-up was 83.33% for the intervention group and 86.67% for the control group.

	Twenty weeks, N=58	Wait list randomisation using matched pairs.	48% female. Mainstream education 52%.	Move it to improve it (Mitii^{TM}), a web-based intervention combining cognitive and motor challenges. Recommended to complete 30 minutes/day, six days/week for 20 weeks.	(2 years 6 months). 41% female. Mainstream education 52%.	following intervention period.	Primary outcome - No significant difference on the Assessment of Motor and Process Skills test between groups. Secondary outcomes - there was a significant between-group difference, favouring Mitii for The Test of Visual Perceptual Skills Figure Ground (Estimated mean difference 3.1, 95% CI 0.2–6.0; p=0.03). There were no between group differences on overall scores for The Test of Visual Perceptual Skills or other visual perception domain scores, upper limb or individualized outcomes. Participants did not adhere to the intervention. Participants completed on average less than one hour of rehabilitation per week (17.6 hours over 20 weeks, not 60 hours as recommended).

M = Mean; SD = Standard deviation; IFS = Informal family supported rehabilitation; DCD = Direct clinical delivered rehabilitation; CP = Cerebral Palsy; pTBI = paediatric Traumatic Brain Injury.

2.4.4 Summary of interventions

Intervention content and targets

Of the six interventions analysed, two targeted improvements in lower limb strength and endurance through sit-to-stands and step-up exercises completed at varying intensities (Katz-Leurer et al., 2008, Katz-Leurer et al., 2009b). Two targeted improvements in upper limb function of children with hemiplegia through constrained induced movement therapy (Karman et al., 2003, Cimolin et al., 2011). One intervention targeted both motor and cognitive function through an integrated programme of bespoke exercises translated into simple activities using illustrations (Braga et al., 2005). One intervention targeted occupational performance, defined as "the accomplishment of the selected occupation resulting from the dynamic transaction among the client, their contexts, and the occupation" (American Occupational Therapy Association, 2020, p.8), upper limb function and visual perception using a multi-modal web-based rehabilitation intervention, Move-It-To-Improve-It (Mitii^{TM}) (Sakzewski et al., 2016).

When considering the target recipient of interventions, only one of the six interventions focused solely on parent delivered rehabilitation to a child following pTBI (Braga et al., 2005). The remaining studies all explicitly referred to parents being involved in either the delivery of aspects of the rehabilitation (Karman et al., 2003, Cimolin et al., 2011) or being present when the child received training on the content of the intervention (Katz-Leurer et al., 2008, Katz-Leurer et al., 2009b, Sakzewski et al., 2016). In all instances, parents were requested to supervise their child completing exercises when parents themselves did not deliver any aspect of the intervention (Katz-Leurer et al., 2008, Katz-Leurer et al., 2009b, Sakzewski et al., 2016).

Behaviour change techniques included in interventions and control groups

In total, 24 BCTs were coded across the six interventions. Interventions included between six (Cimolin et al., 2011) to 16 BCTs (Braga et al., 2005, Sakzewski et al., 2016) with an average of 11.67 BCTs per intervention. The two most frequently coded BCTs which were each coded 10 times in total across the six interventions and deemed to be present beyond all reasonable doubt were '1.1 Goal setting (behaviour)' and '4.1 Instruction on how to perform the behaviour'. BCT '1.4 Action planning' was also coded in all six interventions and was coded eight times in total.

Due to the comprehensiveness of the analysis, including BCTs, intervention target (parent or child), intervention functions, mechanisms of action and COM-B target for each intervention, the table is too lengthy to include within the chapter and can be found in Appendix 5. Instead, a summary of the key findings is presented as a heat map representing BCT coding and the level of certainty across interventions (see Table 2.3). Additionally, a summary of all the included BCTs together with their corresponding intervention functions, mechanism of action and COM-B targets is also provided (Table 2.4).

Table 2.3 - Heat map representing behaviour change technique coding and level of certainty per intervention

Behaviour change technique coded as being present	**Interventions included in accepted papers**						**Frequency of coding**
	Braga et al. 2005	Cimolin et al. 2011	Karman et al. 2003	Katz-Leurer et al. 2008	Katz-Leurer et al. 2009	Sakzewski et al. 2016	
1.1 Goal setting (behaviour)	🟩	🟩	🟩	🟩	🟩	🟩	10
1.2 Problem solving	🟩	🟥	🟥	🟥	🟩	🟩	5
1.3 Goal setting (outcome)	🟩	🟥	🟥	🟥	🟥	🟥	2
1.4 Action planning	🟨	🟩	🟩	🟩	🟩	🟩	8
1.5 Review behaviour goal(s)	🟩	🟥	🟥	🟥	🟥	🟥	1
1.7 Review outcome goal(s)	🟨	🟥	🟥	🟥	🟥	🟩	4
2.1 Monitoring behaviour by others without feedback	🟥	🟥	🟨	🟥	🟨	🟩	5
2.2 Feedback on behaviour	🟥	🟥	🟩	🟥	🟥	🟩	3
2.3 Self-monitoring of behaviour	🟥	🟥	🟨	🟩	🟩	🟥	3
2.4 Self-monitoring of outcome(s) of behaviour	🟥	🟥	🟨	🟥	🟥	🟥	1
2.7 Feedback on outcomes of behaviour	🟨	🟥	🟥	🟥	🟥	🟥	1
3.1 Social support (unspecified)	🟩	🟥	🟥	🟥	🟩	🟩	5
3.2 Social support (practical)	🟥	🟥	🟥	🟩	🟩	🟩	3
3.3 Social support (emotional)	🟨	🟥	🟥	🟥	🟥	🟥	1
4.1 Instruction on how to perform the behaviour	🟩	🟩	🟩	🟩	🟩	🟩	10
5.1 Information about health consequences	🟨	🟥	🟩	🟥	🟥	🟩	4
6.1 Demonstration of the behaviour	🟩	🟩	🟩	🟩	🟥	🟩	9
8.1 Behavioural practice/rehearsal	🟩	🟩	🟩	🟩	🟥	🟩	8
8.3 Habit formation	🟨	🟥	🟥	🟥	🟥	🟨	2
8.7 Graded tasks	🟨	🟥	🟨	🟩	🟩	🟨	7
9.1 Credible source	🟩	🟥	🟩	🟥	🟥	🟥	4
10.2 Material reward (behaviour)	🟥	🟥	🟩	🟥	🟥	🟩	3
12.5 Adding objects to the environment	🟥	🟩	🟩	🟥	🟥	🟩	3
14.4 Reward approximation	🟥	🟥	🟩	🟥	🟥	🟥	1
Total number of behaviour change techniques per intervention	16	6	15	8	9	16	24 coded in total

Key	Colour
Behaviour change technique coded, deemed to be present beyond all reasonable doubt '++'	🟩
Behaviour change technique coded, deemed to be present in all probability '+'	🟧
Behaviour change technique not coded as being present	🟥

As identified in Table 2.3 above, several BCTs were consistently coded together: '1.1 Goal setting (behaviour)' and '1.4 Action planning' were coded together in five of the six intervention descriptions (Karman et al., 2003, Katz-Leurer et al., 2008, Katz-Leurer et al., 2009b, Cimolin et al., 2011, Sakzewski et al., 2016). Furthermore, BCTs '4.1 Instruction on how to perform the behaviour', '6.1 Demonstration of the behaviour' and '8.1 Behavioural practice/rehearsal' were coded together in five of the six interventions (Karman et al., 2003, Braga et al., 2005, Katz-Leurer et al., 2008, Cimolin et al., 2011, Sakzewski et al., 2016). These BCTs were coded where participants received instruction or training in preparation for repeating exercises independently.

In three of the four studies which included a control group, no BCTs could be coded as control groups were reported to have either received no intervention (Cimolin et al., 2011), or 'usual care' (Katz-Leurer et al., 2009b, Sakzewski et al., 2016). In one study, three BCTs were coded which were also included in the intervention (Braga et al., 2005).

Intervention functions identified in intervention and control groups

From the nine possible intervention functions, eight were coded as being present within the interventions, all except for 'Restriction'. The three most frequently coded intervention functions were 'Enablement', 'Training' and 'Incentivisation' (coded 55, 44 and 17 times, respectively, across all interventions).

Within the descriptions of the control groups, three intervention functions were coded: 'Education' (coded once), 'Persuasion' (coded once) and 'Enablement' (coded twice).

Mechanisms of action identified in interventions and control groups

In total, 19 different mechanisms of action were coded in relation to the intervention BCTs identified. The three most frequently coded were ‘Beliefs about capabilities’, ‘Skills’ and ‘Goals’ (coded 29, 25 and 17 times, respectively, across all interventions).

Within the description of the control groups, eight mechanisms of action were coded: ‘Knowledge’, ‘Beliefs about consequences’, ‘Intention’, ‘Attitude towards the behaviour’, ‘Perceived susceptibility/vulnerability’, ‘Social influences’, ‘Beliefs about capabilities’ and ‘Behavioural regulation’ (all coded once).

Components of capability, opportunity and motivation of interventions and control groups

From the six individual components of the COM-B model, all were coded as being targeted by the identified intervention BCTs. In descending order, ‘Reflective Motivation’ was coded 85 times; ‘Psychological Capability’ was coded 43 times; ‘Physical Capability’ was coded 34 times; ‘Social Opportunity’ was coded 18 times; ‘Automatic Motivation’ was coded 10 times; and ‘Physical Opportunity’ was coded six times.

Within the control groups, three components of the COM-B model were coded: ‘Social Opportunity’ (coded once), ‘Psychological Capability’ (coded twice) and ‘Reflective Motivation’ (coded twice).

Table 2.4 - Coded behaviour change techniques presented alongside corresponding intervention functions, mechanism of action and COM-B targets

Intervention content		**Mechanism of action**	
Behaviour change technique	**Intervention functions**	**Theory and techniques tool**	**Capability, opportunity, motivation-behaviour (COM-B)**
1.1 Goal setting (behaviour)	Enablement	Intention Goals	Ref M
1.2 Problem solving	Enablement	Beliefs about capabilities Behavioural regulation	Ref M Psy C
1.3 Goal setting (outcome)	Enablement	Goals Motivation	Ref M
1.4 Action planning	Enablement	Behavioural cueing	Ref M
1.5 Review behaviour goal(s)	Enablement	Goals	Ref M
1.7 Review outcome goal(s)	Enablement	Goals	Ref M
2.1 Monitoring behaviour by others without feedback	Incentivisation Coercion	None identified	Ref M
2.2 Feedback on behaviour	Education Persuasion Incentivisation Coercion Training	Motivation Feedback processes	Ref M
2.3 Self-monitoring of behaviour	Education Incentivisation Coercion Training Enablement	Behavioural regulation Feedback processes	Ref M
2.4 Self-monitoring of outcome(s) of behaviour	Education Incentivisation Coercion Training Enablement	None identified	Ref M
2.7 Feedback on outcomes of behaviour	Education Persuasion Incentivisation Coercion Training	Feedback processes	Ref M
3.1 Social support (unspecified)	Enablement	Social influences	Soc O
3.2 Social support (practical)	Enablement	Environmental context and resources Social influences	Phys O Soc O
3.3 Social support (emotional)	Enablement	None identified	Soc O
4.1 Instruction on how to perform the behaviour	Training	Skill Beliefs about capabilities	Phys C Psy C Ref M
5.1 Information about health consequences	Education Persuasion	Knowledge Beliefs about consequences Intention Attitude towards the behaviour Perceived susceptibility/vulnerability	Psy C Ref M
6.1 Demonstration of the behaviour	Training Modelling	Beliefs about capabilities Social learning/imitation	Phys C Psy C Soc O Ref M
8.1 Behavioural practice/rehearsal	Training	Skill Beliefs about capabilities	Phys C Psy C Ref M
8.3 Habit formation	Training	Behavioural cueing	Auto M

8.7 Graded tasks	Training Enablement	Skill Beliefs about capabilities	Phys C Psy C Ref M
9.1 Credible source	Persuasion	Attitude towards the behaviour General attitudes/beliefs	Ref M
10.2 Material reward (behaviour)	Incentivisation	Reinforcement	Auto M
12.5 Adding objects to the environment	Environmental restructuring, Enablement	Environmental context and resources Behavioural cueing	Phys O Auto M
14.4 Reward approximation	Incentivisation	None identified	Auto M

COM-B – Capability Opportunity Motivation-Behaviour model comprising of: Phys C – Physical Capability, Psy C – Psychological Capability, Phys O – Physical Opportunity, Soc O – Social Opportunity, Ref M – Reflective Motivation, Auto M – Automatic Motivation

2.4.5 *Quality appraisal and risk of bias*

Overall, three studies were assessed for risk of bias using the RoB-2 tool and all were deemed to be at high risk of bias (Braga et al., 2005, Katz-Leurer et al., 2009b, Sakzewski et al., 2016), see Appendix 6 for full details. The main potential sources of bias were the impact of missing outcome data and the measurement of outcomes, with particular concern from lack of assessor blinding.

Two studies were assessed for risk of bias using the ROBINS-I tool (Katz-Leurer et al., 2008, Cimolin et al., 2011). The studies were deemed to be at either serious (Cimolin et al., 2011) or critical (Katz-Leurer et al., 2008) risk of bias, see Appendix 7 for full details. The main sources of risk of bias were selection of participants to the intervention and deviations from the intended intervention particularly due to high participant withdrawal rates. Measurement of outcomes with lack of assessor blinding was also problematic.

The feasibility study consisting of multiple case studies (Karman et al., 2003) was not assessed for risk of bias as an appropriate tool could not be identified.

2.5 Discussion

Parents experience increased stress and significant challenges following their child's pTBI (Kirk et al., 2014, Tyerman et al., 2017). Parents are required to deliver rehabilitation to their child in the home environment after leaving hospital, however, little is known about how parents are supported to do this. For the first time, this systematic review has identified and unpacked the components of interventions involving parents delivering, supervising or supporting rehabilitation exercises undertaken by CYP following pTBI.

Six studies, evaluating six interventions, delivered to 211 participants, were analysed. Whilst parents were the target population for this systematic review, only one intervention focussed directly on the question of how to support parent delivered rehabilitation (Braga et al., 2005). This may reflect the current lack of awareness and understanding about a parent's role in their child's physical rehabilitation and indicates the lack of emphasis given to this area of clinical research to date. One intervention, for example, considered parental involvement entailing no more than their mere presence in the room whilst the child received training from a physiotherapist. Katz-Leurer and colleagues (Katz-Leurer et al., 2008) describe that parents were "passive observers" (pp.73) in meetings where the child was taught how to complete the rehabilitation exercises. In this case, parents were said to be entirely passive, however were expected to incidentally learn the exercises through observation then have the capability to appropriately supervise their child at home.

The systematic review has identified that parents are involved in their child's rehabilitation in three main ways. Firstly, parents were taught to actively deliver rehabilitation exercises following education from appropriately qualified professionals (e.g., physiotherapists) (Karman et al., 2003, Braga et al., 2005, Cimolin et al., 2011). Secondly, parents were supervisors of their child's rehabilitation (Katz-Leurer et al., 2008, Katz-Leurer et al., 2009b, Sakzewski et al., 2016). Finally, parents were involved in the planning and logistical tasks related to their child's rehabilitation such as scheduling appointments and taking their child to see the physiotherapist. This is particularly relevant as logistical reasons - such as travel distance and travel time - were sighted as being the main reason for participant withdrawal from two accepted studies (Braga et al., 2005, Katz-Leurer et al., 2008). It is therefore important for interventions to consider support for parents in all three of these ways.

These findings align with literature relating to unpaid/family carers in that parents must continue their existing role as a parent, whilst also informally assuming a new and challenging role of being an unpaid carer for their injured child (Brandt et al., 2022, Patty et al., 2024). Informal family carers have their own health needs and are both the clients of, and co-workers with, health professionals and formal care services (Farquhar, 2022, Brandt et al., 2022).

Within the systematic review I have identified common active ingredients across all interventions. Three BCTs were present in all interventions and primarily deemed to be present beyond all reasonable doubt by two coders, as demonstrated in Table 2.3: 'Goal setting (behaviour)', 'Action planning' and 'Instruction on how to perform the behaviour'. BCTs 'Goal setting (behaviour)' and 'Action planning' were frequently coded together which is appropriate as they are complimentary techniques and in circumstances where behavioural goals are defined by context, frequency, duration or intensity the BCTs require joint coding (BCT Taxonomy v1: Online training, 2023). As demonstrated in Table 2.4, 'Goal setting (behaviour)' and 'Action planning' are BCTs which are both delivered through the intervention function

Enablement, meaning that they can change behaviour through increasing means or reducing barriers to increasing capability or opportunity to perform a behaviour (Michie et al., 2014). Additionally, they share the target of reflective motivation meaning that they both involve reflective processes involving plans (intentions) and evaluations (beliefs about what is good and bad) of the individual enacting the behaviour (Michie et al., 2014).

Additional BCTs which were coded as being present beyond all reasonable doubt and were coded together multiple times in five of the six included interventions were those of 'Instruction on how to perform the behaviour', 'Demonstration of the behaviour' and 'Behavioural practice/rehearsal' (see Appendix 5 for full details). These BCTs share the common feature that they are all delivered through the intervention function Training, which involves the imparting of skills (Michie et al., 2014). Furthermore, they share the behavioural targets of Reflective motivation as well as Physical capability which is the physical skills, strength or stamina to perform a behaviour, and Psychological capability which is knowledge or psychological skills, strength or stamina to engage in the necessary mental processes (Michie et al., 2014).

These groups of BCTs are key findings from the review as when active ingredients are grouped this can aid their delivery and effectiveness (van Genugten et al., 2016). Goals and planning as well as training, demonstration and practice are essential processes required for learning, planning and implementing rehabilitation exercises. In addition, all five of these clustered BCTs target reflective motivation which supports the participant to actively engage in the intervention and consciously enact new behaviours through the creation of plans and evaluations which informs the intention to act (Hankonen, 2021, Gardner et al., 2022).

Given the necessary repetitive, long-term nature of rehabilitation exercises required for neuroplasticity, it is surprising that interventions have not prioritised the maintenance of behaviour and delivery of exercises over time. Our analysis revealed that some active ingredients are notably absent from the interventions. The BCT 'Prompts/cues', which considers the environmental or social stimuli for prompting or cueing the behaviour, was not coded in any interventions, however was found to be present in another systematic review of interventions with significant positive effect for supporting the maintenance of physical activity (James et al., 2022). Furthermore, 'Generalisation of target behaviour' is also absent, which would include advice to implement rehabilitation exercises outside of a specific context (for example, implement balance-based exercises in the local park in addition to the home environment). Included studies in this review were primarily feasibility studies conducted over a period of weeks to a few months, which may explain the focus on initiation as opposed to maintenance of rehabilitation exercise delivery.

The nature of repetitive daily physical rehabilitation exercises would appear to lend itself well to the development of habits, as has been seen elsewhere (James et al., 2022). Habitual behaviours are enacted when a situation triggers an action with little or no conscious forethought, learned through practice and rehearsal (Gardner et al., 2023). Habit also supports the maintenance of behaviours when conscious motivation decreases (Gardner et al., 2022). This goes beyond the conscious processes of planning and initiating behaviours to more automatic processes which are triggered by the environment. The corresponding BCT 'Habit formation' has been coded only twice across interventions, with coders concluding the BCT was present in all probability (colour coded yellow on the heat map – Table 2.3). This is because study authors referred to incorporating rehabilitation exercises into family routines, as opposed to building habits, per se (Braga et al., 2005, Boyd et al., 2015). Notably, 'Habit formation' was coded in the two interventions with the longest study durations of the accepted studies: 20 weeks (Boyd et al., 2015, Sakzewski et al., 2016) and one year (Braga et al., 2005). Again, this emphasises the need for future interventions to include BCTs which support the maintenance of rehabilitation exercise delivery over time.

Similarly, 'Problem solving' is an evidence-based BCT worthy of further consideration in the context of empowering parents to deliver rehabilitation exercises. The BCT 'Problem solving' was coded six times across interventions, however these primarily related to professional problem solving following participant feedback or problem solving technical issues. According to the BCTTv1, 'Problem solving' is about empowering parents to analyse factors, which help overcome barriers or increase facilitators to delivering rehabilitation exercises (Michie et al., 2013). This could be considered as part of the wider discourses around family-centred care and parent delivered rehabilitation (also referred to in the literature as 'parent self-management') where support seeks to move from a paternalistic model to one of shared power and ownership (Wong Chung et al., 2021). Wong Chung et al. investigated healthcare professionals' motivation to support parental self-management when working with children with physical disabilities. They found that around 90% of participants taking part in a mixed-methods study believed that parents should take an active role in their child's rehabilitation, whereas fewer than 10% considered parents taking the initiative and being independent actors in the rehabilitation process as being important (Wong Chung et al., 2021). The study additionally found that sharing responsibility could be difficult for professionals as they navigate maintaining authority and control with sharing responsibility with parents. This is echoed in the findings of a qualitative synthesis of literature relating to parent-delivered therapy interventions for children with cerebral palsy; Lord and colleagues highlight the need for support, trust and shared decision-making in helping to build trusting relationships between parents and therapists (Lord et al., 2018).

It is noted that four of the six included studies involve mixed samples of CYP diagnosed with acquired brain injury and/or cerebral palsy. Both conditions encapsulate complex neurological disorders which frequently lead to motor impairments; however, they also include a high degree of variability in nature of injury and timing of neurological insult on the developing brain (Mimouni-Bloch et al., 2023). The need for supporting parent delivered rehabilitation amongst diverse populations should not be homogenised and assumed. Rather, appropriate investigation and stakeholder engagement needs to be undertaken to ensure that interventions are created to adequately meet the needs of their end users (Skivington et al., 2021).

The findings from this review suggest that much more research is needed to develop theory- and evidence-based interventions providing support for parents to deliver rehabilitation exercises. There is a need to go beyond the initial education, goal setting and planning for the delivery of exercises to consider the longer term, complex nature of rehabilitation delivery in a real-world setting and helping to support maintenance of exercise delivery over time.

2.5.1 Strengths, limitations, and directions for future research

This review is the first to examine support for parent delivered rehabilitation exercises following childhood pTBI, generating evidence to inform practice. The fine-grained approach to identifying strategies and coding BCTs is a real strength of this review, however it is possible that not all BCTs included within interventions were identified. This is due to insufficient reporting of the intervention content, which limits detailed understanding and the ability to adapt interventions for different contexts (Skivington et al., 2021).

Another strength of the review is that risk of bias tools suited for study methodology were completed by two reviewers. All studies had methodological flaws and were deemed to be at high, serious or critical risk of bias. This leads to caution about the interpretation of results. Having said that, the primary purpose of the review was to complete an in-depth analysis of the strategies used to support parents to deliver rehabilitation to their child and that has been achieved.

There is a paucity of evidence for parent delivered rehabilitation exercises for children following pTBI and only one randomised controlled trial was identified (Braga et al., 2005). This is a limitation of the evidence reflected by the fact that the studies that I identified include clinical heterogeneity from the perspective of both study participants and the study methodologies used. Future research should seek to understand the needs of users and other key stakeholders from their own perspectives through qualitative research. This is recommended by best-practice guidance for intervention development and will support the acceptability and usability of interventions (Craig et al., 2008, Hankonen, 2021, Skivington et al., 2021). Evidence from the present systematic review and subsequent qualitative research could then be used in conjunction to provide an evidence-base when co-designing interventions with parents, physiotherapists and other key stakeholders. Such approaches to co-design will go some way in helping to address power imbalances and better support parent self-management (Wong Chung et al., 2021).

Future research should also seek to provide detailed descriptions about the content of interventions and underlying theory to provide rigour and transparency to the design process and enable replication of interventions (Skivington et al., 2021). This will help to develop further evidence about parent delivered rehabilitation and suggest which behavioural targets, BCTs and elements of interventions are particularly important in supporting behaviour change (Michie et al., 2014).

2.6 Conclusions

This is the first systematic review to examine in depth how interventions have supported parents to deliver rehabilitation exercises to their child following pTBI. The active ingredients and intervention content identified can be used to inform future theory- and evidence-based interventions. Findings suggest that instruction, demonstration and practice, as well as goal setting and planning are particularly important elements of interventions aimed at increasing the skills and motivation of parents who deliver, or support the delivery of, rehabilitation exercises. However, future interventions need to consider the longer-term maintenance of behaviours related to rehabilitation delivery. Intervention developers should consider co-designing interventions with the intended users and other key stakeholders and provide clear descriptions of their content to aid evaluation, implementation and adaptation for different contexts.

2.7 Chapter summary and next steps

As described in *Chapter 1: Introduction to the thesis*, the COM-B model is the central hub of the BCW and is key in understanding influences on behaviour. As such, the COM-B model is the key model upon which I will map new and existing evidence throughout the chapters of this thesis to collectively inform the intervention development process.

The findings from this systematic review are summarised according to the COM-B model sub-constructs and presented in Table 2.5 below. Further work is required to consider the experiences, views and needs of parents and other key stakeholders from their own perspectives. These important considerations will be explored and discussed through qualitative studies undertaken with parents of children with pTBI and paediatric physiotherapists (see *Stages 2 and 3 – Collecting new qualitative evidence* below).

Table 2.5 - Summary of key findings from this chapter mapped on to the COM-B model

COM-B sub-constructs	**Identified within existing interventions? Yes/No**	**Key findings**	
		Frequency of coding	The relevance of the COM-B sub-construct within interventions
Physical Capability	Yes	Coded 34 times across interventions	This intervention target was particularly relevant to acquiring skills through instruction, demonstration and practice in a graded way
Psychological Capability	Yes	Coded 43 times across interventions	This intervention target was particularly relevant to problem solving, acquiring knowledge and psychological skills through instruction, demonstration and practice in a graded way
Reflective Motivation	Yes	Coded 85 times across interventions	This intervention target was particularly relevant to planning, monitoring and reviewing behaviour as well as acquiring skills through instruction, demonstration and practice in a graded way. This intervention target was also relevant to problem solving and receiving information about health consequences
Automatic Motivation	Yes	Coded 10 times across interventions	This intervention target was particularly relevant to habit formation, rewarding behaviour and adding objects to the environment
Physical Opportunity	Yes	Coded 6 times across interventions	This intervention target was particularly relevant to social support (practical) and adding objects to the environment
Social Opportunity	Yes	Coded 18 times across interventions	This intervention target was particularly relevant to all forms of social support and demonstration
Summary	All sub-constructs of the COM-B model feature across interventions	Reflective motivation was coded almost twice as frequently as any other sub-construct	-

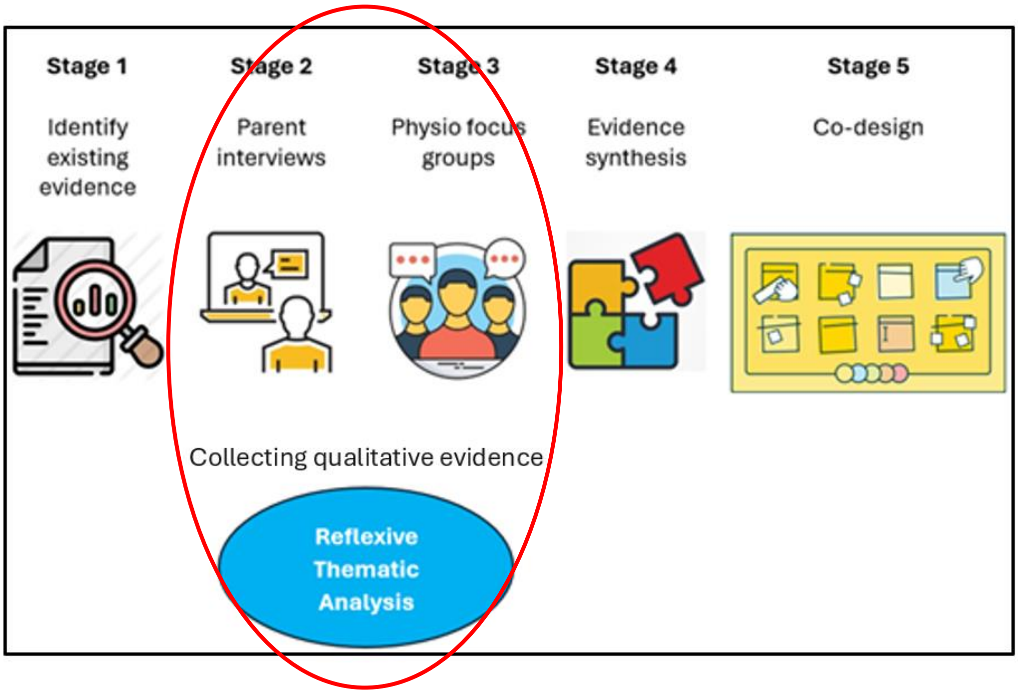
Key: The colours within the table represent those within the COM-B model itself, whereby red refers to Capability, yellow refers to Motivation and green refers to Opportunity. See Figure 1.4 on page 44 for further details about the COM-B model.

Stages 2 and 3: Collecting new qualitative evidence

Chapter 3: An introduction to the qualitative studies

As recommended within the MRC complex intervention development and evaluation guidance, the following two chapters present new primary research in the form of two qualitative studies which I undertook to generate new evidence (Craig et al., 2008). These studies will be presented in *Chapter 4: Qualitative study involving parent interviews*, and *Chapter 5: Qualitative study involving physiotherapy focus groups*, with the new evidence supplementing existing evidence generated from *Chapter 2: Systematic review* (Craig et al., 2008). As such, the qualitative studies have been undertaken to generate new evidence to feed into the conceptual design of the intervention (Michie et al., 2014). The qualitative studies represent Stages 2 and 3 of the intervention development process, as identified in the Figure 1.1 below.

Figure 1.1 - Figure providing an overview to the thesis structure



This brief introduction to the qualitative studies serves two main purposes. Firstly, I will outline reasoning and rationale related to the methodological decisions based on the ontological and epistemological positions that I adopted throughout the studies, together with my orientation to the data (Braun and Clarke, 2022). Secondly, in acknowledging my active role in the study conduct and analysis process, I introduce the essential role of reflexivity within the qualitative studies (Olmos-Vega et al., 2023). This introduction serves the purpose of beginning to document my reflexivity which will continue throughout the following chapters.

3.1 Outlining my methodological approach

3.1.1 The merits of inductive and deductive data analysis

From the outset, it is important to reiterate that the focus of my PhD research is the development of a theory- and evidence-based digital behaviour change intervention to support parents of children with pTBI to adhere to delivering physiotherapy exercises (West and Michie, 2016, O'Cathain et al., 2019). Therefore, several decisions were made *a priori* and have been explicitly laid out from the beginning of the research design process and conduct of individual studies.

Firstly, the Behaviour Change Wheel is the theoretically informed framework upon which the conceptual design of the intervention is to be based (Michie et al., 2011). As outlined previously in *Chapter 1: Introduction to the thesis*, to enable deeper understanding of influences on behaviour, and targets for behaviour change, the COM-B model exists at the centre of the Behaviour Change Wheel. Utilising the COM-B model is extremely advantageous in gaining insight and a detailed understanding of the influences on behaviour from different data sources in a consistent and organised way (Michie et al., 2014). However, within qualitative data analysis, adopting a primarily deductive orientation to the data and utilising existing theoretical constructs to shape the analysis has its limitations. A primarily deductive orientation to data analysis offers a real possibility that the nuances, complexities and richness within participants' accounts of their experiences may be overlooked in favour of prioritising theory-based coding (McGowan et al., 2020, Byrne, 2022, Turner et al., 2023).

This has the potential to be particularly consequential within an under researched area whereby a plethora of existing evidence does not yet exist within the literature (McGowan et al., 2020). This is certainly relevant within pTBI as no research has yet been undertaken exploring parents' experiences and perspectives related to influences on delivering physiotherapy, nor the perspectives of the physiotherapists that support them (Young et al., 2024a). Therefore, rigorously conducted qualitative research adopting a more inductive data-driven orientation to analysis has a lot to contribute to the evidence base (McGowan et al., 2020).

In this regard, a primarily inductive orientation to the data during analysis can be advantageous as the analysis is situated by the data themselves through data coding and the generation of themes (Braun and Clarke, 2022). Conversely, however, adopting a primarily inductive orientation to the data without any deductive element of analysis presents the potential limitation that new and existing evidence may not be effectively integrated to inform intervention development (Craig et al., 2008, O'Cathain et al., 2019). Similarly, where there is no application of existing theoretical understanding on influences on behaviour, the COM-B model has the potential to become surplus to requirements.

3.1.2 Combining inductive and deductive data analysis

Considering this juxtaposition, the research objectives for the following qualitative studies reflected two independent, but interlinked research priorities most appropriately answered using combined inductive and deductive analysis, undertaken sequentially. Firstly, I used inductive analysis to explore the experiences of participants from their own perspectives to generate new evidence which will contribute rich, positioned and nuanced findings to the evidence base. Then I used deductive analysis to map the findings against the COM-B model and feed the detailed understanding of behavioural influences into the conceptual design process (Michie et al., 2014, Turner et al., 2023).

Within the second stage of analysis, the TDF was additionally employed to support deductive data analysis as it provided a more detailed description of behavioural influences than the COM-B model alone (Atkins et al., 2020). In addition, the TDF is a complementary framework to the COM-B model which is recommended for use following initial inductive data analysis in qualitative research (Cane et al., 2012, McGowan et al., 2020, Turner et al., 2023).

There are parallels between the approach described above and another approach to intervention development, namely the Person Based Approach (Llahana et al., 2023). The Person Based Approach provides a framework to glean valuable insights into how individuals experience interventions, focusing on user needs and perceptions to optimise the acceptability of interventions (Yardley et al., 2015, Curran et al., 2025).

Both approaches to intervention development, the Behaviour Change Wheel and Person Based Approach, emphasise the importance of a detailed understanding of the target behaviour and how to best to support behaviour change. The focus of *Stages 2 and 3: Collecting new qualitative evidence* is to generate new evidence which provides a detailed understanding of parental adherence. To achieve this, I have opted to utilise the Behaviour Change Wheel - including the COM-B model - plus the TDF as they offer the opportunity for a rigorous and structured behavioural analysis which will feed into intervention development (Curran et al., 2025).

3.2 Ontology and epistemology

3.2.1 The role of critical realism

Related to the priorities for the qualitative research, the ontological and epistemological positions of critical realism were well placed to support me to answer my research questions. This is because the research questions relate initially to participants' construction and perception of their reality, best answered with an inductive orientation to the data (constructivist paradigm). Additionally, the research questions consider the underlying causal processes related to participants' behaviour as a result of behavioural influences, best answered with a deductive orientation to the data (positivist paradigm) (Alderson, 2021, Braun and Clarke, 2022).

If I were to adopt a purely constructivist epistemology, then it is entirely possible that I would do a good job of producing knowledge about how participants describe and make sense of their reality. However, this would be at the expense of not generating knowledge about the underlying influences on their behaviour relating to delivering physiotherapy exercises (Braun and Clarke, 2022). Likewise, if I adopted a purely positivist epistemology, then the converse would be true, and I would likely miss highly contextualised and nuanced details about parents' experiences, failing to generate knowledge about their construction and perception of reality. Therefore, by adopting the perspective of critical realism in acknowledging the value and contribution of both constructivist and positivist research paradigms, I have explored participants' construction of reality together with underlying causal mechanisms (Braun and Clarke, 2022). In keeping with this, I selected a congruent methodological approach to data analysis, as I will outline further in the following section (Alderson, 2021).

3.2.2 Reflexive thematic analysis

Within the qualitative studies I have utilised reflexive thematic analysis which is consistent with the ontological and epistemological positions of critical realism, allowing for the incorporation of both inductive and deductive data analysis (Braun and Clarke, 2022, Fryer, 2022). I utilised a sequential two-stage analysis process to address the research objectives. Firstly, I utilised inductive analysis which enabled the interpretation of experiences and consideration of participants' construction of reality in generating new evidence. I secondly applied the COM-B model, together with the TDF, to deductively map the data to the behaviour change framework and feed this new evidence forward into the intervention design process (Atkins et al., 2020, Byrne, 2022, Turner et al., 2023).

The qualitative studies detailed within chapters 4 and 5 present new primary research related to the experience and views parents (*intervention end-users*), as well as those of physiotherapists (*key stakeholders* with a vested interest in the intervention). Specifically seeking the views of both groups was important in providing new insights to contribute to the existing evidence-base, whilst generating new data to inform the conceptual design of the intervention, as guided by the Behaviour Change Wheel (Craig et al., 2008, Michie et al., 2014).

3.3 Introducing reflexivity within qualitative research

An important consideration of qualitative data analysis is the process of acknowledging and examining my own views, perspectives and positionality in relation to the research (Olmos-Vega et al., 2023). Doing this in a reflexive way is crucial when conducting qualitative research due to the active role that I took in designing, conducting and analysing data from the studies (Braun and Clarke, 2022). It is important to also acknowledge that the analysis process was not an individual endeavour. As will be detailed further in the following chapters themselves, throughout the studies I met regularly with supervisors to review progress and challenges with the research, and to discuss, explore and probe my interpretations of the data. Furthermore, I sought the perspectives of highly experienced and knowledgeable colleagues as well as the PPI group to support and enhance the analysis process.

In this section I will begin the reflexive process and consider some key aspects of my positionality to the research with regards to important professional and personal attributes. I will also introduce the concept of insider-outsider researcher positionality and its relevance to the qualitative studies. This section offers a starting point to my personal reflexivity, with continued reflexivity presented throughout the following chapters.

3.3.1 Insider-outsider researcher positionality

As a paediatric physiotherapist myself, with many years of experience working with CYP, parents and families affected by pTBI, it is important to consider my professional positionality with regards to being an insider researcher. An insider researcher is someone who shares a particular attribute, or attributes, with study participants that they are conducting research with (Bukamal, 2022). This is relevant here because it can influence the quality of the data gathered through developing rapport with participants, creating an atmosphere of openness, honesty and acceptability where participants feel able respond to questions and communicate openly (Bukamal, 2022).

My position as an insider researcher is relevant to both the parent interviews and the physiotherapy focus groups. For the parent interview study, I made it clear within the participant information sheet that I am a paediatric physiotherapist conducting research as part of my PhD. In this context, I could be considered an insider researcher as I have experience of working with parents of CYP with pTBI and I am familiar with some of the situations which were being discussed. For example, I am very familiar with the acute hospital environment which parents attended following their child's injury. I am also a parent of young children myself, although I am not the parent of a child that has suffered a pTBI. In that sense, I may also be considered an outsider researcher.

Being an insider researcher is also very relevant for the physiotherapy focus groups as I am a fellow paediatric physiotherapist working in a similar clinical area to many of the participants. Moreover, I had existing professional relationships with some of the participants, many of which were familiar with my PhD research and the purpose of the focus groups. In this sense, I was an insider researcher sharing this important attribute with the participants.

3.3.2 Personal reflexivity

It is important to also consider reflexivity from a personal perspective and the influence that I had on the study conduct and data analysis. I have had a range of interactions with the health service throughout my life, ranging from primary care to specialist inpatient care. These have been as a patient and the recipient of healthcare services myself, as a husband and a father to my two children who were born in NHS hospitals, and as a friend and relative to loved ones receiving healthcare. Importantly, I have also had very frequent interactions with the health service as an employee of three different NHS Trusts over the course of my physiotherapy career. Likewise, it is important to acknowledge that I entered this research with my own personal experience of brain injury which I will briefly outline below.

One of my most personally significant experiences of encountering the health service was in 2004 when my older brother, Jonny, suddenly died following an unexpected and short illness. My brother did not sustain a traumatic brain injury but rather a spontaneous subarachnoid haemorrhage; a form of acquired brain injury. This happened when I was an 18-year-old, one week before I got my A-level results, and the month before I started University to study for my Undergraduate Physiotherapy degree.

The experience of suddenly receiving 'the phone call' that something awful had happened and rushing to the hospital to see my bother on a ventilator are stark and very clear memories for me. I can also clearly recall experiencing the initial uncertainty that I, together with my family and friends, faced about whether my brother would live or die. I feel that alongside my clinical experience, this personal experience has greatly informed my sensitivity, compassion and empathy towards the families that I work with, as well as the studies that I will go on to present in this thesis.

Chapter 4: Qualitative study involving parent interviews

4.1 A brief overview of this chapter

To date, qualitative studies have explored parents' experiences of attending hospital following their child's pTBI. However, no research has been undertaken which specifically explores parents' experiences of delivering physiotherapy, or sought to identify behavioural influences on adherence. The focus of this chapter is to present new qualitative evidence about parents' experiences of learning and delivering physiotherapy exercises to their child following pTBI, and influences upon their adherence to delivering physiotherapy.

With support from the Child Brain Injury Trust, the leading charity in the UK and Northern Ireland working with children, young people and their families following brain injury, parents were recruited to participate in remote semi-structured interviews. Consideration was given to parents' experiences spanning their child's initial admission to hospital, through to meeting and working with the physiotherapist, then returning home and delivering home-based physiotherapy themselves.

Using sequential inductive and deductive analysis, this chapter will present both inductive data-driven findings through themes, as well as deductively map those findings against the COM-B model. This chapter will build on the findings of Chapter 2: Systematic review which identified that current interventions to support parent-delivered physiotherapy work across a range of contexts from inpatient rehabilitation to home.

Importantly, the new evidence presented in this chapter will provide novel insights which go beyond our current understanding from existing interventions. The evidence will also feed into the conceptual design for a digital behaviour change intervention to support parent-delivered physiotherapy.

4.2 Introduction

It has been outlined in *Chapter 1: Introduction to the thesis* that pTBI occurs following a sudden force or forces causing damage to the brain resulting in altered brain function (National Institute of Neurological Disorders and Stroke, 2024). Whilst the injury itself occurs to the brain, depending on the location and severity of the injury it can present in a range of different ways. This includes motor deficits affecting both gross and fine motor activity, speech and language deficits, social, cognitive and processing difficulties (Schuchat et al., 2018).

As a leading and potentially devastating cause of long-term disability amongst CYP, consequences of pTBI can be significant for the individual affected (Wade et al., 2018). It is well documented that the impacts of pTBI also affect parents and the wider family with many parents experiencing significant and prolonged emotional distress (Brown et al., 2013, Jenkin et al., 2022b). The initial fear and uncertainty relating to the child's survival then moves to fear for the future and the emerging consequences of injury, coupled with ongoing and dynamic processes of sadness, grief, and loss (Anderson et al., 2011, Brown et al., 2013, Jones et al., 2020).

Parents and the family context are of central importance for CYP, with outcomes following pTBI being shown to be bidirectional for the CYP and family (Taylor et al., 2001, Jenkin et al., 2022b). Context is important when considering the impact of pTBI as parents have been described as "the central 'contextual factor' in their children's lives" (Rosenbaum and Gorter, 2011, p.460). This serves to reinforce the importance of both physical and social context when seeking to adequately support parents through suitable family-centered approaches in rehabilitation (Novak-Pavlic et al., 2023). With the perspective that parents are a central factor of children's lives in all contexts then, to be optimally effective, rehabilitation following pTBI must be family-centered (Jenkin et al., 2022a).

Following pTBI, physiotherapists support CYP and families initially within the acute hospital setting, continuing through subacute rehabilitation and follow-up in the community (Gmelig Meyling et al., 2023a). Physiotherapists are experts of movement and movement dysfunction, working towards individual goals based on the child and family's needs and challenges (The Association of Paediatric Chartered Physiotherapists, 2016, Chartered Society of Physiotherapy, 2023). Physiotherapists support rehabilitation through approaches such as therapeutic exercises, the use of assistive devices and education, whilst making specific recommendations to support improved motor function and quality of life (American Physical Therapy Association, 2020).

The regular repetition of recommended task-specific physiotherapy exercises and activities over time, together with the integration of rehabilitation into everyday life are vital for continued improvement (Maier et al., 2019, Kleynen et al., 2020). This is because repetition of exercises is necessary for increased function and ability, whilst making rehabilitation meaningful within the context of everyday life and promoting functional carryover of progress (Braga et al., 2005, Gauthier et al., 2023). Best practice recommends the involvement and inclusion of parents in physiotherapy as they are well placed to support the repetition of rehabilitation within everyday life following discharge from hospital after pTBI (Jones et al., 2020, Young et al., 2024a). This is due to the parents' deep understanding of their child, their overview of family life and the opportunities available to them to integrate rehabilitation into daily activities (Braga et al., 2005, Novak, 2011).

Orientating behaviours towards rehabilitation and integrating physiotherapy into daily life is of vital importance following pTBI (Braga et al., 2005, Felsberg et al., 2019, Gauthier et al., 2023). Having said that, learning and delivering physiotherapy is a complex, multi-faceted and challenging process for parents, as the findings from *Chapter 2: Systematic review* demonstrate (Young et al., 2024a). An identified limitation of the current evidence is that no study has yet explored the experiences and views of parents related to learning and delivering physiotherapy exercises to their child following pTBI. This evidence gap informs the aim and objectives of this qualitative study.

4.3 Study aim and objectives

The aim of this qualitative study is to explore parents' experiences of delivering physiotherapy exercises and identify factors which influence parental adherence to the delivery of recommended physiotherapy.

The research objectives are:

1) To identify parents' first-hand experiences of learning and delivering physiotherapy exercises to children and young people following pTBI.
2) To identify behavioural influences on adhering to physiotherapy recommendations.
3) To generate new data to inform the development of a digital behaviour change intervention.
4) To identify parents' perspectives on possible content of the digital intervention.

4.4 Methodology

4.4.1 Study design

This qualitative study used remote semi-structured interviews to explore parents' experiences of learning and delivering physiotherapy exercises, and influences affecting their adherence. Ethical approval was obtained from the University of East Anglia Faculty of Medicine and Health Sciences Research Ethics Committee, Ref: ETH2223-2371 (see Appendix 8).

Methods for data collection were informed by the aims and objectives of this study, by the perspectives of the PPI group, and by the context of the global Covid-19 pandemic. Preparation of the protocol for this study commenced in late 2021 when University guidance was in place around social distancing and the avoidance of non-essential human interaction. Remote semi-structured interviews were deemed suitable as they enabled the collection of data to help address the research objectives, whilst also adhering to local and national policies related to Covid-19 (Wade et al., 2020, Carter et al., 2021).

There was no target sample size for this study: sample size relates to the concept of data saturation which is incongruent with reflexive thematic analysis (Braun and Clarke, 2022). The focus was to collect high quality in-depth qualitative data using remote semi-structured interviews. For further discussion about sample size and generalisability, please see section '4.6 Discussion' below.

4.4.2 Participants

Parents of children hospitalised following a pTBI were purposively recruited if they met the following inclusion criteria:

- Their child sustained a pTBI below the age of 18 years requiring a period of hospitalisation lasting at least 72 hours, with or without admission to a paediatric intensive care unit.
- Physiotherapy exercises were recommended to be delivered by the parent.
- The child and their parent had returned home from hospital prior to recruitment to the study.

Participant recruitment was supported by the Child Brain Injury Trust: a registered charity specialising in child and family support following brain injury in the United Kingdom and Northern Ireland: charity no. 1113326 (Child Brain Injury Trust, 2025).

Recruitment commenced in June 2022 and was completed in two phases as agreed by Mr Gerard Anderson, Head of Brain Injury Services at the Child Brain Injury Trust (Appendix 9). Phase one involved direct email contact from the charity's brain injury coordinators to parents known to meet inclusion criteria. Phase two was completed through an online flyer posted on the charity's social media pages including Facebook and Twitter, now X (Appendix 10).

To facilitate the recruitment of non-English speaking participants, support was available from accredited medical translators for translating participant-facing written materials, such as the participant information sheet (Appendix 11) and consent form (Appendix 12). Real-time verbal translation during interviews was additionally available for non-English speaking participants.

4.4.3 Patient and public involvement in the study

During this study, three parents of children that experienced a brain injury in childhood, and thus considered to be experts-by-experience, were consulted as part the research PPI group. The parents provided recommendations and guidance on running the study. For example, I consulted them on what approximate duration after the pTBI should participants become eligible to participate in the study. The group expressed that parents respond differently following their child's pTBI so a specific duration (for example, three months) would not be appropriate. Instead, they recommended that the CYP and parents needed to have returned home from hospital prior to participating in the study, and this recommendation is reflected in the participant inclusion criteria outlined above.

The PPI group also recommended that interviews take place remotely due to the challenges and demands for parents to meet face-to-face for interviews. PPI group members supported the ethics application through consultation and feedback, and contributed to participant facing materials, including the participant information sheet. They also supported the iterative development of the interview topic guide by reviewing and offering feedback on proposed topics and questions.

4.4.4 Procedure

Prospective participants completed an online eligibility and demographics questionnaire, and eligible participants completed an online consent form generated using Microsoft Forms. One-to-one semi-structured interviews were carried out online via Zoom using the common interview topic guide (see Appendix 13).

I led the iterative development of the interview topic guide with support from the PPI group (please see above for details). The topic guide was piloted with a post-graduate student prior to being finalised for use within interviews.

I conducted all the remote semi-structured interviews. With consent, online interviews were recorded using Zoom with a backup recording using a digital voice recorder. Audio footage from interviews was used to generate verbatim transcripts and I personally transcribed three interviews to begin the data familiarisation process. Due to time constraints the remaining interviews were transcribed by an experienced administrator within the University of East Anglia's School of Health Sciences. Transcripts were member-checked by participants to ensure accuracy and meaning of the interviews were retained following transcription. No changes were made to transcripts following member-checking.

4.4.5 Data analysis

Data analysis was undertaken using reflexive thematic analysis in two phases: firstly, inductive data-driven analysis explored the first-hand experiences of parents. This was followed by deductive analysis mapping the inductively generated findings against the TDF and COM-B model to identify behavioural influences on adherence. Please see paragraphs below for further details about data analysis, plus *Chapter 3: An introduction to the qualitative studies* for rationale and justification for the two-phase analysis process.

Inductive reflexive thematic analysis (Braun and Clarke, 2022) was undertaken to explore and interpret patterns represented through parents' accounts of their experiences of delivering physiotherapy exercises. I led the inductive analysis with support from academic and clinical colleagues as well as the PPI group.

To address research objective 1, I commenced inductive analysis through data familiarisation by reading interview transcripts multiple times, coding sections of transcripts, then iteratively generating, developing and refining themes (Braun and Clarke, 2022). Initial themes were reviewed together with academic supervisors with relevant expertise, Prof Duschinsky and Dr Mares, and subsequently refined following feedback and discussion. The iterative refinement of themes continued with paediatric health professionals with relevant clinical experience based on additional feedback and discussion. The paediatric health professionals that supported theme refinement included three physiotherapists, two clinical psychologists and a consultant paediatric neurologist, plus two experts-by-experience within the PPI group. The preliminary themes were shared with the PPI group and discussed to seek guidance on their perspectives of the themes. Their verbal and written feedback was incorporated into the refinement of the themes. The PPI group members were signposted to the Child Brain Injury Trust counselling service if they wished to seek any additional support following their involvement in the data analysis. The themes were then sent to participants for review, which resulted in no further changes.

To address research objective 2, the second phase of analysis involved reviewing each theme in turn and deductively mapping the data against theoretical frameworks of behaviour – the TDF and then COM-B model - to identify underlying causal processes. This deductive data mapping was completed independently by two reviewers, myself and Prof Naughton, to produce a detailed breakdown for each theme of behavioural influences on parental adherence, according to the COM-B model. This is an approach which has been used previously (Turner et al., 2023).

To achieve this, we independently reviewed themes and completed the two-step deductive analysis process. Data within themes were initially mapped against the theoretical constructs and 14 domains of the TDF (step 1), and subsequently behavioural targets were identified using the COM-B model (step 2) (Cane et al., 2012). Discrepancies were discussed until agreement was reached (see Table 4.2 below for details). This phase was completed to align data analysis with the COM-B model and enable findings to inform the behavioural diagnosis of what needs to change for parents to adhere to delivering physiotherapy exercises.

The evidence generated through combined inductive and deductive analysis will be taken forwards to inform the conceptual design of the intervention according to the Behaviour Change Wheel and contribute to the development of a digital behaviour change intervention (research objective 3).

In addition to the above data analysis, during interviews participants were asked about possible content of the intervention to feed into the intervention design process (research objective 4). For ease of organisation and presentation, participant quotes were extracted from transcripts and grouped based on the suggested content of the intervention, with no additional analysis or interpretation of the data. These suggestions can be found in Table 4.5 below.

As outlined previously, reflexivity forms a key component of qualitative research. As a means of personal reflexivity, I kept a reflexive log during data analysis and interpretation as a means of documenting critical review of the process and the impact of what, how and why the analysis was completed as it was (Braun and Clarke, 2022, Olmos-Vega et al., 2023). Importantly, I am a Caucasian male in my late 30s from England. I am a paediatric physiotherapist by profession with over 15 years of experience in paediatric rehabilitation. I have worked mainly in the NHS in England across acute hospital settings with some experience of community rehabilitation in

England and Tanzania. I was involved in all stages of study design, data collection and analysis. Please note that a further reflexive summary is provided within section *4.6 Discussion* below to expand upon my influences on data analysis and interpretation.

4.5 Findings

Between July 2022 and February 2023, 26 prospective participants signed up for the study, of which 14 met the inclusion criteria. Of the 14 eligible participants, five participated in interviews, including four mothers and one father. The reasons for non-participation of nine eligible participants were either that incorrect contact details had been provided, or that the online consent form was not completed despite multiple reminders.

For parents that were interviewed, participant and child characteristics were extracted from the eligibility and demographics questionnaire (see Table 4.1). The average age of participants was 41 years and interviews lasted an average of 54 minutes (range 35 to 64 minutes).

All participants had a child who required hospitalisation following pTBI and physiotherapy exercises were recommended following discharge from hospital. The ages of children when they sustained a pTBI were between three months and 16 years. Up to six years had elapsed between the child’s injury and parent’s interview. Please see Table 4.1 for ranges.

Table 4.1 – Participant and child characteristics

Participant characteristics	**n = 5**
Participant (parent) gender	n (%)
Female	4 (80%)
Male	1 (20%)
Age (years)	
Mean (SD)	41 (6.9)
Range	33 – 51
Child characteristics	**n = 5**
Child gender	n (%)
Female	2 (40%)
Male	3 (60%)
Age at injury	
<4 years	1 (20%)
4 – 10 years	1 (20%)
11 – 14 years	2 (40%)
15 – 18 years	1 (20%)
Admission to acute hospital including the Paediatric Intensive Care Unit	4 (80%)
Duration spent in acute hospital (weeks)	
Mean (SD)	3.8 (2.3)
Range	<1 to 6
Time elapsed since injury (years)	
Mean (SD)	2.5 (2.1)
Range	<1 to 6

n = number; SD = Standard Deviation

4.5.1 Inductive thematic analysis

Following completion of inductive analysis, four themes were identified:

1. Purpose and motivation
2. The importance of receiving clear information
3. Gaining confidence and skills through the learning process
4. Learning how to integrate physiotherapy into everyday life

The four themes are outlined below together with anonymised illustrative participant quotes (e.g., Participant-1 is written as P1). Names and places have been replaced by general descriptions to protect participant anonymity.

Throughout the remainder of this chapter, parents that participated in interviews will be referred to as 'participants'. This is to distinguish the participants of the study from parents of children with pTBI more generally.

Theme one: Purpose and motivation

This theme relates to changing priorities that participants expressed when their child was hospitalised following pTBI. From this change in priorities, being involved in physiotherapy and actively supporting their child's recovery gave participants a sense of purpose and motivation.

All five participants expressed a change of existing priorities when it came to attending the hospital and supporting their child. Being in hospital became participants' main priority as 'I felt like I had to be there the whole time' (P4). This was all-consuming and likened to being in a bubble where 'your whole life is in that hospital, in a little bubble, where you're just focusing on getting [my son] better and nothing else matters' (P1).

Whilst supporting their child was important, it was also deeply challenging for some participants, not least around the idea of initiating rehabilitation within physiotherapy sessions. Once medically appropriate, initiating movement seemed horrifying as parents felt overwhelmed due to being 'fearful about anything that meant moving [my son]' (P5). At first, their child being moved during rehabilitation threatened the relative safety that participants experienced when their child was kept still in bed. This is exemplified by the following quote:

> "Horrified. Yeah, just, just extremely overwhelming...you just want [my son] to rest and you just want him to relax and you want him to be okay and then the first time they [the physiotherapists] came in and said "we're going to sit him on the edge of the bed" I just thought what on earth are you thinking – No. You don't need to. He needs to stay still. Leave him alone" (P1)

In response to this experience participants were reassured and kept informed by the physiotherapists, which was said to be important. A participant described how the initial overwhelming feelings associated with physiotherapy changed with appropriate support; 'I think they [the physiotherapists] saw, even from my face. They were lovely and they explained it and then, I can't remember if he had physio then once or twice a day...in the end, it became like the norm' (P3).

Reflecting participants' priorities, in hospital they were gradually supported to deliver physiotherapy to their child and support their recovery. One participant expressed that 'you just do it [physiotherapy] because you haven't really got a choice. Because if you don't do it, then your child's not going to get up and not going to get any better' (P1). This was even the case when participants themselves felt exhausted by the situation, as 'I had to learn a lot of it because, you know, it's really exhausting on me, but I had to learn it for [my daughter]' (P2).

Delivering physiotherapy to their child gave some participants a focus and a purpose following the injury. One participant said ‘at that time, after having all of that trauma, it gave me a focus on this is now what I have to do, and this is what I have to do to make him better. Yeah, I jumped in with two feet’ (P3). Helping their child led participants to feeling positive and encouraged about doing something proactive as it gave ‘a little boost where you think I’m doing something, I am helping’ (P1). Additionally, delivering physiotherapy exercises offered some glimmers of hope which motivated many participants in the midst of the fear and uncertainty that they found themselves, their child, and their family in. One participant said that seeing ‘little tiny steps of progression fuelled my fire. I was like, “no, no, no. We’re going to do this every single day and you’re going to be the best that you can be.” So, these little, tiny steps that’s what it is, the motivator was hope’ (P3).

Theme two: The importance of receiving clear information

This theme relates to participants’ desire for information which is clear and easy to understand. Whilst wanting information, participants also expressed a feeling of being bombarded by information that they were unable to take in.

When in acute emotional distress following their child’s hospitalisation, some participants experienced being ‘bombarded with information, information, information, information’ (P2). Such was the level of distress that ‘I couldn’t take any of it in’ (P2). That said, many participants actually wanted information as they ‘wanted to understand. I wanted to understand prognosis. I wanted to understand what else we needed to be doing’ (P5). Therefore, information needed to be very clear and easy to understand.

First and foremost, it was important for participants to have clear information about the role of physiotherapists and how they could support the child’s rehabilitation. Clear information helped to establish a plan for the physiotherapists’ involvement and was given as early as the initial interactions with participants. A participant said that ‘one of the leading physiotherapists came out first…and explained what she was, what they were going to do to me and with [my daughter] in the next few weeks, and what the plan was’ (P2).

Clearly communicated information included having a purpose for physiotherapy and understanding the reason behind doing rehabilitation exercises. A participant explained that ‘everything that we do with [my son], has a reason for it. So, like you play with the toy, and you’ll be going “This is now for hand-eye coordination, and this is for grasp”’ (P3). This extends to the importance of having clear targets or goals that the participant and child worked towards. A participant said that it’s ‘a matter of just understanding your goals. Our goal was to get home.

That was my son’s main goal’ (P1). It was also important to break goals down into smaller parts, supporting engagement with more tangible and meaningful activities. One participant explained this to her son by saying ‘“Once you start walking we’ll get you home” and once he started walking, it was “once we take the stairs” because we have stairs at home, “then we can go home” and then it’s “once we can get you safely in and out of the bath”’ (P1).

In the hospital, clear information extended to having relevant resources to support participants in independently delivering physiotherapy exercises. Such resources included pictures and descriptions of exercises. A participant described that ‘even when they [the physiotherapists] weren’t there at the weekend they were leaving stuff for me to do with [my daughter]’ (P2). The need for clear supporting resources continued at home following discharge, as the physiotherapist ‘would send a follow-up email with a PDF [portable document format] of all the exercises, which suited [my son] extremely well’ (P5).

The need for clear information was consistent for all participants, with some explaining that new information added to relevant prior knowledge about the value of physiotherapy. One participant described previous visits to a physiotherapist, reflecting ‘I know that these things [exercises] work and the fact that, that was my experience it was very easy to say “Look, we need to do these exercises”’ (P4). Whilst this was the case, participants continued to require clear information related to the importance of physiotherapy specific to their child. For one participant, the physiotherapist explained this by saying ‘She does appear to have some low-tone, reduced control of her left hand. Therefore, try to do lots of fine motor control activities with the left or both hands, i.e., playing with Lego, beads etcetera’ (P4).

Theme three: Gaining confidence and skills through the learning process

This theme relates to how participants were supported to learn necessary skills to help their child, and the important role physiotherapists played in guiding them whilst building their confidence.

Most participants described a deep sense of uncertainty when they initially needed to learn and deliver physiotherapy exercises to their child. They felt scared for fear of doing something wrong or causing their child more harm, as ‘the thing with physiotherapy is that you can be doing it wrongly without knowing’ (P5).

Being in hospital was a time when participants worked closely with physiotherapists to learn necessary skills to support their child. Physiotherapists actively involved participants in rehabilitation sessions in a graded way, introducing new equipment and using the sessions as a teaching tool as the physiotherapists ‘were slowly teaching me the skills for me to take it over’ (P3). A participant described that the physiotherapist ‘showed me on [my daughter], and then said if you could maybe do [the exercise]’ (P2). In this way, physiotherapists were said to initially demonstrate the exercises to participants, provide instructions and the opportunity for practice.

Concurrent to the graded exposure and teaching was a change in participants’ confidence which often happened with reassurance and validation given by a physiotherapist. A participant said that ‘I was scared and that gave me the confidence as well then to have that reassurance from them [the physiotherapists] saying, you know, “yes, that’s fine” and “hang on a minute. Put your thumb here.”’ (P3). Participants’ confidence and belief in the value of physiotherapy also increased through seeing their child make progress. A participant said that seeing her son ‘being able to hit these milestones that we never thought that he’d be able to do. Again, it’s just confidence in me assuring that physio helps’ (P3). Similar was true of receiving feedback about progress, as the physiotherapist would explain that the child ‘has done this today, she wasn’t doing this three weeks ago’ (P2). A key component of having these concrete experiences was that they fed into participants’ sense of hope for the future, as seeing progress ‘does lift you, it does give you light at the end of the tunnel’ (P2).

This learning process was important as delivering physiotherapy initially learned in the hospital helped to provide some continuity and routine when first returning home. Many participants experienced uncertainty when leaving hospital as they were ‘so used to this routine at the hospital…then being at home to being like what do we do?’ (P1). Participants described that ‘we tried to keep some sort of semblance of a routine going’ (P4) and doing physiotherapy exercises helped with this.

As time went on following their child’s injury, the skills initially learned through structured support and practice became more automatic for participants, as ‘even the way that we pick him up, his physio is kind of ingrained into us now’ (P3). Importantly, initial learning provided participants with the skills, confidence and a foundation to build on as their child’s needs changed, with participants eventually becoming experts and knowing their child best. A participant explained ‘it’s confidence…as a parent carer, as times gone on, it gets to some point when you think, OK, I know my child better than anyone else’ (P3).

Theme four: Learning how to integrate physiotherapy into everyday life

The final theme relates to the gradual process of weaving physiotherapy into everyday life whilst navigating daily challenges.

For one participant 'because of [my son's] condition, like every day is physio...He goes in a standing frame every day. Hand splint every day. Every day is physio' (P3). Contrary to this was the recognition that 'every day is not the same, you know, every day brings something different' (P2). Participants found doing physiotherapy with their child challenging with limited time and other responsibilities which required their attention. There was a sense that, at times, flexibility around the overall plan was needed as everyday life can get in the way of doing rehabilitation.

A participant described the need to adapt how and when she did physiotherapy and to fit it in where she could: 'I just fitted in as much as I could. Even if we've done many minutes in the morning. Waiting rooms of hospitals. Anywhere that we could' (P3). Physiotherapists initially supported participants to incorporate this flexibility, as the physiotherapist 'taught us "Right, just do this, and if she can't do it 7 times, let her do it 5, cutting this bit, and do this bit"' (P2). However, it was ultimately the participant and the family that were navigating the everyday realities of life.

Encountering new or unfamiliar situations in everyday life proved challenging for participants. Some participants became hypervigilant, either anticipating or problem solving through challenging circumstances as 'most of it [problem solving] is happening while you're in the moment. And there's so much going on, as well as physio, it's a lot to contend with' (P1). This was also true of anticipating and managing their child's fatigue following the pTBI as 'you learn to recognise what areas would give him more fatigue than others' (P1). Additionally, some participants proactively sought support from a physiotherapist if needed, as 'I had access to him [the physiotherapist] on email. So, if I had any questions that were burning questions that couldn't wait, he would answer' (P5).

All participants expressed that it was important for their child to physically participate in activities which the child enjoyed, such as walking the dog or playing football. One participant achieved this by hiring 'a one-on-one football coach... [my son] would be in the goal because that was [my son's] favourite position' (P1). Also, having fun helped to integrate physiotherapy into everyday life as 'we built her up throwing the ball and things like that. We could make it fun' (P2). Activities could be made fun for not only the child but also the whole family, with physiotherapy becoming 'a family affair' (P1). Moreover, by making rehabilitation fun, participants supported their child without the child even realising that they were doing physiotherapy. A participant described that his daughter 'didn't know she was doing anything that was necessarily physio related. It was more fun' (P4).

Many participants expressed that in integrating physiotherapy into everyday life 'you just have to do your best. That's all you can do' (P1). Participants emphasised the everyday reality of family life and the potential for emotional turbulence: 'If [my daughter] is sick, for example, we’ve had to miss a couple of physio sessions with [my son] which makes me feel awful. You think you’re a really bad parent though. And then I kind of tell myself, you know “this is daily life and this is how it is” … so, I do as much as I can’ (P3). Finally, a participant reflected that doing physiotherapy supported a positive outcome, as physiotherapy ‘was absolutely an integral part of [my daughter] getting back to where she is today’ (P4).

Continuing the two-stage analysis process, the four inductively developed themes were then deductively mapped against the TDF and COM-B model to identify the underlying behavioural influences upon parental adherence (Michie et al., 2011, Alderson, 2021, Turner et al., 2023).

4.5.2 Deductive framework analysis

Deductive framework analysis of the themes using the TDF and COM-B model was completed as a second phase of analysis. Across the themes, all 14 domains of the TDF and all six constructs of the COM-B model were mapped as being present: see Tables 4.2 for full details.

The following examples demonstrate the deductive coding process based on the themes and participant quotes. For example, theme one included the following illustrative quote from Participant-3 ‘They were lovely and they explained it and then, I can’t remember if he had physio then once or twice a day…in the end, it became like the norm’. Against this quote, the TDF domains ‘1.Knowledge’ and ‘12.Social influences’ were coded which correspond to constructs ‘Psychological capability’ and ‘Social opportunity’ of the COM-B model, respectively.

From theme two, Participant-4 was quoted as saying ‘I know that these things [exercises] work and the fact that, that was my experience. It was very easy to say “Look, we need to do these exercises”’. Against this quote, the TDF domains ‘6. Beliefs about consequences’ and ‘8. Intentions’ were coded which both correspond to the COM-B model construct ‘Reflective motivation’.

Table 4.2 – The deductive mapping of participant quotes against the Theoretical Domains Framework and Capability, Opportunity, Motivation - Behaviour model

Theme	TDF domain*	COM-B construct	Example quote(s)
1. Purpose and motivation	9. Goals	Reflective motivation	“your whole life is in that hospital, in a little bubble, where you’re just focusing on getting [my son] better and nothing else matters”
	8. Intentions	Reflective motivation	“I felt like I had to be there the whole time”
	13. Emotion	Automatic motivation	“fearful about anything that meant moving [my son]”
	6. Beliefs about consequences 10. Memory, Attention and Decision Processes 13. Emotion	Reflective motivation Psychological capability Automatic motivation	“Horrified. Yeah, just, just extremely overwhelming…you just want [my son] to rest and you just want him to relax and you want him to be okay and then the first time they [the physiotherapists] came in and said “we’re going to sit him on the edge of the bed” I just thought what on earth are you thinking – No. You don’t need to. He needs to stay still. Leave him alone”
	1.Knowledge 12. Social influences	Psychological capability Social opportunity	“They were lovely and they explained it and then, I can’t remember if he had physio then once or twice a day…in the end, it became like the norm”
	6. Beliefs about consequences	Reflective motivation	“you just do it [physiotherapy] because you haven’t really got a choice. Because if you don’t do it, then your child’s not going to get up and not going to get any better”
	1.Knowledge 3. Social/professional role and identity 10. Memory, Attention and Decision Processes	Psychological capability Reflective/automatic motivation Psychological capabilities	“I had to learn a lot of it because, you know, it’s really exhausting on me, but I had to learn it for [my daughter]”
	6. Beliefs about consequences 8. Intentions 9. Goals	Reflective motivation Reflective motivation Reflective motivation	“it gave me a focus on this is now what I have to do, and this is what I have to do to make him better”
	7. Reinforcement 13. Emotion	Automatic motivation Automatic motivation	“a little boost where you think I’m doing something, I am helping”
	5. Optimism 6. Beliefs about consequences	Reflective/automatic motivation Reflective motivation	“little tiny steps of progression fuelled my fire. I was like, “no, no, no. We’re going to do this every single day and

	8. Intentions	Reflective motivation	you’re going to be the best that you can be.” So, these little, tiny steps that’s what it is, the motivator was hope”
2. The importance of receiving clear information	10. Memory, Attention and Decision Processes 13. Emotion	Psychological capability Automatic motivation	“bombarded with information, information, information, information” (P2). Such was the level of distress that “I couldn’t take any of it in”
	1.Knowledge	Psychological capability	“wanted to understand. I wanted to understand prognosis. I wanted to understand what else we needed to be doing”
	1.Knowledge 6. Beliefs about consequences	Psychological capability Reflective motivation	“everything that we do with [my son], has a reason for it. So, like you play with the toy, and you’ll be going “This is now for hand-eye coordination, and this is for grasp””
	9. Goals	Reflective motivation	it’s “a matter of just understanding your goals. Our goal was to get home. That was my son’s main goal”
	6. Beliefs about consequences 9. Goals	Reflective motivation Reflective motivation	““Once you start walking we’ll get you home” and once he started walking, it was “once we take the stairs” because we have stairs at home, “then we can go home” and then it’s “once we can get you safely in and out of the bath””
	2. Skills 11. Environmental context and resources	Psychological/physical capability Physical opportunity	“even when they [the physiotherapists] weren’t there at the weekend they were leaving stuff for me to do with [my daughter]” “would send a follow-up email with a PDF of all the exercises, which suited [my son] extremely well”
	6. Beliefs about consequences 8. Intentions	Reflective motivation Reflective motivation	“I know that these things [exercises] work and the fact that, that was my experience. It was very easy to say “Look, we need to do these exercises””
	1.Knowledge 2. Skills 9. Goals	Psychological capability Psychological/physical capability Reflective motivation	“She does appear to have some low-tone, reduced control of her left hand. Therefore, try to do lots of fine motor control activities with the left or both hands. I.e., playing with Lego, beads etcetera”
3. Gaining confidence and skills through the learning process	1.Knowledge	Psychological capability	“the thing with physiotherapy is that you can be doing it wrongly without knowing”
	2. Skills 12. Social influences	Psychological/physical capability Social opportunity	“were slowly teaching me the skills for me to take it over” “showed me on [my daughter], and then said if you could maybe do [the exercise]”
	2. Skills 4. Beliefs about capabilities	Psychological/physical capability	“I was scared and that gave me the confidence as well then to have that reassurance from them [the physiotherapists]

	13. Emotions	Reflective motivation Automatic motivation	saying, you know, “yes, that’s fine” and “hang on a minute. Put your thumb here.””
	4. Beliefs about capabilities 6. Beliefs about consequences	Reflective motivation Reflective motivation	“being able to hit these milestones that we never thought that he’d be able to do. Again, it’s just confidence in me assuring that physio helps”
	4. Beliefs about capabilities	Reflective motivation	“has done this today, she wasn’t doing this 3 weeks ago”
	5. Optimism 6. Beliefs about consequences 13. Emotions	Reflective/automatic motivation Reflective motivation Automatic motivation	participants’ sense of hope for the future, as seeing progress “does lift you, it does give you light at the end of the tunnel”
	14. Behavioural regulation	Psychological capability	“so used to this routine at the hospital...then being at home to being like what do we do?” “we tried to keep some sort of semblance of a routine going”
	2. Skills 14. Behavioural regulation	Psychological/physical capability Psychological capability	“even the way that we pick him up, his physio is kind of ingrained into us now”
	4. Beliefs about capabilities	Reflective motivation	“it’s confidence...as a parent carer, as times gone on, it gets to some point when you think, OK, I know my child better than anyone else”
4. Learning how to integrate physio-therapy into everyday life	11. Environmental context and resources	Physical opportunity	“I just fitted in as much as I could. Even if we’ve done many minutes in the morning. Waiting rooms of hospitals. Anywhere that we could”
	1.Knowledge 2. Skills	Psychological capability Psychological/physical capability	The physiotherapist “taught us “Right, just do this, and if she can’t do it 7 times, let her do it 5, cutting this bit, and do this bit””
	11. Environmental context and resources	Physical opportunity	Encountering new or unfamiliar situations in everyday life proved very challenging for participants as “most of it [problem solving] is happening while you’re in the moment. And there’s so much going on, as well as physio, it’s a lot to contend with”
	1.Knowledge 2. Skills 6. Beliefs about consequences	Psychological capability Psychological/physical capability Reflective motivation	“you learn to recognize what areas would give him more fatigue than others”

	12. Social influences	Social opportunity	“I had access to him [the physiotherapist] on email. So, if I had any questions that were burning questions that couldn’t wait, he would answer”
	7. Reinforcement	Automatic motivation	One participant achieved this by hiring “a one-on-one football coach…[my son] would be in the goal because that was [my son’s] favourite position” Having fun helped to integrate physical therapy into everyday life as “we built her up throwing the ball and things like that. We could make it fun” “didn’t know she was doing anything that was necessarily physio related. It was more fun”
	7. Reinforcement 12. Social influences	Automatic motivation Social opportunity	Activities could be made fun for not only the child but also the whole family, with physiotherapy becoming “a family affair”
	8. Intentions	Reflective motivation	in integrating physiotherapy into everyday life “you just have to do your best. That’s all you can do”
	3. Social/professional role and identify 11. Environmental Context and Resources 13. Emotions	Reflective/automatic motivation Physical opportunity Automatic motivation	“If [my daughter] is sick, for example, we’ve had to miss a couple of physio sessions with [my son]. Which makes me feel awful, you think you’re a really bad parent though. And then I kind of tell myself, you know “this is daily life and this is how it is”…so, I do as much as I can”
	6. Beliefs about consequences	Reflective motivation	physiotherapy “was absolutely an integral part of [my daughter] getting back to where she is today”

*Numbers included within the ‘TDF domain’ column relate to the 14 individual behavioural domains of the Theoretical Domains Framework
TDF = Theoretical Domains Framework; COM-B = Capability, Opportunity, Motivation – Behaviour model

Deductive coding was then collated and is presented within Tables 4.3 and 4.4 below. Overall, the most frequently coded domain of the TDF was '6.Beliefs about consequences' which was coded 11 times across all four themes. Following this, '1.Knowledge' was coded eight times across themes and represents the second most frequently coded TDF domain. In addition, '8.Emotion' was expressed across all four themes and was coded seven times in total, and '2.Skills' was expressed in three of the four themes and was coded seven times in total. The remaining domains were coded less frequently across one or more themes. See Table 4.3 for a full breakdown of deductive coding against the TDF.

Table 4.3 – Breakdown of deductive coding against the Theoretical Domains Framework

TDF domain*	**Theme one**	**Theme two**	**Theme three**	**Theme four**	**Total**
1. Knowledge	2	3	1	2	8
2. Skills	-	2	3	2	7
3. Social/Professional Role and Identity	1	-	-	1	2
4. Beliefs about Capabilities	-	-	4	-	4
5. Optimism	1	-	1	-	2
6. Beliefs about Consequences	4	3	2	2	11
7. Reinforcement	1	-	-	2	3
8. Intentions	3	1	-	1	5
9. Goals	2	3	-	-	5
10. Memory, Attention and Decision Processes	2	1	-	-	3
11. Environmental Context and Resources	-	1	-	3	4
12. Social influences	1	-	1	2	4
13. Emotion	3	1	2	1	7
14. Behavioural Regulation	-	-	2	-	2

*Numbers included within the 'TDF domain' column relate to the 14 individual behavioural domains of the Theoretical Domains Framework
TDF = Theoretical Domains Framework
Theme one: Purpose and motivation
Theme two: The importance of receiving clear information
Theme three: Gaining confidence and skills through the learning process
Theme four: Learning how to integrate physiotherapy into everyday life

From the constructs of the COM-B model, 'Reflective motivation' was expressed in all four themes and coded most frequently (29 times across the themes). Other frequently coded COM-B constructs were 'Psychological capability' (coded 20 times across all themes), and 'Automatic motivation' (coded 14 times across all themes). Less frequently coded constructs were 'Physical capability' (coded seven times in three themes), 'Social opportunity' (coded four times in three themes) and ‘Physical opportunity’ (coded four times in two themes). See Table 4.4 for a full breakdown of deductive coding against the COM-B model.

Table 4.4 – Breakdown of deductive coding against the COM-B model

COM-B construct	**Theme one**	**Theme two**	**Theme three**	**Theme four**	**Total**
Psychological capability	4	6	6	4	20
Physical capability	-	2	3	2	7
Social opportunity	1	-	1	2	4
Physical opportunity	-	1	-	3	4
Reflective motivation	11	7	7	4	29
Automatic motivation	6	1	3	4	14

COM-B = Capability, Opportunity, Motivation – Behaviour model
Theme one: Purpose and motivation
Theme two: The importance of receiving clear information
Theme three: Gaining confidence and skills through the learning process
Theme four: Learning how to integrate physiotherapy into everyday life

Related to study objective four, for ease of organisation and interpretation, data representing participant suggestions of considerations and content of the intervention were extracted and grouped together (see Table 4.5 for details). These groupings include elements of physical accessibility of the intervention itself and accessibility of information. Participants additionally gave suggestions about specific content within the intervention.

Table 4.5 - Participant suggestions of considerations and content within the intervention

Suggested consideration or content	**Illustrative participant quotes**
Physical accessibility and usability	‘So it needs to be something that is idiot friendly as well [laughs]. It needs to be easy for parents’ (P2) ‘Yes, I'm going to say this. Hopefully, it'll be free...That's really important because I had to leave work to care for my child and now, I’m on benefits. And on top of expense of parenting a child with complex needs...yeah, price. Well, price is a reality, isn't it? I think that's got to be in there somewhere. Maybe not free but like I wouldn't pay a lot of money for an app’ (P3) ‘So, you probably need things to be very clear and very low effort in terms of having to think about what you need to proactively be doing, because you have so many other things to deal with’ (P5) ‘In terms of apps, in terms of usability, I would say something that allows you to see at a glance what you need to do today and how to do it would be really helpful’ (P5)
Accessibility of information	‘Do you know what would be helpful David, if it was in video format, instead of loads of words. Because you're, you just can't take it all in. You just can't’ (P1) ‘Videos of the physio exercises, just videos of any kind of information, like if it's a fact sheet trying to see how we can make that into a video format and just make it more accessible. Because I know speaking with many parents, it's so hard to take it all in, it really is, and remember it all’ (P1) ‘They just need to be shown how to do it. Push this button and listen’ (P2) ‘In an app, that would be really good if you could just... so there’s been a couple of times when physio have shown me a hold and then I've gone, ah, I can't remember it. So, to have an app you could then go, there's a video here, this is how you do it. That would be fantastic’ (P3) ‘Both [audio and text-based information] I’d say. Because if I'm in the middle of doing something with [my son], someone talking about it would be easy because I won't have to look at my phone. But then in the evening, I do this quite a lot, so when [my son’s] in bed, I'll be going, oh yeah, I spend a lot of my time flicking through my phone. But to read it would be quite nice at the same time as well, this would be really lovely, I think’ (P3)
Supporting guidance and explanations alongside	‘A guideline that way, you know, to say this is how far you take it with the child, or this is if you feel a pain on the right shoulder you know to stop, or you know’ (P2) ‘A wee bit of explanation at the front, at the start just to say you're not being judged on this. This is just to help you and your child, you know. Reassurance. Reassurance’ (P2)

physiotherapy exercises	‘Maybe an explanation of why, that would be really good’ (P3) ‘It would have been great to be shown on a face-to-face consultation like we did. Followed by either a leaflet with the, with the exercises. Ideally even better, an app which has the exercises, which has an explanation of how to do it on a video which allows you, as a physiotherapist to check if people are doing them or not’ (P5)
Fun, engagement and rewards	‘I think if the element of fun for a child at that age, they won't even think about what they're what the goal is, potentially, as long as there's the fun element in there’ (P4) ‘Just making it fun, just getting them engaged. Fun. I think that an app would be a really good way’ (P4) ‘I think that you could, for her age, I think that you could it's taking it away from physio. At the moment, she's she uses her Rockstar maths, which is something that if you look at the way that that works, it's just times tables. But when you get things right, you can earn these little coins and then you can dress up a little character. I think that if you were trying to maybe get children to use fingers and stuff, you could maybe do some something on an app that was intricate and if they did it right, then I think that you maybe get something similar to Lego, but through an iPhone or whatever. I mean, you could do something along those lines, and I think I'd kind of feel like you probably would get something like a similar outcome’ (P4) ‘I think if you get, yeah, engagement and reward. I think it's just, yeah. It's the same with the spelling app that she's got as well. It's kind of the same sort of thing. You achieve something, you earn something, you can dress up something with different outfits and it's, you know, yeah’ (P4)
Self-monitoring and making notes	‘Maybe having something at the end of it to say they’ve done this section, a wee tick mark’ (P2) ‘To state whether “Yes, this worked for my child”, “This didn't work for my child”. Because they'll forget when they’re speaking to their own physiotherapist. Oh, I can't remember how she performed doing that’ (P2) ‘What would be handy… So, if you did something like that, somewhere I could write – this worked well, this didn’t work well. Remind me to tell physio’ (P3)
Signposting to support and additional resources	‘A contact number or something’ (P2) ‘It would be handy to like signposting would be handy. Because I have found so much out through our physio. Just saying “hey, have you checked Cerebra?” “Hey, have you done this?” “Hey, have you done that?”’ (P3)
Emotional support	‘Emotional support’ (P1)
Calendar feature	‘Like a calendar that would track [my son’s] appointments’ (P3)

4.6 Discussion

For the first time this study has explored parents' experiences following their child's pTBI with a specific focus on learning and delivering physiotherapy exercises, together with identifying influences on adherence. The research aim has been met by addressing the four research objectives. Firstly, by conducting inductive reflexive thematic analysis, new evidence has been generated regarding parental experiences of delivering physiotherapy based on the rich, descriptive data gathered from purposively sampled participants (Braun and Clarke, 2022) (objective 1). Secondly, by completing deductive analysis, key insights into underlying behavioural influences on parental adherence to delivering physiotherapy exercises have been identified (Cane et al., 2012, McGowan et al., 2020, Turner et al., 2023) (objective 2). These key insights plus suggestions about possible content of the intervention will be taken forward to inform the development of the theory- and evidence-based digital behaviour change intervention (O'Cathain et al., 2019, Ojo et al., 2019) (objectives 3 and 4).

An important finding from this study is that parents of children following pTBI experienced a variety of very strong, distressing, and at times conflicting emotions such as fear, sadness, motivation and hope. This is in keeping with the findings of previous qualitative research amongst parents of children following both pTBI and acquired brain injury that their emotional response was profound (Clark et al., 2008, Tyerman et al., 2017). In the initial stages following the injury, parents look to and rely on healthcare professionals in the hospital for support (Clark et al., 2008, Roscigno and Swanson, 2011, Brown et al., 2013, Jones et al., 2020).

Evidence from other pertinent research literature in paediatric critical care shows that having a child that sustains a serious and potentially life-threatening injury is very distressing for parents (Muscara et al., 2015). It is also known that having a critically unwell child admitted to the paediatric intensive care unit (PICU), the case for four out of five participants in this study, is distressing and overwhelming for parents (Oxley, 2015, Dahav and Sjostrom-Strand, 2017). Further evidence regarding parents' longer term stress response comes from a recently published analysis of 66 parents that completed the Davidson Trauma Scale following their child's discharge from PICU (Colville and Pierce, 2023). Analysis showed that over half of participants (n=36) presented with symptoms of post-traumatic stress disorder at either three months or 12 months post discharge. Of these participants, a highly significant proportion (35/36, p=<0.001) were parents of a child admitted to PICU as an emergency (Colville and Pierce, 2023). This is an important consideration in the context of pTBI as CYP are often admitted to hospital, and indeed the PICU, as an emergency and deemed to be critically unwell at the point of their hospital admission (Paediatric Critical Care Society, 2021, National

Institute for Health and Care Excellence, 2023b). Parents of children with pTBI may therefore be at heightened risk of developing post-traumatic stress disorder (Ganesalingam et al., 2008).

Within this study, participants' use of terms such as 'fear' and 'horror' to describe reactions to their child initiating physiotherapy indicates that participants' heightened distress was ongoing and continued when commencing rehabilitation following pTBI. This may be due to a parents' desire to be protective and prevent further harm when moving (Ames et al., 2011, Jones et al., 2018). Additionally, the simple act of moving may be in stark contrast to the prior need to remain still which is an essential element of neuroprotective measures following severe traumatic brain injury (Vella et al., 2017).

Going beyond the inductive analysis, the deductive analysis revealed that all components of the COM-B model represent influences upon parental adherence. This includes the COM-B component 'Automatic Motivation' which was found to be a key influence on parental behaviour across all four themes. Despite their distress, participants expressed that being in hospital and supporting their child remained their priority in keeping with their role and identity as a parent (Cane et al., 2012). These are new insights providing novel contributions to knowledge, starkly demonstrated by the fact that 'Automatic motivation' is a key influence on parental adherence, however, was found to feature infrequently within existing interventions, as analysed in *Chapter 2: Systematic review* (Young et al., 2024a).

4.6.1 The role of capability and opportunity in influencing parental adherence

Further important findings from this study include the complex interactions of processes that took place as participants became actively involved in delivering physiotherapy to their child. Physiotherapists were said to initially provide clear information, explanations about physiotherapy and reassurance about the role of parents in supporting their child. Here we see participants' 'Psychological capability' being supported through increasing knowledge and skills in line with their ability to retain information (Cane et al., 2012, Jones et al., 2020). Participants described having opportunities to become actively involved in physiotherapy sessions in a practical and supported way. Here, such sessions were recounted as being a setting for participants to receive teaching from physiotherapists and the development of physical skills, their 'Physical capability', for them to take over and be able to deliver physiotherapy independently. Participants described the important role that physiotherapists played in supporting them. As such, enhancing parents' capability to deliver physiotherapy is closely intertwined with the interpersonal interactions with physiotherapists and highlights the vital role that physiotherapists play in supporting parental adherence through social influences.

The deductive analysis highlighted the important role of social influences and social support from physiotherapists through the COM-B component ‘Social opportunity’. This was particularly relevant for participants to learn how to care for their child whilst also adjusting to their new role as the parent of a child following pTBI (Ames et al., 2011, Oxley, 2015, McLorie et al., 2023). In this way, physiotherapists are key stakeholders in empowering parents to understand the needs of their child and aid their rehabilitation through parent delivered physiotherapy. The study has shown that parental empowerment increases through a complex array of factors. Such factors include increasing relevant knowledge, the development of skills and implementation of physiotherapy exercises initially with support from physiotherapists, then more independently over time. In this sense, it has been said that healthcare professionals, including physiotherapists, are ‘gatekeepers’ within healthcare, shaping peoples access to resources, services and knowledge (Collyer et al., 2017, Drake et al., 2024). Therefore, physiotherapists play an important role in meeting parents’ social and emotional needs, whilst shaping the way in which parents gain knowledge and become involved in delivering physiotherapy exercises themselves (Tipping et al., 2010).

These findings have important implications for practice as they emphasise the need for parents to receive positive social support from physiotherapists, delivered in a structured and constructive way. This includes the need for clear information that is easy to understand (Bray, 2015) with participants identifying that verbal information and the use of supporting resources, such as pictures and written descriptions of exercises, were also important.

New insights identified by this study are that from the initiation of neurorehabilitation, physiotherapists can begin to meet parents’ essential needs following trauma. Hobfoll and colleagues outline five essential elements of human trauma intervention: the promotion of a sense of safety, calming, a sense of self- and community efficacy, connectedness, and hope (Hobfoll et al., 2007). This study demonstrates that by clearly explaining the role of physiotherapy and providing reassurance to parents, physiotherapists are promoting a sense of safety and calm. By involving parents in actively supporting their child, physiotherapists facilitate a sense of connectedness to their injured child and build self-efficacy regarding their ability to deliver physiotherapy. This is followed by hope through seeing signs of their child’s improvement which further motivates parents to continue to deliver physiotherapy (Hobfoll et al., 2007, Foster et al., 2017).

4.6.2 *The important interplay between beliefs, optimism, hope and motivation*

Parents' belief about physiotherapy, their optimism and hope for the future and how these relate to motivation to deliver physiotherapy exercises will be explored in this section.

When working with physiotherapists, participants described that they received reassurance and feedback from the physiotherapist and observed their child's physical improvement. The deductive analysis uncovers that receiving feedback on progress and seeing improvement firsthand reinforced participants' belief in the positive consequences of their actions related to physiotherapy which in turn acted as an important motivator for adherence. In other words, the TDF domain 'beliefs in consequences', an aspect of the COM-B component 'Reflective motivation', played an important role in influencing behaviour. Participants' beliefs about positive consequences fed into their optimism for the future and supported a sense of hope. Hope is shown to be a vital component of how parents respond to their child's pTBI and manage to get through each day following the injury (Bray, 2015, Jones et al., 2020).

Furthermore, the findings from this study around the important interplay between hope and motivation are consistent with the results of previous qualitative research. Piggot et al. (2003) described the role of hope and motivation that parents of children with cerebral palsy experienced when participating in home therapy programmes, whilst seeing their child making improvements and adjusting to their child's diagnosis (Piggot et al., 2003). The deductive analysis demonstrates that both 'Reflective' and 'Automatic motivation' were of the utmost importance and greatly influenced participants' behaviour in adhering to delivering physiotherapy (Michie et al., 2014). These new insights are important because they highlight the need for an intervention designed to support parent delivered physiotherapy to increase end-users' motivation through targeting both reflective and automatic motivation. For example, the use of goals, plans and intentions (reflective motivation) together with feedback and reinforcement of progress with physiotherapy (automatic motivation) can foster optimism and a sense of hope, thus supporting the end-users' motivation (Young et al., 2024a).

Over time, as participants continued to deliver physiotherapy to their injured child and learned to navigate the challenges and demands of everyday life after leaving hospital, they felt increasingly capable and confident to support their child. Participants described navigating everyday challenges and problem solving through difficult situations within the context of ultimately becoming the expert of their child's newly acquired physical needs following the pTBI. This is an excellent illustration of participants' increasing self-efficacy over time. Self-efficacy is an important component of parental adherence: it is inherently linked with one's confidence and beliefs about one's capability, and maps onto the COM-B component 'Reflective motivation' (Bandura, 1977, Cane et al., 2012, Foster et al., 2023). These findings further underscore the importance of motivation in influencing parents' adherence to delivering physiotherapy to their child. Observational studies show high self-efficacy to be associated with parents' increased involvement in their child's care (Bravo et al., 2020), plus greater engagement in rehabilitation following adult stroke (Szczepanska-Gieracha and Mazurek, 2020, Gangwani et al., 2022).

As time progressed following the child's pTBI, participants expressed the importance of flexibility in the context of navigating the challenges and demands of everyday life. In doing so, participants described a movement away from delivering structured physiotherapy programmes to embracing more flexibility, having fun and participating in important and engaging activities, both for themselves and the family as a whole. Research amongst parents of children with cerebral palsy has demonstrated that when parents can embrace flexibility and include rehabilitation as 'part of life' (p.203) within their role as a parent, this supported rehabilitation delivery (Novak, 2011). Furthermore, participating in meaningful activities and having fun are essential aspects of play; a fundamental right for all children, and a primary occupation for childhood (Royal College of Occupational Therapists, 2023).

4.6.3 Individualised rehabilitation is central to physiotherapy

This study reinforces the need for physiotherapy to be approached in an individualised way within the context of the parent, child and family circumstances, including their hopes and priorities for rehabilitation (Baldwin et al., 2013, Bray, 2015, Jenkin et al., 2022a). At its core, rehabilitation is highly personalised and a collaborative endeavour between the child, parent and healthcare professional (Lord et al., 2018). Thus, rehabilitation has the potential to empower individuals and families to increase their functioning and collective ability to interact within their environment in a positive way (Rosenbaum, 2022, World Health Organization, 2024). Such an approach is congruent with a strength based and family-centred approach based on what is possible according to the ecology of an individual family, through which physiotherapy can be personalised and be empowering for parents (Ziegler and Hadders-Algra, 2020, Rosenbaum, 2022). This is epitomised by the simplicity and holistic nature of the F-words of childhood disability which offers important insights into an individual family unit engaged in rehabilitation (Rosenbaum and Gorter, 2011). Such holistic, strength based and family-centred approaches sit in sharp contrasts with a disability focused approach which views rehabilitation primarily as a process of managing disability (Palisano et al., 2012, Rosenbaum and Gorter, 2011, Baldwin et al., 2013, Schwellnus et al., 2020, Novak-Pavlic et al., 2023).

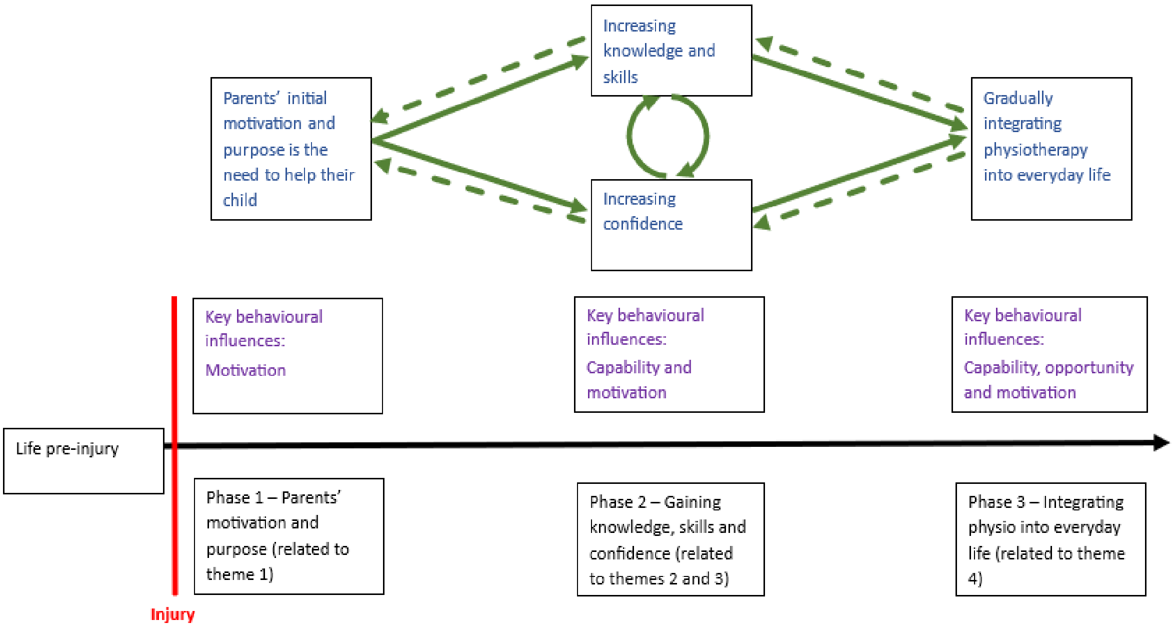
This study has shed new light on influences upon parental adherence to delivering physiotherapy which builds on the findings of *Chapter 2: Systematic review*. Parents expressed that important aspects of delivering physiotherapy were the ability to navigate everyday challenges and problem solve within everyday life. The findings of this study relate closely to published evidence summaries within occupational therapy which emphasise the importance of embedding therapy into everyday life within the context of family activities (Dunford et al., 2020). The benefits include an increase in the dose of therapy that the child receives in the context of collaboratively agreed goals. In addition, parents are supported by occupational therapists with increasing their confidence in delivering therapy which, overtime, is said to become a way of life for the family (Dunford et al., 2020).

Furthermore, this supports the need for physiotherapists to empower parents to enact 'parental self-management' reinforcing the need to move the emphasis of treatment and control away from physiotherapists, towards the child, parents and family (Ziegler and Hadders-Algra, 2020, Wong Chung et al., 2021, National Institute for Health and Care Excellence, 2023b). In keeping with the idea of parental empowerment to adhere to delivering physiotherapy, the next section will consider the phases that parents move through following their child's pTBI.

4.6.4 The phases that participants move through: integrating inductive and deductive findings

I have summarised the key findings of the study within Figure 4.1 below which broadly describes three phases that participants moved through following their child's pTBI. The first phase is their initial shock together with their motivation and purpose to help their child – the key behavioural influence during this phase is motivation. The second phase is gaining knowledge, skills and confidence, related to self-efficacy, to personally deliver physiotherapy exercises to their child. The process of gaining knowledge and skills, plus increasing confidence are reciprocal and develop over time – the key behavioural influences during this phase are capability and motivation. The third and final phase is integrating physiotherapy into everyday life which is influenced by a combination of capability, opportunity and motivation. Whilst the findings may suggest that participants moved through these three phases sequentially, it is also apparent that this is not a linear process. Rather, participants can move back and forth through different phases, depicted in Figure 4.1 by the dashed green lines. For example, within the inductively generated themes a participant described moving between phases 2 and 3 whilst integrating physiotherapy into everyday life. Alongside problem solving through new or unfamiliar situations encountered within everyday life, a participant described proactively seeking support from a physiotherapist via email. It is evident within this example that a participant proactively sought additional knowledge and guidance from the physiotherapist within the wider context of integrating physiotherapy into everyday life.

Figure 4.1 - A diagram depicting participants' experiences of delivering physiotherapy exercises to their child, divided into three phases



4.6.5 Reflexivity and considering my impact on the analysis process

During study design, and then data collection and analysis, I was in frequent contact and met regularly with my supervisors. I also maintained a reflexive log throughout to document my preconceptions, thoughts and ideas. Through initial supervision sessions, I gained greater insight into the complexity of the clinical scenario that I am researching and regularly drew upon the support of the PPI group to provide personal insights and reflections whilst helping inform the study plans. The following excerpt is taken from my personal reflexivity log in the early stages of the analysis process and speaks to my ever-deepening insights: '*From discussion [with supervisors] I realised that the complexity that we deal with on a daily basis as a clinician is quite astounding and that taking a step back and considering this from a more distant 'research' perspective has helped me to appreciate this'*. Acknowledging the complexity of the situation and my ability to consider the context and clinical scenario from a researcher perspective were important. As I transcribed the initial interviews and familiarised myself with the data, these insights led me to consider examples of complexity that participants described during interviews.

Participants' descriptions of their emotional responses including their shock, terror and fear when initially attending the hospital following their child's head injury were stark. Emotions were expressed with such rawness and clarity - even the acknowledgement that their child may die as a result of the injury. From the first couple of interviews, participants offered profoundly personal and individualised accounts of their experiences, yet I saw some consistency between them. I have also experienced similar emotions personally relating to my brother's sudden illness and admission to hospital which sadly preceded his death. Plus, having worked with many parents experiencing such distressing emotions, this became an important aspect of the analysis – how do these strong emotions impact parents and their work with the physiotherapist?

During the analysis, I interpreted that many participants expressed similar shock and fear when first meeting the physiotherapists who attended intensive care to commence rehabilitation. For participants, helping their child was their primary concern and they expressed that receiving information, explanations and reassurance from the physiotherapist were important aspects of the early interpersonal interactions, making physiotherapy more acceptable and normalised.

I reflected that there was a juxtaposition between parents wanting to be involved in physiotherapy and help their child, whilst also wanting to protect them from further harm. These insights led me to explore how parents themselves became involved in physiotherapy sessions and the role that physiotherapists played in supporting this. Participants described physiotherapists demonstrating activities within sessions and inviting them to become more 'hands-on' themselves. Due to my personal and professional experience, I interpreted that this process occurred **gradually**. I was drawn to participant descriptions such as 'building confidence' and 'providing reassurance'. Reflecting on the overall complexity of the clinical context, it became increasingly evident to me that the inter-personal interactions impacted parents alongside the practical elements of demonstration and helping parents to learn particular techniques or skills. In fact, through data analysis the importance of the inter-personal interactions between parents and physiotherapists became evident, and how they often preceded and complimented the practical, hands-on, skills-based aspects of physiotherapy. From here, I decided to explore these aspects of the data further through participants' accounts of interacting with and learning from physiotherapists.

As the analysis progressed, I interpreted that participants were **motivated** to help their child and that doing physiotherapy gave them **purpose**. I decided then to explore further and grapple with the more nuanced and latent aspects of the data to understand why having purpose was so important for participants and their response to their child's head injury. The following excerpt is taken from my reflexive log and speaks to my interpretation of the data: physiotherapists provide support by '*giving parents back an 'element of control' amongst the complexity and confusion where they are completely stripped of all sense of control, that this may hopefully lead to some positive adjustment for them and their family*.'

Participants' accounts of navigating the complex interactions of processing trauma alongside learning to deliver physiotherapy to their child were very powerful. The following quote from Participant-3 stood out to me as it helped me clarify my thinking and decision that somehow processing trauma and delivering physiotherapy were related: *"The thing that physio gave me, I've said it now, it gave me a focus and it gave me a reason. What made it easier for me. The fact that I felt like I was doing something proactive for my child to help him recover"*.

Whilst examining my own thoughts and understanding, I can appreciate now that when developing this programme of research and indeed this study, I had some awareness of the fact that parents want to help their child. My understanding now is far greater and richer as underlying this is a parents' deep sense of motivation to help their child and that even from the very acute phase of care, physiotherapy can offer a means by which to do this. This motivation does not come purely through setting goals and achieving outcomes, or even through the intellectual understanding that physiotherapy is beneficial when recovering from a head injury. This is a more automatic and instinctive motivation which comes from a parents' desire to care for and nurture their child.

As the analysis moved from the early interactions between physiotherapists and participants, to when they returned home and independently delivered physiotherapy to their child, I continued to gain new insights. For example, I documented in my reflexive log that '*There is an idea coming out that one grows in confidence in the things that they have done repeatedly over the years*'. Being a physiotherapist myself and appreciating that in many cases rehabilitation is repetitive and required over the long term aligns with the analysis. I interpreted that participants' growing confidence was related to repetition and practice of physiotherapy exercises, as well as receiving feedback and seeing positive outcomes from delivering physiotherapy. This led on to participants becoming the expert of their child's needs.

Beyond participants' growing confidence were their very honest accounts of how daily life is so challenging and how every day is different. Participants reflected that it was not simply a case of continuing to deliver a static physiotherapy programme in a pre-determined or rigid fashion, but rather parents required flexibility and insight whilst anticipating challenges or problem solving their way through difficult circumstances. The vast majority of my professional experience is within acute hospital settings therefore I was somewhat blinded to the realities of families once they leave hospital, and their changing perspective over time. Through using my reflexive diary and revisiting the analysis my assumptions were challenged: '*It just came to me that* ***things change****. This is part of the fourth theme and demonstrates a clear distinction between theme three which is about the learning process and gaining confidence in delivering physio and seeing the benefits (which reinforce what the parent is doing is 'working'). When looking at 'things change', this encompasses the flexibility that parents need, the problem solving, the delivery of physio in waiting rooms and doing what you can when you can, it also starts to acknowledge the acceptance side of things that parents express some years down the line'*.

The thought processes that I had during this time when refining and naming theme four took me back to a much earlier conversation that I had with Wendy, my primary supervisor. The discussion was about the behaviour change technique '8.6 Generalisation of target behaviour' which considers the performance of the wanted behaviour (i.e., adherence to delivering physiotherapy) which is already performed in a particular situation, in another situation. I had originally considered home-based physiotherapy which took place in the home environment; however, participants described going out, attending hospital appointments, going on holiday. I realised at this point that my pre-conceived notion of establishing home-based physiotherapy may be a good starting point for parents, however this is somewhat naïve, over simplified and limiting. Instead, the data was challenging me to think more broadly, to consider the important initial work that is completed in the hospital environment, continued when returning home from hospital and later when parents navigate the challenges of integrating physiotherapy into everyday life.

Overall, the inductive analysis has been both challenging and extremely enlightening. Maintaining a reflexive log, participating in regular supervision and inviting colleagues and PPI members to comment on the evolving analysis have been essential ways for me to reflect and capture my perspectives and influence in an honest and transparent way.

4.6.6 Implications for the proposed intervention

It is evident from the findings of this study that parent delivered physiotherapy occurs across a wide range of different contexts and timeframes following the child's pTBI. The findings demonstrate that as early as the initial interactions between the parent and the physiotherapist, elements of knowledge transfer and social support are taking place. These are necessary prior to parents becoming involved in delivering physiotherapy, gaining confidence and learning the necessary skills to deliver the physiotherapy exercises themselves. Without this initial support in the acute hospital environment, adherence to delivering physiotherapy once at home, and integrating physiotherapy into everyday life, may be negatively impacted. Therefore, the intervention needs to be developed for use by parents across a range of different contexts with the ability to commence early in the clinical journey following pTBI.

Due to the level of interpersonal interaction between parents and physiotherapists, the intervention will need to have the capacity to support these in-person interactions. The intervention will also need to be highly tailored to individual users which is in keeping with individualised, patient centered care (National Institute for Health and Care Excellence, 2023a). The capacity for digital interventions to tailor content to the needs and characteristics of individual users have been considered essential for several decades now (Dijkstra and De Vries, 1999).

The deductive findings further demonstrate that each component of the COM-B model represents a relevant target for influencing behaviour, with ‘Reflective motivation’, ‘Automatic motivation’ and ‘Psychological capability’ being the most influential.

4.6.7 Strengths, limitations, and directions for future research

An important strength of this study is that guidance from experts-by-experience within the PPI group was central to its design and conduct. For example, the use of online recruitment and remote interviews were deemed highly important to the PPI group. The group highlighted that the broad geographical reach of online recruitment across the United Kingdom and Northern Ireland was beneficial for this study (Carter et al., 2021). Furthermore, the PPI group expressed that parents would prefer online or telephone interviews over face-to-face as travelling to interviews would only add to the burden that they already face with multiple hospital appointments (Young et al., 2024a). This approach to online recruitment and data collection facilitated participants’ involvement in interviews in a more flexible way around participants’ availability (Carter et al., 2021). Some potential imitations of online recruitment and data collection will be considered further within this discussion – please see below for details.

The combined inductive and deductive analysis is a further strength of the analysis process. This approach enabled me to contribute new knowledge to the literature through rich data driven analysis, whilst supporting the triangulation of data using the COM-B model to inform the development of a theory- and evidence-based intervention (O'Cathain et al., 2010, Michie et al., 2014, Croot et al., 2019, Young et al., 2024a). I led the inductive analysis with regular review and feedback from academic supervisors, highly skilled and experienced clinical colleagues and the PPI group. Importantly, the deductive mapping of data against the TDF and COM-B model did not restrict my interpretation of the data by prematurely imposing an analytical framework (McGowan et al., 2020). This is because I purposefully completed the analysis in two sequential stages: initial inductive analysis followed by deductive analysis (Braun and Clarke, 2022, Turner et al., 2023).

A further strength of this study are the multiple endeavours which I have used to enhance the rigour, trustworthiness and generalisability of the findings (Smith, 2017). This includes the credibility, transferability, dependability and confirmability of the findings (Lincoln and Guba, 1985). Credibility has been enhanced by conducting semi-structured interviews based on the same interview topic guide, maintaining a detailed reflexive log and considering how my own biases may have influenced the study findings. Transferability has been supported by consistently recruiting participants using the same recruitment strategy and determining their eligibility against the pre-stated inclusion criteria, plus providing detailed contextual descriptions when reporting the study findings. The dependability of the findings is enhanced by detailing the methodological steps and clearly outlining the two-stage data analysis process, together with maintaining an audit trail. Furthermore, the confirmability of the findings has been supported through member checking of transcripts by participants to ensure that their experiences and views are accurately represented. This was further supported by maintaining a detailed reflexive log and engaging with supervisors, highly experienced colleagues and the PPI group to review, feedback on and validate my interpretations.

Considerable efforts were made to facilitate the recruitment of non-English speaking participants reflecting the cultural and ethnic diversity of families receiving rehabilitation following pTBI. Having said that, only English-speaking participants were recruited. A limitation of the study is that the sample lacked diversity and therefore the findings may reflect this as opposed to reflecting the breadth of diversity of those accessing rehabilitation services following pTBI (Allmark, 2004). Possible reasons include the possibility that only English-speaking parents were approached and invited to participate in the first recruitment phase, or that the online flyer published in phase two of recruitment was in English only. The consequence of these shortcomings of recruitment may be that the eventual intervention is not suitable or accessible to non-English speaking parents, rendering it futile in such instances (Squires et al., 2023). Future research should seek to adopt specific recruitment strategies amongst diverse groups of parents to increase the range of perspectives and experiences captured within the data (Allmark, 2004, Squires et al., 2023).

A further limitation is that participants were recruited through a single charity and may therefore differ in systematic ways from those who utilise rehabilitation services with access to physiotherapy, as acknowledged above. Potential biases from this sampling strategy could be that only parents who regularly engaged with the charity, The Child Brain Injury Trust, or were familiar with technology were recruited. Consequently, the findings may reflect the perspectives of already engaged and digitally literate participants. This means that the content and format of the eventual intervention may be suboptimal, or even inappropriate, for other members of the target population (Allmark, 2004, Squires et al., 2023, NHS England, 2024b).

In addition to the above limitations, it is acknowledged that semi-structured interviews were the only method of data collection used for this study. This is partly due to the scope of this study being completed within the context of a PhD, therefore having very defined timescales. Furthermore, it is important to acknowledge that at the time of conducting this study, the Covid-19 pandemic was ongoing, and the study protocol met the University's policy for remote working and avoiding non-essential travel and human interaction (Keen et al., 2022). This method of data collection was therefore deemed suitable to address the research aim and objectives and duly received ethical approval. However, a potential impact of recruiting and interviewing participants remotely may be that they have greater digital literacy levels than those less familiar with technology, or groups at risk of facing digital exclusion (NHS England, 2024b). Digitally literate participants may be more likely to want a digital intervention which could bias the findings towards a digital solution. This may not be the preferred, or indeed accessible, option for all parents of CYP with pTBI (NHS England, 2024b).

With regards to the online recruitment of participants, a further limitation is that if a participant entered incorrect contact information (i.e., an incorrect email address) then they could not be contacted and invited for interview. In addition, after completing the initial online eligibility questionnaire, prospective participants may not have seen or responded to further email contact requesting them to complete the consent form, therefore not retaining these participants in the study. A learning point from this study was the need to request at least two methods of communication, for example, email address and mobile phone number, to have a 'back up' option should it be required.

Given the small sample size that participated in this study (n=5) and limited representativeness of the sample, an important consideration is the potential for limited generalisability of these findings beyond this study. First, I did not intend to recruit a generalisable sample, but a purposive sample which was suitable to address my study aim and objectives via the ontological and epistemological positions of critical realism (Allmark, 2004, Alderson, 2021, Hays and McKibben, 2021).

Furthermore, the term generalisability is often used in qualitative research as a way of referring to the extent to which study findings can or cannot be transferred to other groups and populations (Hays and McKibben, 2021). Generalisability is frequently referred to as a limitation or weakness of qualitative research: a concept which has been challenged based on a misunderstanding about generalisability (Smith, 2017). It has been argued that the lack of generalisability within qualitative research is a key misunderstanding. This occurs when it is considered in relation to statistical-probabilistic generalisability, more commonly associated with the positivist paradigm of quantitative research (Smith, 2017, Carminati, 2018).

The purpose of this study was to explore the experiences of purposively sampled parents in relation to their delivery of physiotherapy exercises, with the data being analysed inductively and then coded deductively. Statistical-probabilistic generalisability is not consistent with this purpose as I did not aim to estimate effect size in a representative sample of participants (Allmark, 2004, Smith, 2017, Carminati, 2018). Rather, my in-depth exploration of participants' experiences using inductive analysis is consistent with transferability or inferential generalisation (Hays and McKibben, 2021). This form of generalisability is concerned with the degree of congruence between different contexts: the context in which the research was carried out and the context in which readers are seeking to apply the findings. Therefore, I have consistently strived to provide a rich and detailed account of the contexts that participants spoke about in relation to learning and delivering physiotherapy exercises (Hays and McKibben, 2021).

In addition to transferability, my research also relates to analytical, or theoretical, generalisability by which the findings can relate to an existing theory (Carminati, 2018). I have applied the findings of this study beyond the inductively analysed data to the COM-B model generated by Michie and colleagues, using deductive analysis (Michie et al., 2011, Braun and Clarke, 2022).

Finally, when considering the size and representativeness of the sample, it is important to consider these in relation to the knowledge that I have been able to generate from the study (Allmark, 2004). All study participants were biological parents of a CYP that sustained a pTBI in childhood. In addition, they were all either British nationals or fluent English speakers. The results that I have generated from this study may have limited transferability beyond the sample to non-English speaking parents, or to parents that either do not have an existing relationship with The Child Brain Injury Trust or do not use digital technology (Allmark, 2004). To this end, it is important to consider the findings with appropriate caution. An important consideration of future research will be to identify and implement robust and appropriate approaches to recruiting a more diverse range of participants that can inform iterative refinement of the intervention (Allmark, 2004, Hays and McKibben, 2021).

Moving forward, future research should seek to integrate these findings into new interventions supporting parents to deliver physiotherapy. Additionally, as physiotherapists have been shown to play a central role in supporting parents to deliver physiotherapy, their experiences and views should also be considered and incorporated when designing new interventions. What's more, it will be important to conduct further research with a diverse array of parents to further deepen our understanding of key influences on parental adherence to delivering physiotherapy.

4.7 Conclusions

This qualitative study sheds new light on both the experiences of parents and the influences on their adherence to delivering physiotherapy exercises to their child following pTBI. Motivation plays a crucial role in influencing parental adherence throughout the rehabilitation pathway, with the influence of capability and opportunity increasing over time when learning new skills and integrating physiotherapy into everyday life.

Physiotherapists play a vital role in supporting parents to deliver physiotherapy, with key initial influences beginning as early as their first interactions in the acute hospital environment. The findings from this study will be taken forwards to inform the conceptual design of a digital behaviour change intervention.

4.8 Chapter summary and next steps

This chapter has collected and analysed qualitative data from parents of CYP with pTBI to understand their experiences of delivering physiotherapy exercises and identify behavioural influences on their adherence. A summary of the deductively coded influences according to the COM-B model are provided in Table 4.6 below. This will be taken forwards to inform the behavioural diagnosis of what needs to change to increase parents' adherence to delivering physiotherapy exercises, included in *Chapter 6: The conceptual design of the intervention*.

Further work is required to explore the experiences of physiotherapists and consider how they, as key stakeholders in parent delivered physiotherapy, influence adherence (see *Chapter 5: Qualitative study involving physiotherapy focus groups* for details).

Table 4.6 - Summary of key findings from this chapter mapped onto the COM-B model

COM-B sub-constructs	**Identified within parent interviews? Yes/No**	**Key findings**	
		Frequency of coding	How is this expressed within themes
Physical Capability	Yes	Coded seven times across three themes	This intervention target is expressed through the acquisition of physical skills
Psychological Capability	Yes	Coded 20 times across all four themes	This intervention target is particularly expressed through the acquisition of knowledge and psychological skills
Reflective Motivation	Yes	Coded 29 times across all four themes	This intervention target is particularly expressed through beliefs about consequences, intentions and goals
Automatic Motivation	Yes	Coded 14 times across all four themes	This intervention target is particularly expressed through emotions and reinforcement
Physical Opportunity	Yes	Coded four times across two themes	This intervention target is expressed through influences from environmental context and resources
Social Opportunity	Yes	Coded four times across three themes	This intervention target is expressed through social influences
Summary	All sub-constructs of the COM-B model were coded across themes	Reflective motivation was coded most frequently, followed by psychological capability and automatic motivation	-

Key: The colours within the table represent those within the COM-B model itself, whereby red refers to Capability, yellow refers to Motivation and green refers to Opportunity. See Figure 1.4 on page 44 for further details about the COM-B model.

Chapter 5: Qualitative study involving physiotherapy focus group

5.1 A brief overview of this chapter

In Chapter 4: Qualitative study involving parent interviews I considered the experiences and behavioural influences on adherence to delivering physiotherapy exercises from the perspectives of parents. It was evident that from the very first interactions with parents, physiotherapists play an essential role in supporting parents to deliver physiotherapy exercises to their child following a pTBI. In Chapter 2: Systematic review, I identified that every intervention included in the analysis involved a physiotherapist educating and empowering parents to deliver or supervise the rehabilitation exercises across a range of different contexts.

This chapter will build on the evidence gathered and presented previously within the thesis by exploring the experiences of physiotherapists who support parents to adhere to delivering physiotherapy exercises. Physiotherapists working with CYP and parents following pTBI are essential stakeholders and heavily involved in supporting parents to learn and deliver physiotherapy exercises to their child.

Adherence is a behaviour whereby components of capability, opportunity and motivation will impact directly on parents' delivery of physiotherapy. By exploring the perspectives of physiotherapists, I intend to gain greater understanding of their key role in supporting parents and generate additional evidence to feed into the intervention design. By doing this, my ambition is that the resultant digital behaviour change intervention will be theory- and evidence-based, be acceptable to end users and key stakeholders, and be deliverable within clinical practice.

I will utilise focus groups with physiotherapists as a means by which to gather data within dynamic group discussions. I will analyse these data through the lens of critical realism, as was also the case in Chapter 4: Qualitative study involving parent interviews. I will sequentially employ inductive data-driven analysis to explore the views and experiences of physiotherapists through the data themselves, then deductive map findings to the TDF and COM-B model. In doing so, I will explore more deeply the causal mechanisms and influences on parental adherence from the perspectives of physiotherapists. The new evidence generated through physiotherapy focus groups will feed into the conceptual design of the intervention.

5.2 Introduction

Physiotherapists are essential in supporting parents to learn and be able to deliver physiotherapy exercises to their child following pTBI. I previously presented in *Chapter 2: Systematic review* the active ingredients (BCTs) of interventions which involve parent delivered and parent supported rehabilitation following pTBI. The most commonly identified BCTs included those related to goal setting and action planning, as well as instruction, demonstration and practice as identified in *Chapter 2: Systematic review* above (Young et al., 2024a).

Related to goal setting, it is acknowledged that the role of physiotherapists, alongside other health professionals with multi-disciplinary care teams, is crucial. The physiotherapists' role is to hear the voices of CYP and parents, support the development of meaningful goals and help to break bigger picture goals which represent longer-term hopes down into smaller steps (Melin et al., 2021, Jenkin et al., 2022a). Physiotherapists also play an active and vital role in educating and empowering parents to deliver physiotherapy exercises to their child (Harniess et al., 2022). In doing so, physiotherapists contribute to a collaborative endeavour between the CYP, parent and physiotherapist based on mutual dialogue and a shared understanding of the focus and aims of rehabilitation following pTBI (Lord et al., 2018, Jones et al., 2020, Jenkin et al., 2022a, Gmelig Meyling et al., 2023b, Drake et al., 2024).

Whilst physiotherapists are vital in empowering parents to deliver physiotherapy exercises, the means by which they achieve this remains an under researched area. For example, no studies to date have directly explored the experiences of physiotherapists that support parents of CYP following pTBI to deliver physiotherapy. Nonetheless, research addressing the views and experiences of physiotherapists related to parental engagement in rehabilitation within other patient groups does exist. Tipping and colleagues undertook a focus group with paediatric physiotherapists working with babies and infants diagnosed with cystic fibrosis, and their families, with particular focus on parental education following the diagnosis (Tipping et al., 2010). Their analysis highlighted that consideration about the volume of education materials, the timing of education and appropriateness of resources was important in influencing the effectiveness of parental education. This was particularly true due to the likelihood of increased parental psychological distress following their child's diagnosis. The authors identified that having a sense of social connectedness was important for parents, identifying that a good relationship between the parent and physiotherapist provided the foundation for education and feedback as parents learned specific treatment techniques. Importantly, physiotherapists additionally highlighted that education can be overwhelming for parents, and they had to weigh up the perceived benefits of offering feedback to parents against the possibility of increasing parental stress and furthering their psychological distress (Tipping et al., 2010).

Another qualitative study explored the nature, value and experience of child and family engagement in paediatric rehabilitation. King and colleagues interviewed CYP diagnosed with a variety of medical conditions, their caregivers and a range of service providers, including physiotherapists, within a rehabilitation hospital in North America (King et al., 2020). The study demonstrated that engagement in rehabilitation fell into three main themes. These included: *Engagement as connection*, whereby connection related to a personal connection with the service provider, a therapy goal or therapy activity; *Engagement as working together* by partnering and working towards/achieving goals; and *Engagement as an affective and motivational process* related to feelings, mood and emotions. Here, the collaborative nature of rehabilitation whereby physiotherapists, parents and CYP developed a partnership whilst working towards mutually agreed rehabilitation goals was emphasised by the authors, as has been echoed elsewhere (Lord et al., 2018, Jones et al., 2020, King et al., 2020, Jenkin et al., 2022a).

From a behaviour change perspective, the ability to gather and triangulate data from multiple different sources strengthens one's understanding of the target behaviour (Michie et al., 2014). Related to parental adherence, existing interventions have been analysed within *Chapter 2: Systematic review* and the experiences of parents have been considered in *Chapter 4: Qualitative study involving parent interviews*. What remains less well understood are the experiences and underlying behavioural influences of physiotherapists in supporting parental adherence to delivering physiotherapy exercises.

Therefore, the aim of this qualitative study is to shed light on the experiences and influences of physiotherapists who support parents to learn and deliver physiotherapy exercises. The data presented within this study will contribute to the understanding of parental adherence and provide new insights to help guide intervention development (Craig et al., 2008, Michie et al., 2014, O'Cathain et al., 2019, Alderson, 2021).

5.3 Study aim and objectives

The study aim is to explore physiotherapists' experiences of supporting parents and identify how physiotherapists influence parental adherence to the delivery of recommended physiotherapy exercises.

The research objectives are:

1) To identify the first-hand experiences of physiotherapists who support parents to adhere to the delivery of physiotherapy exercises to children and young people following pTBI.
2) To identify behavioural influences of physiotherapists that support parents to adhere to physiotherapy recommendations.
3) To generate new data to inform the development of a digital behaviour change intervention.

5.4 Methodology

5.4.1 Study design

This qualitative study used remote focus groups with qualified physiotherapists to explore their experiences of supporting parents of CYP with pTBI to deliver physiotherapy exercises. I selected focus groups as the method by which to collect qualitative data as it enabled a range of participants to contribute to data collection simultaneously, whilst providing scope for gaining additional depth within the data through dialogue within the group (Sim and Waterfield, 2019). Ethical approval for this study was received from the University of East Anglia Faculty of Medicine and Health Sciences Research Ethics Committee, Ref: ETH2223-1002 (see Appendix 14).

I aimed to recruit participants for two focus groups to provide the basis for triangulation between the focus groups and facilitate the participation of physiotherapists based in different clinical settings (e.g., acute hospitals and community). Regarding sample size, I aimed for each focus group to consist of up to eight participants, so up to 16 participants in total. It was deemed that this group size would allow all members to contribute in a meaningful way with facilitation from myself as the research student (Carlsen and Glenton, 2011).

The data collection phase of this study was conducted between May and June 2023. I decided to conduct focus groups remotely due to the ability to recruit nationally throughout the UK and Northern Ireland whereby participants were able to access focus groups without the need to travel (Carter et al., 2021). Remote data collection also provided greater flexibility allowing focus groups to be hosted around participants' work commitments (Keen et al., 2022). I additionally considered remote data collection to be feasible following successful recruitment and interviews with parents, reported in *Chapter 4: Qualitative study involving parent interviews*.

Due to the proximity of the study with the Covid-19 pandemic, at the time of data collection healthcare staff, including physiotherapists, were familiar with the use of digital technology, online software and remote videocalls as part of day-to-day clinical work (Haines et al., 2023, NHS England, 2025a). Remote focus groups were therefore deemed to be an appropriate and suitable means for collecting data to help address the research aim and objectives (Bennell et al., 2021, Lange and Danielsson, 2024).

5.4.2 Participants

Qualified paediatric physiotherapists with relevant clinical experience were purposively recruited for this study. Paediatric physiotherapists were recruited if they met the following inclusion criteria:

- Qualified physiotherapists with relevant experience of working with children and young people following pTBI, and their parents.
- Physiotherapists based within the acute hospital environment, community settings, charitable organisations or private practice in the United Kingdom or Northern Ireland.
- Able to communicate verbally in English.

Participant recruitment was supported by the Association of Paediatric Chartered Physiotherapists (APCP) with prior agreement from Dr Jane Simmonds, the APCP research lead (Appendix 15). The APCP is one of the largest professional networks of the Chartered Society of Physiotherapy specifically for paediatric physiotherapists with national membership spanning the UK and Northern Ireland. Within the APCP, there is a specialist committee dedicated to neurodisability, including acquired and traumatic brain injuries in childhood (The Association of paediatric Chartered Physiotherapists, 2022).

Study recruitment commenced in May 2023 using research advertisements sent out by the APCP within their fortnightly email bulletins (Appendix 16). The advertisement invited those interested in the study to follow a link or scan a QR code to access the Participant Information Sheet (Appendix 17) and express their interest in participating by completing a demographics and eligibility questionnaire (Appendix 18).

5.4.3 Stakeholder involvement in this study

Participant facing materials including the participant information sheet, plus the focus groups topic guide (Appendix 19) were developed in conjunction with the PPI group, a paediatric physiotherapist and trauma rehabilitation coordinator working within an NHS major trauma centre. This helped to ensure that the questions asked provided the basis for the highest quality data to address the research aim and objectives.

5.4.4 Procedure

Prospective participants initially completed an online eligibility and demographics questionnaire. I screened participant eligibility against the inclusion criteria, as outlined above. I emailed all eligible physiotherapists inviting them to follow a link and complete the online consent form (Appendix 20). Both the online eligibility and demographics questionnaire, as well as the consent form, were generated using Microsoft forms.

Following successful recruitment of participants, I identified suitable times for two different focus groups and circulated emails to participants: one email for participants in focus group one and another email for participants in focus group two. Each email included a secure Zoom link and password to access the focus group at the allocated time.

I hosted and facilitated both online focus groups. With prior consent the focus groups were recorded using Zoom with a backup recording using a digital voice recorder. Audio footage from interviews were used to generate verbatim transcripts by an experienced administrator within the University of East Anglia’s School of Health Sciences.

5.4.5 Data analysis

As outlined in *Chapter 3: A brief introduction to the qualitative studies*, to address my research objectives I approached data analysis from the qualitative paradigm of critical realism (Alderson, 2021, Fryer, 2022). The focus of this study was to explore participants’ construction of reality as well as understand the underlying causal relationships influencing parents’ adherence (Alderson, 2021). To achieve this, I undertook data analysis using reflexive thematic analysis in two sequential phases with support from academic supervisors and experienced clinical colleagues. As a result, the methods employed for data analysis were very similar to those utilised in the *Chapter 4: Qualitative study involving parent interviews*, with each phase of data analysis addressed different research objectives.

To address research objective 1, in phase one of my analysis I firstly undertook inductive data-driven analysis to explore the first-hand experiences of physiotherapists through their own accounts of supporting parents to adhere to delivering physiotherapy exercises. I completed this through data familiarisation by reading focus group transcripts multiple times, coding sections of transcripts, then iteratively generating, developing and refining themes (Braun and

Clarke, 2022). Initial themes were reviewed together with two academic supervisors, Prof Duschinsky and Dr Mares, who challenged my construction of developing themes and recommended that I revisit the data when refining themes. This iterative refinement process continued following review and feedback from two highly experienced paediatric physiotherapists currently working in paediatric rehabilitation. Once the inductively generated themes had been developed, I progressed to phase two of analysis.

To address research objective 2 and identify behavioural influences of physiotherapists on parental adherence, phase two of analysis involved deductive coding of themes against the TDF and COM-B model. This phase was undertaken independently by two reviewers: myself and Prof Naughton. We independently reviewed themes and completed a two-step deductive analysis process to identify behavioural influences using a framework approach (Turner et al., 2023). Data within themes were initially mapped against the theoretical constructs and 14 domains of the TDF (step 1), then behavioural targets were identified using the COM-B model (step 2) (Cane et al., 2012). Discrepancies were discussed until agreement was reached (see Table 5.2 for details).

The evidence generated through sequential inductive and deductive analysis will be taken forwards to inform the conceptual design of the digital behaviour change intervention (research objective 3).

As an active element of the analysis process myself, reflexivity has been an integral aspect of the data analysis process. This was particularly important from my position as an ‘insider researcher’ as I am a paediatric physiotherapist and share this important professional attribute with all the participants (Braun and Clarke, 2013, Bukamal, 2022). I was also known by and had existing professional relationships, both clinical and academic, with some of the participants. In addition, at the time of data analysis I had recently completed the parent interview study and was already somewhat sensitised to the experiences and behavioural influences of parents (Bowen, 2006).

5.5 Findings

Twenty qualified physiotherapists expressed an interest in participating in focus groups, with 18 meeting the eligibility criteria. From the 18 eligible participants, 13 signed the consent form and 11 physiotherapists participated in two focus groups across May and June 2023 (six participants in focus group one and five participants in focus group two). One eligible participant was unable to attend the focus group at the designated time, and another participant was sent the secure link to join the online focus group, however, did not attend. Interviews were not offered to participants as an alternative means of collecting data.

Participant characteristics for those who took part in focus groups were analysed from data collected using an eligibility and demographics questionnaire (see Table 5.1). Participants were physiotherapists that had been qualified for an average of 18.3 years and had on average 11.2 years of experience working with CYP following pTBI. All participants were employed within the NHS, with almost 82% of participants working within designated regional major trauma centres within the UK. All participants were employed between bands 6 and 8 according to the Agenda for Change banding, whereby over half (55%) worked as band 7 physiotherapists (NHS England, 2024a). The majority of participants (73%) described themselves as working part time.

Table 5.1 – Participant characteristics across the focus groups

Eligibility criteria	**Focus group 1 (n = 6)**	**Focus group 2 (n = 5)**	**Across all participants**
Agenda for change banding	Band 6 = 1 (16.7%) Band 7 = 4 (66.7%) Band 8* = 1 (16.7%)	Band 6 = 2 (40%) Band 7 = 2 (40%) Band 8* = 1 (20%)	Band 6 = 3 (27.3%) Band 7 = 6 (54.5%) Band 8* = 2 (18.2%)
Years of experience as a qualified physiotherapist Mean (range)	19.8 (range 3 - 36)	16.5 (range 4.5 – 32)	18.3 (range 3 – 36)
Years of experience working with CYP following pTBI Mean (range)	14.6 (range 0.5 – 30)	7.1 (range 0.75 – 25)	11.2 (range 0.5 - 30)
Employment setting	NHS MTC = 5 (83.3%) NHS acute = 1 (16.7%)	NHS MTC = 4 (80%) NHS community = 1 (20%)	NHS MTC = 9 (81.8%) NHS community = 1 (9.1%) NHS acute = 1 (9.1%)
Employment status	Part time = 4 (66.7%) Full time = 2 (33.3%)	Part time = 4 (80%) Full time = 1 (20%)	Part time = 8 (72.7%) Full time = 3 (27.3%)
Additional relevant qualifications	Higher degree** = 4 (66.7%) None = 2 (33.3%)	Higher degree** = 1 (20%) Specialist training = 1 (20%) None = 3 (60%)	Higher degree** = 5 (45.5%) Specialist training = 1 (9%) None = 5 (45.5%)

*Participants expressed banding as Band 8, further subcategorisation (a-d) was not specified; ** Higher degree, including Masters or PhD;
NHS = National Health Service; MTC = Designated regional major trauma centre; CYP = Child or young person; pTBI = Paedaitric traumatic brain injury

5.5.1 Inductive thematic analysis

Through the process of inductive thematic analysis, four themes were identified. These are:

1. Actively involving parents as part of the team
2. Supporting parental adjustment to life following their child's brain injury
3. Aligning physiotherapy with the interests of the child and parents
4. Working within contextual constraints

Themes are outlined below with anonymised participant quotes included to illustrate pertinent thematic findings. To maintain participant anonymity, names, locations and places of work have been replaced by descriptions, and quotes are attributed to participant alpha-numeric identifiers (e.g., Participant-2 is written as P2).

Theme 1: Actively involving parents as part of the team

This theme covers the important role that parents play in their child's care and the need for physiotherapists to actively involve them in physiotherapy following pTBI. Actively involving parents commenced within acute hospital care and continued throughout rehabilitation at home and in the community.

The initial interactions between parents and physiotherapists were said to be important as 'I think that building the trust and building that rapport straight away is the biggest thing' (P8). Developing an inter-personal relationship between the parent and physiotherapist then supported good communication and understanding. This provided the basis for 'two-way communication. You know that they're understanding what you say and you're understanding what they're saying' (P9). Such communication allowed parents to ask questions and seek information as well as contribute to the assessment and care of their child. This was due to parents being a 'massive part of the team. So, you need to have that good communication' (P10).

When initially interacting with a parent and involving them, participants were considerate and sensitive to parents' emotional and psychological needs as well as their ability to take in information. It was important to not overwhelm parents further and being cognisant of this then 'completely influences kind of how you engage and interact' (P6). An inherent part of being a physiotherapist was said to be the ability to adapt one's approach and communication according to the situation and the needs of the parent, acknowledging that these may change over time. A participant said that ‘part of your therapeutic skill is being able to adapt your approach to the different circumstances that you find yourself. And being able to be flexible and adapt to change’ (P3).

Alongside good communication, actively involving parents included physically and practically involving parents within physiotherapy sessions. In doing so, a key consideration was to ‘understand the cultural context that that family is coming from’ (P1) and involve parents in a considered and culturally sensitive way, in some cases using interpreters if there was a language barrier. Physically involving parents was gradual and, where possible, began early in the rehabilitation journey. This was important as it enabled a parent to begin to actively support their child in a meaningful and empowering way. This was a conscious decision with one participant commenting that ‘I’m trying to always think when I'm doing a session with a patient that straight away the parents are involved as much as possible…I think that’s really empowering for parents’ (P8). This process often began with support from the participants to develop parents’ hands-on skills and confidence ‘so that they [parents] are from the get-go quite hands-on and not afraid of doing that handling’ (P5). Participants broke activities and exercises down into smaller steps and were flexible in ‘adapting as you go, as their [parents’], you know, abilities and confidence changes’ (P11). This process went alongside explaining why physiotherapy was important, and giving ‘feedback, lots of feedback and you know, what they're getting right, so that they know that they're happy with what they're doing’ (P7).

Within the acute setting, there was also a focus on preparation for discharge home. By gradually ‘building them [parents] into the sessions and getting them to do more and more of it outside of our time. So, hopefully upon discharge…they are able to completely provide the therapy programme that's needed’ (P2). Throughout the rehabilitation pathway involving parents, plus extended family, in physiotherapy was deemed to have tangible benefits. Their involvement enhanced rehabilitation quality as ‘we get some of our best interactions when we engage extended family, and our rehab quality is improved by their engagement and their involvement’ (P1). Another identified benefit was increased therapy dosage outside of specific physiotherapy sessions, as ‘If we can get parents doing therapy, then I can increase that [therapy dose] to multiple hours a day’ (P2).

Theme 2: Supporting parental adjustment to life following their child’s brain injury

The essence of theme two is the understanding that a physiotherapist’s role goes beyond hands-on therapy and supporting parents to learn physiotherapy exercises, to supporting parents to adjust to life following their child’s pTBI.

When reflecting on their understanding of the impact of the pTBI on parents’ lives, participants described that parents were on ‘this journey that you thought you were on, and suddenly you’re not’ (P7). Participants described that they played a part in supporting parental adjustment across the rehabilitation pathway.

Beginning in the hospital setting, participants encountered parents experiencing acute emotional distress related to their child’s injury. Parents gained practical skills and knowledge from participants, which was accompanied by reassurance that they were ‘not here to test you…or criticise what you're doing’ (P10). Instead, the emphasis was on collaboratively working together with parents to support their child. Therefore, whilst trying to cope under extremely challenging circumstances, participants provided opportunities for parents to ‘help their child, which is all they want to do’ (P8). Participants described that the physiotherapists’ role involved supporting parents’ immediate needs whilst they also ‘set the scene for the patient’s onward journey, I think we have a responsibility to do that’ (P3).

Likewise, when parents returned home this support was ongoing. At that stage parents were said to have ‘overcome the realisation that their child has had, you know, a life changing injury…I think reality obviously starts to hit a lot more once they've come out of rehab and they're back home. And so, I think as a physio, your role is so much more than just hands on physio’ (P11). It was the participants’ overall aim to help develop parents’ proficiency and their ability to adjust to different situations and circumstances, including those outside the hospital or home. One participant spoke about ‘transferring your skills and [parents] being able to become proficient in a different place, in a different environment, different context…that's what we're all trying to do. It isn't just about being at home, being in hospital and being able to do it, you need to be in different environments, you need to be doing what you want to be doing’ (P7).

Parental adjustment took time and was expressed by participants in terms of parental expertise. This was demonstrated by a community physiotherapist’s perception that ‘parents are the expert on their child’ (P11), whereas initially following the injury there was a different perception that ‘I think there's this transient period where they [parents] feel they've lost that expertise’ (P7). These references to parents’ loss and later regaining of expertise speaks to the adjustment that parents undergo following the pTBI and the time required for this to take place.

Participants also described that parental adjustment may involve identifying a support network around them which could help with 'sharing the load' (P7) so that parents weren't alone in trying to support their child. At times, participants helped parents to identify their support networks, such as 'bringing in family members and bringing in their community, whoever that is' (P8) and engage them in rehabilitation too.

Theme 3: Aligning physiotherapy with the interests of the child and parents

This theme is concerned with getting to know the child and parents, then aligning physiotherapy advice and recommendations with their interests. Doing this was said to help the initial engagement with physiotherapy and supported sustained engagement over time.

A suggested starting point was to ask 'what does the child like to do for fun…then trying to use that in every session that we then do, even if they obviously can't play sports to the same level, or try and use what they enjoy straight away in therapy if we can' (P8). From the outset, utilising existing frameworks such as the 'F-words [of childhood development] from…CanChild' (P8) could help to guide conversations around physiotherapy and better align recommendations with what was important and interesting to the child and parents. The F-words stand for fitness, functioning, friends, family, fun and future, and are derived from the World Health Organizations' International Classification of Disability, Function and Health (as cited previously in *Chapter 1: Introduction to the thesis*).

Moving beyond delivering a physiotherapy programme to participating in interesting and enjoyable activities was said to help support regular and sustained engagement in physiotherapy over time. Here, a participant suggested 'if we can find active hobbies for children, then that helps to introduce it [physiotherapy] into their routine…that's definitely going to help build it into something that they do regularly' (P1). Participants provided pertinent examples of this, including: if a child with pTBI enjoys horse riding, could they go 'horse riding once a week and that is their therapy and it's fun as opposed to doing a therapy programme, which becomes over time really challenging and really boring because life takes over' (P5). Another example was incorporating physiotherapy into 'the functional things that that family would do together. You know, if they do go out at weekends or whatever and the child can be riding a bike, rather than doing a physio programme' (P3).

Supported goal setting additionally provided parents with the basis for collaboratively agreeing what the physiotherapist, parent and child were jointly working towards. Breaking larger longer-term goals down into individual steps provided a meaningful focus for physiotherapy plus the opportunity 'to see what goals they've already achieved, and what they are moving towards'

(P2). Again, flexibility and adapting the timing of goal setting for each parent and family was important as for some it was ‘just adding to the stress because they're like, this is new...it's introducing all those things just really slowly, at that family's pace’ (P6).

Alongside this, being realistic about what is achievable for parents was also important as unrealistic expectations could add barriers to engaging in physiotherapy. The importance of being realistic was exemplified by a participant who said, ‘if we're saying, actually, your therapy would be really supported by you swimming every week, but that's not achievable for that family, then you know, that's another barrier’ (P1). Participants expressed that physiotherapists with access to the home environment may have some advantages as they could see what parents were ‘dealing with at home, so that you can be a little bit more realistic in what you're asking them to’ do (P11). Physiotherapists working in the community may additionally be able to support access to ‘after school clubs...different kind of sports and activities’ (P1) to continue ongoing engagement with physiotherapy.

Theme 4: Working within contextual constraints

The fourth theme draws upon physiotherapists being adaptable and flexible whilst working within contextual constraints. Such contextual constraints included environmental constraints, geographical constraints and constraints related to resources and pathways of care.

When working with a child with pTBI in hospital, participants needed to be adaptable to support parents in the best way they could to deliver physiotherapy. The ward-based environment could be challenging as ‘if you haven't got the room to get your child out into their chair or into their standing frame...then it’s hard’ (P1). In addition, it was necessary to be adaptable within physiotherapy sessions as ‘hospitals are so unpredictable...you could plan to go at one time and then there's something else happening. There's a scan or there's another medical professional’ (P8). In response to these challenging circumstances, it was expressed that ‘all physios have to be very flexible but particularly in the hospitals, you have to be flexible to change your plan or change what you're thinking of doing at that point’ (P8).

Contextual constraints also related to distance and geography. When a child was admitted to hospital far away from their home, it limited opportunities for parents to go home and return to the hospital, or limited trips home for the injured child once they were well enough for this. For example, ‘we've had patients that have got like maybe a three-hour drive in traffic, so they can't go home when actually, if they live closer, they would go home for a few hours’ (P10). Additionally, therapy services differed based on geography, with children admitted to hospital with pTBI from regions where ‘there's completely different therapy services here compared to elsewhere’ (P9). Similar challenges were faced when there were long or unknown waiting times for ongoing physiotherapy in the community as it was difficult to set parents up with realistic expectation for ongoing input. In such situations, to improve communication and continuity of care, where possible participants working in acute hospitals would ‘try to get referrals in really soon and because…the waiting list can be you know a long time’ (P9). Likewise, from a community perspective, ‘We try and get involved in discharge planning meetings as well. Well before the child is going to be coming home. So again, we can give that information in terms of level of input at that point’ (P11).

Within the constraints and challenges that participants faced, they did their best to provide optimal physiotherapy to the injured child and supported parents themselves to deliver physiotherapy. Acknowledging the constraints and putting the needs of the families first helped with this.

5.5.2 Deductive framework analysis

In the secondary phase of analysis, deductive framework analysis of the themes using the TDF and COM-B model was completed. Across the themes all 14 domains of the TDF and all six constructs of the COM-B model were mapped as being present within the data; see Table 5.2 for full details.

The following example illustrates the deductive coding process based on the themes and participant quotes. For example, in theme one, Participant-8 was quoted as saying ‘I’m trying to always think when I'm doing a session with a patient that straight away the parents are involved as much as possible…I think that’s really empowering for parents’. Against this quote, the TDF domains ‘12. Social influences’ and ‘8. Intentions’ were coded which correspond to constructs ‘Social opportunity’ and ‘Reflective motivation’ of the COM-B model, respectively. This process of deductive coding was completed across the themes to provide a detailed breakdown of underlying behavioural influences (Cane et al., 2012, Turner et al., 2023).

Table 5.2 - The deductive mapping of participant quotes against the Theoretical Domains Framework and Capability, Opportunity, Motivation – Behaviour model

Theme	TDF domain*	COM-B domain	Example quote(s)
1. Actively involving parents as part of the team	12. Social influences	Social opportunity	‘I think that building the trust and building that rapport straight away is the biggest thing’
	10. Memory, attention and decision processes	Psychological capability	This provided the basis for ‘two-way communication. You know that they're understanding what you say and you're understanding what they're saying’
	3. Social/professional role and identity	Reflective & automatic motivation	Parents being a ‘massive part of the team...’
	2. Skills	Psychological capability	‘So, you need to have that good communication’
	10. Memory, attention and decision processes	Psychological capability	It was important to not overwhelm parents further and being cognisant of this then ‘completely influences kind of how you engage and interact’
	2. Skills 14. Behavioural regulation 3. Social/Professional Role and Identity	Psychological capability Psychological capability Reflective & automatic motivation	‘part of your therapeutic skill is being able to adapt your approach to the different circumstances that you find yourself. And being able to be flexible and adapt to change’
	1. Knowledge	Psychological capability	‘understand the cultural context that that family is coming from’
	12. Social influences 8. Intentions	Social opportunity Reflective motivation	‘I’m trying to always think when I'm doing a session with a patient that straight away the parents are involved as much as possible...I think that’s really empowering for parents’
	2. Skills	Physical capability	‘so that they [parents] are from the get-go quite hands-on and not afraid of doing that handling’
	12. Social influences 4. Beliefs about capabilities 14. Behavioural regulation 2. Skills 7. Reinforcement	Social opportunity Reflective motivation Psychological capability Psychological & physical capability Automatic motivation	Participants broke activities and exercises down into smaller steps and were flexible in ‘adapting as you go, as their [parents’], you know, abilities and confidence changes.’ This process went alongside explaining why physiotherapy was important, and giving ‘feedback, lots of

			feedback and you know, what they're getting right, so that they know that they're happy with what they're doing’
	2. Skills	Psychological & physical capability	By gradually ‘building them [parents] into the sessions and getting them to do more and more of it outside of our time. So, hopefully upon discharge…they are able to completely provide the therapy programme that's needed’
	12. Social influences	Social opportunity	‘we get some of our best interactions when we engage extended family, and our rehab quality is improved by their engagement and their involvement’
	6. Beliefs about consequences	Reflective motivation	‘If we can get parents doing therapy, then I can increase that [therapy dose] to multiple hours a day’
2. Supporting parental adjustment to life following their child’s brain injury	12. Social influences	Social opportunity	Parents were on ‘this journey that you thought you were on, and suddenly you’re not’. Participants described that they played a part in supporting parental adjustment across the rehabilitation pathway
	12. Social influences	Social opportunity	Reassurance that they were ‘not here to test you…or criticise what you're doing’
	12. Social influences	Social opportunity	Participants provided opportunities for parents to ‘help their child, which is all they want to do’
	3. Social/professional role and identity	Reflective & automatic motivation	The physiotherapists’ role involved supporting parents’ immediate needs whilst they also ‘set the scene for the patient’s onward journey, I think we have a responsibility to do that’
	3. Social/professional role and identity	Reflective & automatic motivation	Parents were said to have ‘overcome the realisation that their child has had, you know, a life changing injury…I think reality obviously starts to hit a lot more once they've come out of rehab and they're back home. And so, I think as a physio, your role is so much more than just hands on physio’
	1. Knowledge 2. Skills	Psychological capability Psychological & physical capability	One participant spoke about ‘transferring your skills and [parents] being able to become proficient in a different place, in a different environment, different context…that's what we're all trying to do. It isn't just about being at home,

	3. Social/Professional Role and Identity 4. Beliefs about Capabilities 5. Optimism	Reflective & automatic motivation Reflective motivation Reflective & automatic motivation	being in hospital and being able to do it, you need to be on different environments, you need to be doing what you want to be doing’
	4. Beliefs about capabilities	Reflective motivation	Community physiotherapist’s perception that ‘parents are the expert on their child’, whereas initially following the injury there was a different perception that ‘I think there's this transient period where they [parents] feel they've lost that expertise’
	12. Social influences 13. Emotion	Social opportunity Automatic motivation	Identifying a support network around them which could help with ‘sharing the load’ so that parents weren’t alone in trying to support their child. At times, participants helped parents to identify their support networks, such as ‘bringing in family members and bringing in their community, whoever that is’ and engage them in rehabilitation too.
3. Aligning physiotherapy with the interests of the child and parents	7. Reinforcement	Automatic motivation	‘what does the child like to do for fun…then trying to use that in every session that we then do, even if they obviously can't play sports to the same level, or try and use what they enjoy straight away in therapy if we can’
	7. Reinforcement 14. Behavioural regulation	Automatic motivation Psychological capability	A participant suggested ‘if we can find active hobbies for children, then that helps to introduce it [physiotherapy] into their routine…that's definitely going to help build it into something that they do regularly’
	7. Reinforcement	Automatic motivation	‘If a child with pTBI enjoys horse riding, could they go ‘horse riding once a week and that is their therapy and it's fun as opposed to doing a therapy programme, which becomes over time really challenging and really boring because life takes over’
	14. Behavioural regulation 11. Environmental context and resources	Psychological capability Physical opportunity	Incorporating physiotherapy into ‘the functional things that that family would do together. You know, if they do go

			out at weekends or whatever and the child can be riding a bike, rather than doing a physio programme’
	9. Goals 8. Intentions	Reflective motivation Reflective motivation	The opportunity ‘to see what goals they've already achieved, and what they are moving towards’
	9. Goals 13. Emotion	Reflective motivation Automatic motivation	Flexibility and adapting the timing of goal setting for each parent and family was important. For some it was ‘just adding to the stress because they're like, this is new…it's introducing all those things just really slowly, at that family's pace’
	11. Environmental Context and Resources 4. Beliefs about capabilities	Physical opportunity Reflective motivation	The importance of being realistic is exemplified by a participant who said, ‘if we're saying, actually, your therapy would be really supported by you swimming every week, but that's not achievable for that family, then you know, that's another barrier’
	11. Environmental Context and Resources 4. Beliefs about capabilities	Physical opportunity Reflective motivation	See what parents were ‘dealing with at home, so that you can be a little bit more realistic in what you're asking them to’ do. Physiotherapists working in the community may additionally be able to support access to ‘after school clubs…different kind of sports and activities’
4. Working within contextual constraints	11. Environmental Context and Resources	Physical opportunity	The ward-based environment could be challenging as ‘if you haven't got the room to get your child out into their chair or into their standing frame…then it’s hard’. In addition, it was necessary to be adaptable within physiotherapy sessions as ‘hospitals are so unpredictable…you could plan to go at one time and then there's something else happening. There's a scan or there's another medical professional’
	14. Behavioural regulation	Psychological capability	‘all physios have to be very flexible but particularly in the hospitals, you have to be flexible to change your plan or change what you're thinking of doing at that point’
	11. Environmental Context and Resources	Physical opportunity	For example, ‘we've had patients that have got like maybe a three-hour drive in traffic, so they can't go home when actually, if they live closer, they would go home for a few

			hours'. Additionally, therapy services differed based on geography, with children admitted to hospital with pTBI from regions where 'there's completely different therapy services here compared to elsewhere'…
	8. Intentions 11. Environmental Context and Resources	Reflective motivation Physical opportunity	Participants working in acute hospitals would 'try to get referrals in really soon and because…the waiting list can be you know a long time'. Likewise, from a community perspective, 'We try and get involved in discharge planning meetings as well. Well before the child is going to be coming home. So again, we can give that information in terms of level of input at that point'

*Numbers included within the 'TDF domain' column relate to the 14 individual behavioural domains of the Theoretical Domains Framework
TDF = Theoretical Domains Framework; COM-B = Capability, Opportunity, Motivation – Behaviour model

The results of the deductive coding were collated and presented within Tables 5.3 and 5.4 below. Within the physiotherapy focus groups, the most frequently coded domain of the TDF was '12. Social influences', coded eight times across two themes. The second most frequently coded domain was '2. Skills', coded six times across two themes. Following this, domains '3. Social/Professional Role and Identity', '4. Beliefs about Capabilities', '11. Environmental Context and Resources' and '14. Behavioural Regulation' were all coded five times across two to three themes. The remaining domains of the TDF were coded less frequently - see Table 5.3 for a full breakdown of deductive coding against the TDF.

Table 5.3 - Breakdown of deductive coding against the Theoretical Domains Framework

TDF domain*	Theme one	Theme two	Theme three	Theme four	Total
1. Knowledge	1	1	-	-	2
2. Skills	5	1	-	-	6
3. Social/Professional Role and Identity	2	3	-	-	5
4. Beliefs about Capabilities	1	2	2	-	5
5. Optimism	-	1	-	-	1
6. Beliefs about Consequences	1	-	-	-	1
7. Reinforcement	1	-	3	-	4
8. Intentions	1	-	1	1	3
9. Goals	-	-	2	-	2
10. Memory, Attention and Decision Processes	2	-	-	-	2
11. Environmental Context and Resources	-	-	3	2	5
12. Social influences	4	4	-	-	8
13. Emotion	-	1	1	-	2
14. Behavioural Regulation	2	-	2	1	5

*Numbers included within the 'TDF domain' column relate to the 14 individual behavioural domains of the Theoretical Domains Framework
TDF = Theoretical Domains Framework
Theme one: Actively involving parents as part of the team
Theme two: Supporting parental adjustment to life following their child's brain injury
Theme three: Aligning physiotherapy with the interests of the child and parents
Theme four: Working within contextual constraints

In terms of the constructs of the COM-B model, 'Reflective motivation' was coded 17 times across all four themes and represents the most frequently coded COM-B construct. Other frequently coded COM-B constructs were 'Psychological capability' coded 14 times across all four themes, followed by 'Automatic motivation' coded 12 times across three themes and 'Social opportunity' coded eight times across two themes. Less frequently coded constructs include 'Physical opportunity' (coded five times across two themes) and 'Physical capability' (coded four times across two themes). See Table 5.4 for a full breakdown of deductive coding against the COM-B model.

Table 5.4 – Breakdown of deductive coding against the COM-B model

COM-B construct	**Theme one**	**Theme two**	**Theme three**	**Theme four**	**Total**
Psychological capability	9	2	2	1	14
Physical capability	3	1	-	-	4
Social opportunity	4	4	-	-	8
Physical opportunity	-	-	3	2	5
Reflective motivation	5	6	5	1	17
Automatic motivation	3	5	4	-	12

COM-B = Capability, Opportunity, Motivation – Behaviour model
Theme one: Actively involving parents as part of the team
Theme two: Supporting parental adjustment to life following their child's brain injury
Theme three: Aligning physiotherapy with the interests of the child and parents
Theme four: Working within contextual constraints

5.6 Discussion

Physiotherapists are essential stakeholders in supporting parents to learn and adhere to delivering physiotherapy exercises to their injured child following pTBI. For the first time, this study examined the views and experiences of physiotherapists regarding supporting parents. I also identified underlying behavioural influences of physiotherapists related to parental adherence to delivering physiotherapy exercises. Physiotherapists were recruited using a research flyer sent to the APCP membership. Whilst the APCP is one of the largest professional networks of the Chartered Society of Physiotherapy, it is an 'opt in' professional network and therefore does not represent the whole target population. This may have impacted the findings: physiotherapists who are not APCP members could have expressed different perspectives (Braun and Clarke, 2022).

The study aim has been addressed by meeting the three research objectives. Firstly, through inductive reflexive thematic analysis I have developed four themes which encapsulate the experiences of physiotherapists that support parents from the acute hospital setting through to supporting the delivery of physiotherapy exercises at home (objective 1). Within the secondary deductive analysis, I have mapped participant data against behavioural domains and targets to identify the causal relationships underpinning physiotherapists' influences on parental adherence to delivering physiotherapy (objective 2). Lastly, these fresh insights from sequential inductive and deductive analysis will help to inform the behavioural diagnosis and conceptual design of the intervention (objective 3).

From the study findings, the four themes identified that participants supported parents in a range of different ways to adhere to delivering physiotherapy exercises. Initially, there appeared to be the need to develop an interpersonal relationship with the parent from which participants were able to gradually involve parents in physiotherapy sessions and teach them the skills to be able to deliver physiotherapy themselves. Participants also expressed the importance of getting to know the CYP and parent in order that physiotherapy could relate to existing interests and support engagement (Gmelig Meyling et al., 2023a). A framework such as the F-words of child development was particularly emphasised by participants as being a helpful means through which to do this (Rosenbaum and Gorter, 2011, Rosenbaum, 2022). Participants described supporting parents to adjust to life and their new roles following the pTBI, understanding physiotherapy to be an important aspect of this process with parents employing their skills within a range of different situations and environments (Piggot et al., 2003). Participants also acknowledged the need for flexibility when supporting parents within identified contextual constraints.

Key potential influences on participants' behaviour included 'Reflective motivation' which related to the need to set clear and agreed goals, the intention to involve parents in physiotherapy and understanding the important role that parents played in their child's rehabilitation. A further behavioural influence appeared to be 'Automatic motivation' whereby participants considered the emotional impact of the pTBI on parents and gauged their approach accordingly. 'Automatic motivation' also related to the value of making physiotherapy fun and relatable whist providing reinforcement to parents when things went well. Beyond motivation, participants were also found to influence parents' behaviour through 'Psychological capability'. This included using skills to develop two-way communication and involve parents in physiotherapy in a way that attempted to not overwhelm them further. This related very closely to 'Social opportunity' whereby participants attempted to develop rapport with parents, enable parents to help their injured child and involve other family members and the wider support network alongside parents.

There are several important findings from this study which have relevance within the fields of research and clinical practice. I will now explore the close alignment of social influences with skills, the role of education and feedback when involving parents in physiotherapy, plus the importance of participation in turn below.

5.6.1 Influencing behaviour through social influences and skills

It is important to note from the outset that participants evidently viewed parents as a 'massive part of the team' (P9) and actively involving a parent in their child's care was said to be crucial (Harniess et al., 2022). An important finding clearly demonstrated in theme 1 is that the role of physiotherapists in supporting parents to adhere to delivering physiotherapy exercises appeared to commence with the interpersonal interactions occurring initially in the acute hospital environment. A starting point, and indeed 'the biggest thing' as described by participant 8, was to establish a good rapport and a sense of trust with a parent which paved the way for parental involvement in physiotherapy (Jones et al., 2020).

Establishing rapport and trust with parents was said to provide a foundation for two-way communication and acted as the bedrock of the therapeutic relationship which developed between the physiotherapist and the parent (Tipping et al., 2010). Developing a sense of trust with a parent following their child's pTBI has previously been shown to support communication and information sharing in a way that a parent can understand (Kirk et al., 2014). Similar results have been replicated elsewhere. In a realist synthesis, Harniess and colleagues identified that building trust and establishing a clear means of communication, in addition to co-designing therapeutic interventions, were essential elements of parental engagement and adherence in a rehabilitation intervention (Harniess et al., 2022). In this case, the intervention consisted of physiotherapy and occupational therapy exercises for infants at high risk of cerebral palsy (Harniess et al., 2022). Similar findings were found in a qualitative study of physiotherapy education for parents of toddlers diagnosed with cystic fibrosis. The study found that parents' social connectedness and their relationship with the physiotherapist supported parent education and feedback, whilst also reducing parents' psychological distress (Tipping et al., 2010).

Establishing rapport and trust closely align with the findings from *Chapter 4: Qualitative study involving parent interviews* where parents described the range of strong and complex emotions that they experienced following their child's admission to hospital following pTBI. Physiotherapists were said to play an important role in supporting parents by providing information and explanations about physiotherapy, whilst gradually involving parents in physiotherapy with their child in a graded way. Findings from this current study reinforce that establishing an initial inter-personal connection between physiotherapists and parents is an important starting point within the complex field of parental adherence to delivering physiotherapy exercises. This is reflected in the repeated mapping of the TDF domain 'Social influences' which is defined as 'Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours' (Cane et al., 2012). Social influences are shown to be key in physiotherapists providing the much-needed social support to parents, delivered through the COM-B domain ‘Social opportunity’ (Atkins et al., 2020). The results additionally suggest that social support did not simply occur, but rather it was cultivated on an individual basis by the participants. The deductive analysis highlights that the participants’ ability to adapt and flexibly tailor their approach and communication to individual parents when working with, supporting and involving them in physiotherapy was considered central to a physiotherapist’s role and professional identity. These are also skills which fall under the COM-B domain ‘Psychological capabilities’ which can be worked on and developed.

These findings have important implications for clinical practice. Physiotherapists should be specifically supported to develop their skills in establishing positive communication, building trust and rapport in an evidence-based way with parents following pTBI. For example, the authors of a recent scoping review identified several ways in which rapport was supported or hindered in clinical practice. The review highlighted that simple behavioural acts such as shaking hands, using a patient or family members’ name and taking the time to connect and get to know them as a person were regarded as important in building rapport (English et al., 2022). Conversely, prioritising efficiency over rapport, overuse of medical jargon or not taking time to explain or check understanding could hinder rapport building (English et al., 2022). Developing such skills are in keeping with the Health and Care Professions Council’s (HCPC) core standards of proficiency for physiotherapists working in the UK and Northern Ireland. Developing trust and communication together with building a partnership, whilst empowering and enabling service users in maintaining their own health, feature as core standards (Health and Care Professions Council, 2023). In addition, receiving personal recommendations from healthcare professionals and trusted individuals, as an extension of the TDF domain ‘social influences’, has been found to positively influence user uptake and use of digital interventions (Szinay et al., 2020). Therefore, these findings also have direct implications for the development and implementation of a digital intervention which will be designed based on theory and evidence, for adoption within clinical practice (West and Michie, 2016).

Alongside the interpersonal interactions between physiotherapists and parents, it was important for physiotherapists to practically and physically involve parents in physiotherapy sessions, as will be explored further below.

5.6.2 Physically involving parents in physiotherapy happens alongside education and feedback

Participants expressed that when initiating physiotherapy with a patient in hospital, where appropriate, parents were involved as early and as much as possible within physiotherapy sessions. In this section I will consider in greater depth how participants facilitated parents to become physically involved in supporting their child through physiotherapy, and how this went hand-in-hand with education and feedback.

Initially involving parents, for example through encouraging them to help with holding their child, was said to begin to gradually normalise the process of parents handling and physically supporting their child (Gmelig Meyling et al., 2023a). Crucial to this was developing parents' understanding about the value or reason behind physiotherapy which supported their engagement with the learning process in a gradual and graded way (King et al., 2020).

When training parents, the combined use of education and feedback have been utilised by physiotherapists in other areas of healthcare to empower parents to deliver physiotherapy to their child (Tipping et al., 2010, Harniess et al., 2022). Where education and feedback are approached sensitively and build on an underlying connection between the parent and physiotherapist they can positively support parents' sense of control (Harniess et al., 2022). Increasing parents' confidence in their ability to positively influence their child's longer-term outcomes and enhancing their self-efficacy are said to also contribute to this process (Hobfoll et al., 2007, Tipping et al., 2010, Barbosa et al., 2021).

Whilst echoing some of the findings from *Chapter 4: Qualitative study involving parent interviews*, it is acknowledged that physiotherapists should gauge how and when they offer feedback to parents as feedback can be intimidating and be a source of additional stress (Tipping et al., 2010). This is important for physiotherapists to consider when training parents to support their child following pTBI. Particularly as physical training appears to follow from the initial social connection and rapport which are established between parents and physiotherapists (Tipping et al., 2010, King et al., 2020). This process of parental training therefore needs to be highly personalised and graded according to the evolving needs of the parent.

These findings have important implications for both the intervention and clinical practice. Although participants proactively involved parents in the physical aspects of physiotherapy, their influence on parental adherence appeared to reach far beyond simply developing their physical skills (or 'Physical capability'). This can be illustrated through the complex interaction of behavioural influences at play when physically involving parents in physiotherapy. For example, developing parents' practical skills, the COM-B domain 'Physical capability', is said to primarily occur within a physical context of involving them in a rehabilitation session with their child, the COM-B domain 'Physical opportunity'. Linked with this process is building knowledge, the COM-B domain 'Psychological capability' alongside giving feedback which enhances confidence targeted through beliefs in their capabilities, the COM-B domain 'Reflective motivation'. All of this is said to occur on the backdrop of establishing an initial rapport and relationship with the parent, the COM-B domain 'Social opportunity'. This level of detail is important to consider as it helps to contextualise the complexity of physically involving parents in physiotherapy and break down some of the processes involved in establishing this key element of empowering parent delivered physiotherapy. Therefore, physically involving parents in physiotherapy provides the context within which a range of influences on parental adherence can be employed. Enhancing physiotherapists' understanding of the complexity of behavioural influences and developing a more consistent approach to involving parents in physiotherapy may be a valuable output from this study.

5.6.3 The role of participation in delivering physiotherapy

A further important finding is the role that participation-based physiotherapy has been shown to play throughout the rehabilitation pathway, and the use of frameworks in guiding physiotherapy (Keetley et al., 2020). The findings demonstrate that participants proactively sought to involve parents in their child's rehabilitation from an early stage in the rehabilitation pathway. In doing so, getting to know the child and their parents was important and helped in aligning physiotherapy with existing interests which held meaning for the child, parents and family as a whole (Ames et al., 2011, Jenkin et al., 2022b). A framework such as the F-words of child development which was specifically mentioned by participants to structure conversations about physiotherapy has been shown to increase family empowerment and satisfaction within rehabilitation (Rosenbaum and Gorter, 2011, Jenkin et al., 2022a).

Getting to know the child and family and then aligning physiotherapy with existing interests helps to foster initial engagement in physiotherapy. This process supports the CYP and parent in feeling listened to, respected and having a say in their care (Melin et al., 2021). Relating physiotherapy to existing interests also provides a meaningful connection between the physiotherapy activity and something the family may find fun to do (King et al., 2020). From a behavioural perspective, taking part in fun and meaningful activities supports parents to receive positive reinforcement about the behaviour and increases their motivation to continue (Cane et al., 2012, Jenkin et al., 2022a). In this way, the influence of positive reinforcement increases adherence to delivering physiotherapy through the COM-B domain 'Automatic motivation' (Cane et al., 2012, Soper et al., 2019).

Beyond the initial engagement with physiotherapy, motivation also plays an important role in structuring physiotherapy enacted through processes such as goal setting (Cane et al., 2012, Melin et al., 2021). It is proposed that the F-words of child development can again assist physiotherapists to gain a holistic understanding of the child and their family (Rosenbaum, 2022) which provides an excellent setting to undertake collaborative goal setting, reviewing goals and receiving feedback (Jenkin et al., 2022a). To be meaningful, goal setting needs to be a collaborative process whereby the physiotherapist acts as a facilitator to hear the important aspirations that CYP and parents may have. This could begin with 'bigger picture' goals which represent longer-term aspirations, and it is said that a role of the physiotherapist is to break these down into smaller more achievable steps (Melin et al., 2021, Jenkin et al., 2022a, Young and Gravett, 2025). In doing so, the intention is that the resultant goals will be important to the child and family, as well as be specific, proximal and challenging, and be reviewed and updated as the needs of the child and family change over time (Pritchard-Wiart et al., 2019, Ryan et al., 2025).

The study findings demonstrate how adherence to physiotherapy is supported through an interplay of 'Automatic' and 'Reflective motivation' in conjunction with relating physiotherapy to participation in daily life and everyday environments (Gmelig Meyling et al., 2023b, Novak-Pavlic et al., 2023). Such processes also enable engagement between physiotherapists and parents through working together to develop plans and share ideas related to physiotherapy (King et al., 2020). Whilst this is the case, physiotherapists noted that goal setting and parental involvement in physiotherapy needed to be undertaken collaboratively and sensitively as some parents may find it too overwhelming. This reiterates the need for physiotherapists to continually monitor parents' responses and approach physiotherapy at an individual family's pace (Tipping et al., 2010).

This has important implications for clinical practice and research as it demonstrates the importance of promoting and fostering collaboration between children, parents and physiotherapists at all stages of the rehabilitation pathway (Gmelig Meyling et al., 2023a, Novak-Pavlic et al., 2023). It also has implications for intervention development through the integration of evidence-based frameworks such as the F-words of child development to provide a holistic understanding of the child and family (Rosenbaum and Gorter, 2011, Soper et al., 2019). Integrating robust processes such as goal setting and review within clinical practice and intervention development will also be important (Jenkin et al., 2022a, Young et al., 2024a).

5.6.4 Reflexivity and considering my impact on the analysis process

This section utilises reflection and reflexivity, together with some direct quotes from my reflexive diary to help document how the data analysis developed as it did, and reasons behind why it developed in this way.

Firstly, I am a paediatric physiotherapist myself with several years' experience of working in mainly acute hospital settings with children and young people as well as their parents and families. I also have some experience of working in community settings supporting physiotherapy, and I brought this experience directly into the analysis process. In this sense, I am an insider researcher and share this important trait with the participants (Bukamal, 2022).

This may have had both positive and negative influences on the data collection process and the quality of data gathered from the focus groups. For example, being an insider researcher with an existing professional relationship with some participants may have been beneficial. I was able to quickly build a strong rapport with participants, facilitating the collection of rich and high quality participant data (Hays and McKibben, 2021). Conversely, assumptions could have adversely affected the quality of the data. For example, participants may have described a hospital based clinical scenario but not delved into great depth due to the assumption that I, a qualified physiotherapist, would intuitively understand what they meant. In such situations, further skilled questioning would be required to probe further into participants' meaning (Braun and Clarke, 2013). Additionally, within the analysis process my own assumptions could have influenced data interpretation: capturing and challenging these assumptions form the bedrock of high-quality reflexivity (Braun and Clarke, 2013, Braun and Clarke, 2022, Olmos-Vega et al., 2023).

As this study forms one aspect of my PhD research, at the time of analysis I had recently undertaken the analysis of parent interviews, presented in *Chapter 4: Qualitative study involving parent interviews,* and the data analysis was fresh in my mind. An example of where this has been influential in shaping the analysis is within the participant descriptions of their initial interactions with parents. During the analysis of parent interviews, parents clearly described the extent of emotional distress that they experienced and the important role that physiotherapists played in providing explanations and reassurance. When analysing the data from the physiotherapy focus groups, a similar emphasis on interpersonal communication was expressed. The following excerpt comes from my reflexive diary and illustrates how the analysis process was shaped:

'when analysing the physio focus group data, I am coding sections of data which relate to the importance of physiotherapists' dialogue with parents in the initial stages of working with them.

This is the physiotherapists' perspective of what parents previously spoke about. What is also evident is that physiotherapists are very conscious to tailor their communication to the individual needs of the parents that they are working with. This is an important aspect of how they establish rapport and develop a relationship with parents'.

From my very initial familiarisation with the transcripts, my prior experience guided my understanding of what participant expressed. The following quote outlines how I reflected upon my own experience when reviewing the data, as *"There is a real sense of rapport building, good communication and building a relationship with families. This echoes my own experience and my increased awareness of speaking to parents away from the bedside after many sessions to…build on the parent's own understanding and needs"*. Before physiotherapists begin to involve parents in their child's rehabilitation, there is a need for good communication and the development of an initial social connection and rapport.

Through the analysis process I was able to see parallels between the two focus group transcripts and deemed the flexible approach that physiotherapists took to be important. The following excerpt speaks to this understanding and the decisions that I made relating to flexibility: *"There seems to be lots of references to flexibility in lots of different ways. Flexibility in how participants approach the family and pitch the level of information. Flexibility with communication styles. Flexibility with context and so much going on all the time in hospital and adapting what you plan to do in a session."* My interpretation of the data was not that flexibility was a distinct theme in and of itself, but rather, flexibility is a vital aspect of physiotherapy practice across all the themes: it is an inherent part of being a physiotherapist.

A further aspect of the analysis which really leapt out to me as being important, and an aspect of theme two, was the role that physiotherapists played in the broader adjustments of parents. I was greatly influenced by the recent analysis I completed of the data from parent interviews, as outlined in the following excerpt from the reflexive diary:

"I am also looking at the 'parents were on this journey' quote from P7. This really relates to journey being life before the pTBI and then life after and the adjustment that is required for parents and the family. This is a complex and nuanced aspect of the data as it appears that the impact and adjustment that are required are enormous. In keeping with the parent interview study…gaining confidence and skills, then learning how to integrate physiotherapy into everyday life is really echoed here. Without completing the parent interview analysis, I don't believe that I would have had this additional insight and therefore perhaps wouldn't have interpreted the data in that way."

Considering this aspect of the analysis further and seeing parallels between the data sets reveals how conducting this research and data analysis have impacted me as an individual, a researcher and a clinician. The process of conducting qualitative research and data analysis have given me additional insights into the impact of pTBI on parents and the important and wide-ranging role that physiotherapists play in supporting parental adherence.

5.6.5 Implications for the proposed intervention

This study provides new evidence from physiotherapists which will feed into the conceptual design of the intervention plus the co-design of a prototype digital behaviour change intervention (Craig et al., 2008, West and Michie, 2016).

Physiotherapists support parents to adhere to delivering physiotherapy exercises in a wide range of different ways. From the deductive analysis, it is evident to see that physiotherapists consciously and intentionally work to establish an initial rapport with parents, and it is this combination of social and emotional support which establishes the foundation for parental involvement (Ames et al., 2011, Gmelig Meyling et al., 2023a). It is important that the intervention is designed in a way that fosters and encourages this rapport and collaboration between parents and physiotherapists (King et al., 2020, English et al., 2022). The intervention must also have capacity to be tailored to individual users and be designed to support the interpersonal interactions between physiotherapists and parents which occur within the existing pathway of care (Dijkstra and De Vries, 1999, National Institute for Health and Care Excellence, 2023a).

By addressing the three research objectives, the findings from this study provide in-depth understanding about how physiotherapists experience working with parents following their child’s pTBI. Additionally, how they approach supporting parents to adhere to delivering physiotherapy exercises. The study findings highlight that each component of the COM-B model represents relevant targets for influencing parental adherence. ‘Reflective motivation’, ‘Automatic motivation’ and ‘Psychological capability’, together with ‘Social opportunity’, are shown to be most influential for physiotherapists to support parents. Therefore, in taking this evidence forward to inform intervention development, it is clear that the intervention needs to include these behavioural influences which can be delivered in a flexible and tailored way.

5.6.6 Strengths, limitations, and directions for future research

There are a range of strengths and limitations of this study. Firstly, the qualitative data was collected within two focus groups meaning that multiple participants contributed to data collection simultaneously. In this way, focus groups which were based on the same interview topic guide offered a consistent structure and format, whilst also allowing participants to interact in a spontaneous and dynamic way by building on one another's contributions (Sim and Waterfield, 2019). This means that there may have been scope for participants to delve into a greater level of detail they reciprocally built on the contributions of others (Sim and Waterfield, 2019).

A further strength is that the remote nature of recruitment and online focus groups meant that it was possible to recruit physiotherapists from a wide geographic spread across the UK (Carter et al., 2021). In addition, different levels of experience and professional banding were represented across the focus groups, with bands 6-8 represented. This meant that a range of perspectives and levels of expertise were included within the data which could be captured in a flexible and time efficient way without the need for participants to travel significant distances or disrupt their existing work commitments (Flayelle et al., 2022).

In much the same way as *Chapter 4: Qualitative study involving parent interviews*, combined inductive and deductive analysis enabled rich data driven analysis, alongside the mapping of data against the COM-B model, supporting the development of a theory- and evidence-based intervention (O'Cathain et al., 2010, Michie et al., 2014, Croot et al., 2019, Young et al., 2024a). This approach allowed for the contribution of new knowledge through inductive analysis without restricting the interpretation of data which is a known potential pitfall of deductive analysis completed in isolation (McGowan et al., 2020, Byrne, 2022).

A further strength are the efforts made to enhance the rigour, trustworthiness and generalisability of the findings. These related to the credibility, transferability, dependability and confirmability of the study findings (Lincoln and Guba, 1985, Smith, 2017). Focus groups which were conducted in a reflexive way using a common topic guide enhance the credibility of the study findings. Providing clarity about the context within which the focus groups took place, and describing the relevant experience of participants contributing to the data enhances the study's transferability. Dependability of the findings has been supported by outlining data collection and analysis processes, including the combined and sequential inductive and deductive analysis. Additionally, the confirmability of the findings is supported by my maintenance of a reflexive log, partaking in regular supervision and feedback from academic supervisors together with highly experienced colleagues to challenge and help to confirm my interpretations of the data.

Limitations of the study also require consideration. Firstly, it is important to acknowledge that whilst efforts were made to include participation of physiotherapists from a range of different settings, there was a skew towards participants working in acute hospitals. This is best illustrated by the fact that at the point of participation in the study over 90% of participants worked in designated major trauma centres or other acute NHS hospitals. It is possible that this skew may have occurred because there are multiple major trauma centres and acute hospitals across the country with well-established care pathways for supporting CYP with pTBI. Perhaps the pathways of care and familiarity of physiotherapists working with pTBI in the community and other settings is less established in the community. Additionally, as The Children's Trust in Surrey is the only residential rehabilitation setting providing rehabilitation for CYP with pTBI and other forms of acquired brain injury then numerically fewer physiotherapists work within that setting than elsewhere.

The potential impact of this skew towards physiotherapists working in an acute setting is that the findings may reflect the initial interactions between parents and physiotherapists with greater emphasis on the inpatient setting. Consequently, this may have resulted in less focus on rehabilitation in the community and the longer-term role of physiotherapists in supporting parents. As a result, there is potential that the resulting digital intervention may have a predominant focus on physiotherapy in the acute setting.

A further potential limitation is that the recruitment strategy for this study involved a blanket recruitment email sent out by the APCP to all members without any stratification based on where physiotherapists worked. Having said that, my objective was not to recruit a representative sample of physiotherapists working across all clinical settings, but rather to explore their experiences and underlying behavioural influences. To this end, the recruitment strategy was appropriate and provided data to help me address my research aim and objectives. As a result of the above limitations, the data may therefore primarily represent perspectives from the acute setting with less emphasis on the role of physiotherapists in the community and other settings. This requires consideration when interpreting the findings (Jones et al., 2020).

A further possible limitation of the study is that both focus groups were conducted remotely which may have limited some of the dynamic interactions possible with face-to-face focus groups (Flayelle et al., 2022). In addition, the remote method of data collection could have made the subtleties of interpreting participants' body language more challenging than face-to-face focus groups (Flayelle et al., 2022). Having said that, I made great efforts to set the scene and put all participants at ease prior to beginning data collection with the aim of optimising the quality of the data. Moreover, some report that potentially richer data may have been captured via online focus groups compared to traditional face-to-face focus groups due to their more informal nature. This is particularly relevant as online platforms are widely used by healthcare professionals (Stewart and Shamdasani, 2017, Flayelle et al., 2022).

Future research should seek to integrate the findings of this study together with different sources of data to generate a behavioural diagnosis of what needs to change to increase parental adherence to delivering physiotherapy exercises (Michie et al., 2014). Consideration should also be given to the perspectives of end-users and other key stakeholders to co-design an intervention which is considered acceptable to those that will use it. In addition, other methods of data collection such as ethnographic research could be undertaken to observe how physiotherapists and parents interact within different clinical settings in relation to parent delivered physiotherapy. Likewise, additional research involving physiotherapists from a more diverse range of clinical settings could be undertaken to explore the range of experiences of physiotherapists related to different clinical contexts.

5.7 Conclusions

This study has explored the perspectives of physiotherapists who provide vital support to parents required to deliver physiotherapy exercises to their child following pTBI. Physiotherapists influence the behaviour of parents in a range of different ways, beginning with establishing rapport and developing two-way communication. This initial social support provides the basis for involving parents in physiotherapy and ensuring that physiotherapy recommendations are relevant and meaningful to CYP and parents within the context of existing interests and everyday life.

5.8 Chapter summary and next steps

Qualitative data from paediatric physiotherapists have been collected and analysed to explore their first-hand experiences of supporting parents and identify behavioural influences on parental adherence. The deductively analysed behavioural influences are summarised in Table 5.5 below.

The next stage is to collate and synthesise the behavioural influences from *Chapter 2: Systematic Review*, *Chapter 4: Qualitative study involving parent interviews* and *Chapter 5: Qualitative study involving physiotherapy focus groups* according to the COM-B model. I will then establish a behavioural diagnosis and specify the conceptual design of the intervention following the design stages of the Behaviour Change Wheel (Michie et al., 2014).

Table 5.5 - Summary of key findings from this chapter mapped on to the COM-B model

COM-B sub-constructs	**Identified within parent interviews? Yes/No**	**Key findings**	
		Frequency of coding	How is this expressed within themes
Physical Capability	Yes	Coded four times across two themes	This intervention target is expressed through the imparting of physical skills
Psychological Capability	Yes	Coded 14 times across all four themes	This intervention target is particularly expressed through behavioural regulation and the imparting of psychological skills
Reflective Motivation	Yes	Coded 17 times across all four themes	This intervention target is particularly expressed through social/professional role and identify and beliefs about capabilities
Automatic Motivation	Yes	Coded 12 times across three themes	This intervention target is particularly expressed through social/professional role and identify and reinforcement
Physical Opportunity	Yes	Coded five times across two themes	This intervention target is expressed through influences from environmental context and resources
Social Opportunity	Yes	Coded eight times across two themes	This intervention target is expressed through social influences
Summary	All sub-constructs of the COM-B model were coded across themes	Reflective motivation was coded most frequently, followed by psychological capability and automatic motivation	-

Key: The colours within the table represent those within the COM-B model itself, whereby red refers to Capability, yellow refers to Motivation and green refers to Opportunity. See Figure 1.4 on page 44 for further details about the COM-B model.

Stage 4 – Evidence synthesis

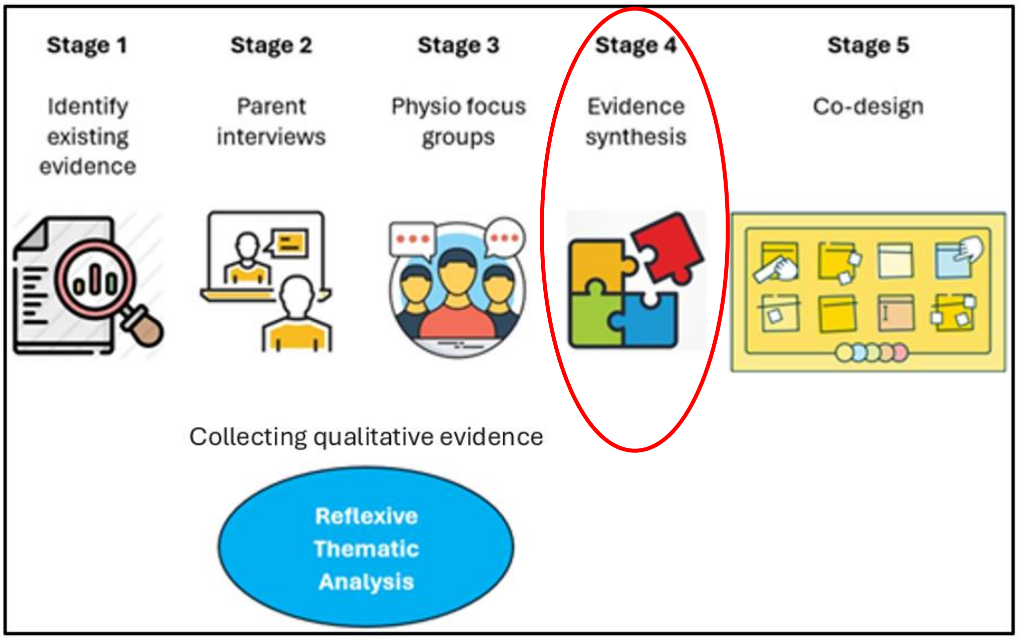
Chapter 6: The conceptual design of the intervention

6.1 A brief overview of this chapter

So far in this thesis I have provided a background about pTBI and the role of parents in delivering physiotherapy exercises to their child following pTBI. Within the subsequent chapters, I then presented empirical findings which addressed identified gaps in the research. I initially presented the strategies and active ingredients within existing interventions involving parent delivered rehabilitation exercises (Chapter 2). I presented a study exploring the experiences of parents and behavioural influences on their adherence to delivering physiotherapy exercises, plus the experiences and behavioural influences of physiotherapists that support parents (Chapters 4 and 5, respectively). In each of these chapters I coded the findings against the COM-B model as it is a theoretically derived framework which I am using as the central framework to organise the evidence. It also provides detailed understanding of influences on parental adherence and what needs to change for parental adherence to occur (referred to as the behavioural diagnosis).

When designing a theory- and evidence-based behaviour change intervention it is important to bring together the different sources of available evidence within a theoretical framework. Within this chapter I will triangulate and synthesise the evidence presented within Chapters 2, 4 and 5 according to the COM-B model. This will provide the conceptual starting point to identify promising intervention options and content within the intervention designed to increase parents' adherence to delivering physiotherapy exercises. This chapter represents work undertaken at Stage 4 of the design process, as detailed in Figure 1.1 below.

Figure 1.1 - Figure providing an overview to the thesis structure



I will follow the design stages of the Behaviour Change Wheel guidance to specify a comprehensive conceptual design of the intervention rooted in theory and informed by empirical evidence. This process involves three stages of intervention development sub-divided into eight steps, as will be outlined in detail below.

6.2 Introduction

Human behaviour can be complicated with potentially multiple behaviours occurring simultaneously or being linked to one another within an individual or group of people (Michie et al., 2014). Consequently, behaviour change is also complicated. In order to address this complexity Michie and colleagues have assimilated 19 different behaviour change frameworks by synthesising common features to form a broad model of behaviour: the Behaviour Change Wheel (Michie et al., 2011). The COM-B model forms the central hub of the Behaviour Change Wheel (BCW) which can be used to identify the source and important influences on a behaviour according to three domains: capability, opportunity and motivation (Michie et al., 2011). Please see section *1.13.2 The Behaviour Change Wheel* for further details.

I previously outlined in *Chapter 1: Introduction to the thesis* that my programme of doctoral research is focussed on the development of a theory- and evidence-based digital behaviour change intervention. The target behaviour for the intervention is parental adherence in the context of delivering physiotherapy exercises to their child following pTBI. Within this chapter I will present a conceptual design of the intervention, guided by my theoretical understanding of influences on parental adherence.

The relevant empirical evidence identified in previous chapters has been organised according to the COM-B model - the key model that I am using to help understand influences on parental adherence. I will proceed to triangulate the evidence that I collected through *Chapters 2, 4 and 5* and detail the findings together with promising behavioural targets, intervention functions and content. I will present this work within a conceptual design of the intervention according to the design stages of the BCW (Michie et al., 2014).

6.3 Aim

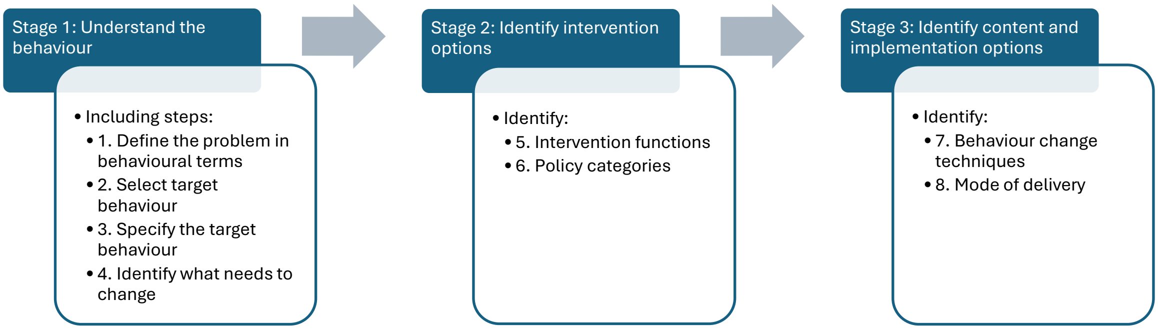
The aim of this chapter is to specify the conceptual design of a theory- and evidence-based intervention utilising Behaviour Change Wheel guidance. The design will be informed by existing evidence, together with new empirical evidence generated by the qualitative studies.

6.4 Methods

To guide the theoretically informed behaviour change intervention, I utilised the BCW as the overarching framework. I followed the guidance outlined in the BCW book (Michie et al., 2014) to progress through the three-stage design process to initially understand the target behaviour, then to identify intervention approaches and intervention content to influence the behaviour.

The three stages guiding the intervention design process included: Understand the behaviour (Stage 1); Identify intervention options (Stage 2); and Identify content and implementation options (Stage 3). Please note, these three stages were further sub-divided into eight distinct steps as outlined below in Figure 6.1. I followed these eight steps and report on them sequentially in the results section below.

Figure 6.1 - The three stages of intervention development according to the Behaviour Change Wheel, sub-divided into eight steps (adapted from Michie et al., 2014, p.25)



Stage 1: Understand the behaviour

- Including steps:
  - 1. Define the problem in behavioural terms
  - 2. Select target behaviour
  - 3. Specify the target behaviour
  - 4. Identify what needs to change

Stage 2: Identify intervention options

- Identify:
  - 5. Intervention functions
  - 6. Policy categories

Stage 3: Identify content and implementation options

- Identify:
  - 7. Behaviour change techniques
  - 8. Mode of delivery

6.4.1 *Making informed judgements about the intervention*

Behaviour change interventions are designed to be implemented in real-world contexts. As a result, judgements based on the best available evidence are required to support decision making around promising components and behavioural targets of the intervention (Michie et al., 2014). Effectiveness is one important consideration when designing and evaluating interventions, however other considerations such as an intervention's acceptability and practicability within a given context are important also (Brierley et al., 2022). With this in mind, I utilised the APEASE criteria to inform strategic judgements about the intervention.

The APEASE criteria stand for Affordability, Practicability, Effectiveness and cost-effectiveness, Acceptability, Side-effects and safety, and Equity (Michie et al., 2014, Brierley et al., 2022). I utilised the APEASE criteria as they have been developed to support strategic judgements and decision making when developing or evaluating interventions (Public Health England, 2019). I applied the APEASE criteria when integrating the data which I had collected from the systematic review and qualitative studies. I initially led this work alone whilst systematically progressing through the stages of the BCW book (Michie et al., 2014) as a guide. I then worked extensively and in collaboration with the PPI group to inform judgements and decisions about the suitability of elements of the intervention at different stages of the design process.

Examples of where my decisions were informed by the APEASE criteria and the PPI group include identification of promising intervention functions, BCTs and the mode of delivery.

Please see Table 6.1 below which presents each of the six APEASE criteria together with their descriptions and relevant considerations for the proposed intervention.

Table 6.1 - The APEASE criteria for assessing interventions and intervention components

APEASE criterion	**Description**	**Consideration for the proposed intervention**
Affordability	Interventions often have an implicit or explicit budget. It does not matter how effective, or even cost-effective it may be if it cannot be afforded. An intervention is affordable if within an acceptable budget it can be delivered to, or accessed by, all those for whom it would be relevant or of benefit.	This research represents the intervention development phase, as defined by the MRC complex intervention development guidance. Sufficient budget from my NIHR funded doctoral research is allocated for the initial co-design and development costs. Consideration will be given to ongoing delivery costs in future research (e.g., within future feasibility and randomised trials).
Practicability	An intervention is practicable to the extent that it can be delivered as designed through the means intended to the target population. For example, an intervention may be effective when delivered by highly selected and trained staff and extensive resources but in routine clinical practice this may not be achievable.	Considerable effort has gone into working with the PPI group supporting this research which indicates that the proposed intervention is practicable. In addition, evidence from *Chapter 5: Qualitative study involving physiotherapy focus groups* demonstrates that the physiotherapists who will deliver the intervention consider the proposed intervention to be practicable. Practicability will be considered further in future research such as a feasibility trial.
Effectiveness and cost-effectiveness	Effectiveness refers to the effect size of the intervention in relation to the desired objectives in a real-world context. It is distinct from efficacy which refers to the effect size of the intervention when delivered under optimal conditions in comparative evaluations. Cost-effectiveness refers to the ratio of effect (in a way that has to be defined, and taking account of differences in timescale between intervention delivery and	This research represents the intervention development phase, as defined by the MRC complex intervention development guidance. Consideration will be given to assessing efficacy, effectiveness and cost-effectiveness in future research (e.g., with future feasibility and randomised trials).

	intervention effect) to cost. If two interventions are equally effective, then clearly the most cost-effective should be chosen. If one is more effective but less cost-effective than another, other issues such as affordability, come to the forefront of the decision making process.	
Acceptability	Acceptability refers to the extent to which an intervention is judged to be appropriate by relevant stakeholders (public, professional and political). Acceptability may differ for different stakeholders. For example, the general public may favour an intervention that restricts marketing of alcohol or tobacco but politicians considering legislation on this may take a different view. Interventions that appear to limit agency on the part of the target group are often only considered acceptable for more serious problems.	My work with the PPI group in addition to research presented in *Chapter 4: Qualitative study involving parent interviews* and *Chapter 5: Qualitative study involving physiotherapy focus groups* indicates that the proposed intervention is acceptable to key stakeholders. The intervention will be co-designed with end-users and key stakeholders. Acceptability of the intervention is a priority for the design process. Ongoing consideration will be given to intervention acceptability in future research (e.g., with future feasibility and randomised trials).
Side-effects / Safety	An intervention may be effective and practicable, but have unwanted side-effects or unintended consequences. These need to be considered when deciding whether or not to proceed.	This research represents the intervention development phase, as defined by the MRC complex intervention development guidance. Insights from *Chapter 4: Qualitative study involving parent interviews* and *Chapter 5: Qualitative study involving physiotherapy focus groups* indicate that the timing of introducing the digital intervention is likely to require consideration on an individual basis. This is because it may unintentionally increase parents' stress levels further, at a time that they are already emotionally overwhelmed. The co-designed intervention will be theory- and evidence-based, and consideration will be given to side-effects and safety in future research (e.g., within a feasibility study).
Equity	An important consideration is the extent to which an intervention may reduce or increase the disparities in standard of living, wellbeing or health between different sectors of society.	Consideration will be given to optimising equity during co-design workshops. Ongoing consideration will be given to equity in future research (e.g., within a feasibility study).

Having initially outlined the three stages of intervention development according to the BCW guidance and presented the APEASE criteria used to inform judgements and guide decision making, I will now present the results and specify the conceptual design of the intervention.

6.5 Results

This results section details the theoretically informed conceptual design according to the three stages of the BCW intervention design guidance.

Stage 1: Understand the behaviour

Step 1: Define the problem in behavioural terms

The initial step in clarifying the scope and requirements of the intervention is to define the problem in behavioural terms. This step was decided from the outset, prior to me commencing the doctoral research and has guided the aims and objectives of the different elements of research within the thesis.

What behaviour? Parental adherence to delivering physiotherapy exercises to their child following a newly diagnosed traumatic brain injury.

Where does the behaviour occur? This begins in the acute hospital environment, throughout rehabilitation, and continues in and outside the home environment following discharge from hospital. This understanding is informed by evidence presented in *Chapter 4: Qualitative study involving parent interviews* and *Chapter 5: Qualitative study involving physiotherapy focus groups*.

Who is involved in performing the behaviour? Parents of children with traumatic brain injury, supported by physiotherapists.

Step 2: Select the target behaviour

As outlined in *Step 1: Define the problem in behavioural terms*, it was decided from the outset, prior to commencing my doctoral research, that parental adherence to delivering physiotherapy exercises was the target behaviour for the intervention. This then guided the aims and objectives of my research presented throughout the chapters of this thesis.

Adherence is defined by the World Health Organisation as 'the extent to which a person's behaviour…corresponds with agreed recommendations from a health care provider' (World

Health Organization, 2003b). This definition of adherence emphasises the active role that a patient (or parent in this context) plays in managing their care, highlighting the importance of collaboration and shared decision making with the healthcare provider (World Health Organization, 2003b, Mir, 2023).

Whilst this is the case, the content of physiotherapy exercises and the focus of rehabilitation will be different for each CYP, in keeping with individualised care (National Institute for Health and Care Excellence, 2023b, Novak-Pavlic et al., 2023). For each individual CYP, the focus of physiotherapy is also likely to change over time as the CYP's function changes and physiotherapy goals are reviewed and updated, as identified in *Chapter 2: Systematic review* (Young et al., 2024a). Therefore, the content of the recommended rehabilitation exercises will need to be individually provided by the treating physiotherapist in a flexible way for each parent and child with pTBI. The intervention therefore needs to provide the means to do this in a consistent and evidence-based way.

According to the evidence and insights from *Chapter 4: Qualitative study involving parent interviews* and *Chapter 5: Qualitative study involving physiotherapy focus groups*, a starting point for this process will be the dialogue between the parent(s) and physiotherapist. This will help to establish a shared understanding of the family context and the CYP's existing interests, leading to the development of meaningful rehabilitation goals (Jenkin et al., 2022a). Then physiotherapy exercises will be recommended in a way that is appropriate for the CYP's level of function and each parent's ability to deliver the physiotherapy exercises. It is important to reiterate that the digital intervention will not exist in isolation, but rather within a pathway of care involving interactions between the CYP, parent and physiotherapist (Lord et al., 2018, Wong Chung et al., 2021, Jenkin et al., 2022b, Young et al., 2024a, Young and Gravett, 2025). The digital intervention will need to be designed to assist and support the interpersonal interactions between the parent and physiotherapist spanning different contexts, and ultimately support parental adherence to delivering physiotherapy.

Through undertaking the systematic review and qualitative studies with parents and physiotherapists, it is evident that parents' delivery of physiotherapy exercises is influenced by a range of factors. For example, a parent's emotional response to the child's injury, the interpersonal relationship that has developed between the parent and physiotherapist, or the knowledge a parent has about the role of physiotherapy in supporting their child's recovery following pTBI. *Chapter 5: Qualitative study involving physiotherapy focus groups* showed that the approach taken by a physiotherapist to support a parent to deliver physiotherapy exercises is very flexible and tailored to the individual. Throughout the themes presented, there were references to flexibility and the need for physiotherapists to adapt to the circumstances that they are working within.

Therefore, based on the qualitative evidence, I decided that it is not suitable to be too prescriptive regarding exactly how a parent is supported to deliver physiotherapy exercises to their child. Rather, this needs to be considered more flexibly and on an individual basis. As a result of these key findings, the overarching target behaviour for the intervention remains 'parental adherence to delivering physiotherapy exercises'. However, parents and physiotherapists should collaboratively decide how the parent approaches delivering physiotherapy exercises based on the individual circumstances of that parent and family, with a view to maintaining adherence over time (Harniess et al., 2022, King et al., 2020). This is further informed by *Chapter 4: Qualitative study involving parent interviews* which showed that delivering physiotherapy exercises became more ingrained and integrated into daily life as a result of repetition and navigating everyday challenges.

A list of examples of how parents can be supported to modify their behaviour and increase adherence to delivering physiotherapy exercises is provided in Table 6.2. These examples are informed by the findings of the qualitative studies (*Chapters 4 and 5*).

Table 6.2 - Examples of how parents of children and young people with traumatic brain injury can adhere to delivering physiotherapy exercises

Identify one part of a more complex activity to practice, and progress the activity over time as ability changes (e.g., bouncing a basketball with the right hand, progressing to shooting for a hoop).

To complete an activity that the child enjoys together with the parent (e.g., riding a bike at the weekend).

Identify an appropriate sports club that the child can attend on a weekly basis (e.g., a local football team).

Step 3: Specify the target behaviour

Building on the decision made in *Step 2: Select the target behaviour,* that the target behaviour is 'parental adherence to delivering physiotherapy exercises', this step is distinct and involves specifying the target behaviour and describing the behaviour in greater detail.

As outlined above, it is necessary for parents and physiotherapists to collaboratively agree how a parent intends to deliver physiotherapy exercises based on their individual and family circumstances: this needs to be based on dialogue between the parent and physiotherapist.

Evidence gathered during *Chapter 5: Qualitative study involving physiotherapy focus groups* detailed physiotherapists' perspective that the 'F-words of childhood development' which map on to the WHO's International Classification of Functioning, Disability and Health could be an accessible and meaningful way to inform this dialogue (Rosenbaum and Gorter, 2011).

It is possible for the digital intervention to provide a platform for parents to offer background information about their child, including their child's existing interests and family, according to the F-words of childhood development (Soper et al., 2019, Rosenbaum, 2022). This background information could then provide the basis for discussion between the parent and physiotherapist and collaboratively guide how physiotherapy exercises can be linked with existing interests. Evidence from *Chapter 4: Qualitative study involving* parent interviews and *Chapter 5: Qualitative study involving physiotherapy focus groups* underpin the assertion that adherence will be promoted through engagement and participation in important, meaningful and potentially fun activities following the pTBI (King et al., 2020).

It is also necessary for the intervention to provide a means for the parent and physiotherapist to collaboratively develop and document rehabilitation goals, plus how the parent intends to deliver physiotherapy to their child. The intervention will need to provide prompts encouraging users to specify physiotherapy delivery in terms of what, when, where, how often and with whom to achieve the target behaviour of adhering to the delivery of physiotherapy exercises (Michie et al., 2014). These will be considered alongside the acknowledgement of the emotional toll that parents are experiencing, to ensure that they are realistic and not too emotionally overwhelming (Ames et al., 2011). Two examples of specified target behaviours are provided in Table 6.3 below.

Table 6.3 - Examples of a specified target behaviour

Specification criteria	**Doing an activity as a family**	**Taking part in a sport**
Specified interest of the child	Cycling	Being a goalie in football
Physiotherapy focus	Dynamic balance and endurance	Hand-eye coordination and balance
Who	Child with a traumatic brain injury and their parent	
What	Riding a bike without stabilisers	Standing and moving then catching a ball with two hands
When	On a Saturday morning	Two afternoons per week
Where	A familiar route in the local area	In the garden
How often	Once a week for 60 minutes	Two afternoons selected flexibly by the parent
With whom	With parents and siblings	Parent and child

Step 4: Identify what needs to change

In this step, I utilised the COM-B model at the centre of the BCW to understand what needs to change in terms of parent capability, opportunity or motivation to promote 'parental adherence to delivering physiotherapy exercises'. Considering the findings from different sources – *Chapters 2, 4 and 5* - according to the COM-B model has aided me in organising and understanding key influences on behaviour in an in-depth way. This has been achieved through exploring where consistency can be identified between different sources of evidence. This is important because Michie and colleagues outline that where agreement is found between different sources of evidence about factors influencing the specified behaviour, there is increased confidence in the behavioural analysis (Michie et al., 2014). It is from this analysis that potentially meaningful intervention targets can be determined through changing parents' capability, opportunity and/or motivation.

To inform step 4 of the conceptual design of the intervention, I triangulated and summarised the empirical evidence according to the COM-B model presented at the end of each of the preceding chapters: *Chapter 2: Systematic review*, *Chapter 4: Qualitative study involving parent interviews* and *Chapter 5: Qualitative study involving physiotherapy focus groups*. Below, I will firstly present the triangulated summary of evidence from the different chapters (see Table 6.4) followed by a short section of text providing greater detail. From the evidence summary, I will then present a behavioural analysis of what needs to change, including the behavioural diagnosis (see Table 6.5).

Table 6.4 - Summary of key findings from different sources of evidence: Using the COM-B model to identify what needs to change for parents to adhere to delivering physiotherapy exercises

COM-B sub-constructs	Key findings from the systematic review	Key findings from parent interviews	Key findings from physiotherapy focus groups	Summary of key findings from different sources of evidence
Physical Capability	Coded 34 times across interventions – intervention target particularly relevant to acquiring skills through instruction, demonstration and practice in a graded way	Coded seven times across three themes – intervention target relevant to the acquisition of physical skills	Coded four times across two themes – intervention target relevant to the imparting of physical skills	Parental adherence supported by acquiring physical skills to deliver physiotherapy exercises through instruction, demonstration and practice in a graded way
Psychological Capability	Coded 43 times across interventions – intervention target particularly relevant to problem solving, acquiring knowledge and psychological skills through instruction, demonstration and practice in a graded way	Coded 20 times across all four themes – intervention target particularly relevant to behavioural domains knowledge and psychological skills	Coded 14 times across all four themes – intervention target particularly relevant to behavioural domains behavioural regulation and the imparting of psychological skills	Parental adherence supported by increased knowledge about the importance of physiotherapy and developing psychological skills to be able to deliver physiotherapy exercises through instruction, demonstration and practice in a graded way. Parents also need support to engage in problem solving
Reflective Motivation	Coded 85 times across interventions – intervention target particularly relevant to planning, monitoring and reviewing behaviour as well as acquiring skills through instruction, demonstration and practice in a graded way. Also relevant to problem solving and	Coded 29 times across all four themes – intervention target particularly relevant to behavioural domains beliefs about consequences, intentions and goals	Coded 17 times across all four themes – intervention target particularly relevant to behavioural domains social/professional role and identify and beliefs about capabilities	Parental adherence supported by information to guide beliefs in consequences of their actions, as well as planning, monitoring and reviewing their behaviour related to delivering physiotherapy. Graded instruction, demonstration and practice is needed to increase

	receiving information about health consequences			skill level and develop beliefs in their capability to deliver physiotherapy
Automatic Motivation	Coded 10 times across interventions – intervention target particularly relevant to habit formation, rewarding behaviour and adding objects to the environment (e.g., a piece of rehabilitation equipment)	Coded 14 times across all four themes – intervention target particularly relevant to behavioural domains emotions and reinforcement	Coded 12 times across three themes – intervention target particularly relevant to behavioural domains social/professional role and identify and reinforcement	Parental adherence supported by emotional support, reinforcement of behaviour (e.g., through having fun) and forming habits
Physical Opportunity	Coded six times across interventions – intervention target particularly relevant to social support (practical) and adding objects to the environment	Coded four times across two themes – intervention target relevant to influences from environmental context and resources	Coded five times across two themes – intervention target relevant to influences from environmental context and resources	Parental adherence supported by having the necessary objects in the environment to support physiotherapy delivery (e.g., equipment) and practical social support
Social Opportunity	Coded 18 times across interventions – intervention target particularly relevant to all forms of social support and demonstration	Coded four times across three themes – intervention target relevant to social influences	Coded eight times across two themes – intervention target relevant to social influences	Parental adherence supported by social support, particularly from physiotherapist as well as friends and family
Summary	Reflective motivation, psychological capability and physical capability most frequently coded	Reflective motivation, psychological capability and automatic motivation most frequently coded	Reflective motivation, psychological capability and automatic motivation most frequently coded	

Key: The colours within the table represent those within the COM-B model itself, whereby red refers to Capability, yellow refers to Motivation and green refers to Opportunity. See Figure 1.4 on page 44 for further details about the COM-B model.

Parents' capability

Across the different sources of evidence, strengthening 'Psychological capability' appears vital to support parents to adhere to delivering physiotherapy. 'Psychological capability' was coded second most frequently behind 'Reflective motivation' across all the sources of evidence feeding into the behavioural analysis. Changes in 'Psychological capability' are particularly relevant through acquiring knowledge (e.g., information about health consequences) and psychological skills (e.g., instruction and demonstration of how to perform a physiotherapy exercise). Additionally, being able to retain information and make decisions as well as define action plans appear to be important influences on behaviour. These changes in psychological capabilities may then support parents to adhere to delivering recommended physiotherapy exercises. The findings from *Chapter 5: Qualitative study involving physiotherapy focus groups* identified how physiotherapists play an active role in increasing parents' 'Psychological capability' and are particularly considerate of parents' emotional response to their child's injury. For example, the focus groups showed that it was important for physiotherapists to be cognisant of not overwhelming parents further, and physiotherapy participant-6 spoke of how this then 'completely influences kind of how you engage and interact'.

In much the same way, parents appear to also require the 'Physical capability' through the training of physical skills to deliver the physiotherapy exercises. This is again actively supported by physiotherapists, demonstrated by the results of *Chapter 4: Qualitative study involving parent interviews*. Parent participant-2 outlined how the physiotherapist 'showed me on [my daughter], and then said if you could maybe do [the exercise]'. In this way, physiotherapists were said to initially demonstrate the exercises, provide instructions and the opportunity for practice, again grading this as deemed appropriate to the needs of the parent. Developing parents' 'Physical capability' has been shown to largely take place during face-to-face interactions with the physiotherapist, and through parents' physical involvement in physiotherapy sessions. Therefore, it is likely that much of the training of physical skills will need to occur independently of the digital intervention, whilst being supplemented by demonstrations and instructions including pictures, videos and written descriptions.

In summary, having prior knowledge about the importance of physiotherapy following pTBI, together with the 'Psychological capability' and 'Physical capability' required to deliver the exercises is proposed to support parental adherence. 'Psychological' and 'Physical capability' also appear to be important precursors to increasing 'Reflective motivation', as will be explored further below.

Parents' motivation

'Reflective motivation' was consistently coded most frequently of all the COM-B domains across the different sources of evidence. Having the prerequisite knowledge about the importance of physiotherapy and the role that parents can play in supporting their child's rehabilitation through physiotherapy would appear to precede parents' beliefs about the consequences of delivering physiotherapy themselves. This has been shown in *Chapter 4: Qualitative study involving parent interviews* to be a crucial motivator for parental delivery of physiotherapy exercises. Continued practice and repetition of physiotherapy exercises was said to support parents to grow in confidence, leading to an increase in belief about their capabilities to deliver physiotherapy exercises. In conjunction with this, the process of setting meaningful goals and outlining intentions (conscious decisions to perform the behaviour) also supported parents' 'Reflective motivation'.

The evidence also revealed the importance of other domains of motivation which span both 'Reflective motivation' and 'Automatic motivation'. An example of this is optimism which comes from parents having hope about the future, understanding their role in supporting their child, and seeing signs of improvement.

Reinforcement and emotion are additional important components of 'Automatic motivation' which influence parents' adherence to delivering physiotherapy. Through *Chapter 5: Qualitative study involving physiotherapy focus groups*, physiotherapists have been shown to provide reinforcement to parents by firstly providing lots of feedback when parents are learning physiotherapy exercises. Additionally, by looking to make physiotherapy fun and integrating physiotherapy within activities that the child already finds fun to do. This is additionally reflected in *Chapter 4: Qualitative study involving parent interviews* where participants expressed that making physiotherapy fun for the whole family (e.g., playing throwing and catching games in the garden) was important. This is because it provided valuable reinforcement and 'Automatic motivation' for delivering physiotherapy.

Emotion appears to be another complex and vitally important influence on behaviour as described by participants in *Chapter 4: Qualitative study involving parent interviews*. Descriptions of fear of their child moving and fear of hurting their child when starting physiotherapy were combined with feelings of hope and a sense of optimism by seeing their child making progress through physiotherapy. Again, in *Chapter 5: Qualitative study involving physiotherapy focus groups*, physiotherapists have been shown to be very aware of parents' emotions and flexibly tailoring their approach accordingly. Physiotherapists also described the high degree of flexibility in their approach to rehabilitation, such as the timing of goal setting discussions, as the process may add to parents' already heightened emotions and stress levels following their child's pTBI.

Parents' opportunity

Opportunity has also been shown to be important in influencing parents' adherence to delivering physiotherapy exercises. Firstly, the 'Physical opportunity' of having documented examples of exercises for the parent to complete was identified through *Chapter 4: Qualitative study involving parent interviews*. Likewise, parents being flexible when delivering physiotherapy exercises due to limited time and other responsibilities, such as hospital appointments, that they are required to attend. *Chapter 5: Qualitative study involving physiotherapy focus groups* highlighted that physiotherapists are very flexible in their approach to supporting parents within busy hospital environments, and attempting to make physiotherapy exercises realistic within the context and resources that an individual family accesses. These are examples of how 'Physical opportunity' may influence parents' adherence to delivering physiotherapy exercises. In addition, having access to the appropriate equipment to support physiotherapy is important, and this will need to be provided independently of a digital intervention designed to support parent delivered physiotherapy.

Finally, 'Social opportunity' also appears to play an extremely important role in parents adhering to delivering physiotherapy. This is said to initially come through accessing social support from physiotherapists when first interacting with them within the hospital environment. Social support is also relevant when learning physiotherapy exercises or having access to the physiotherapist by telephone or email after leaving hospital and returning home. Furthermore, the varied and flexible approach that physiotherapists have been shown to utilise when working with parents and involving them in physiotherapy session, plus wider social support networks of friends or family, are examples of the important influence of social support.

Consideration of context

In summarising the evidence and important influences on behaviour, it is imperative to acknowledge the complexity of physiotherapy across the pathway of care. For example, the qualitative evidence presented in the previous chapters illuminate the complex range of different contexts that parents move through when delivering physiotherapy. This includes, but is not limited to, the PICU where many parents first meet physiotherapists, inpatient ward settings in hospital, specialist residential rehabilitation, the home environment, hospital out-patient departments and local community settings. Likewise, parents encounter a range of different health professionals across the continuum of care, with physiotherapists representing just one professional group that they interact with (National Institute for Health and Care Excellence, 2023b). In addition, parents may have varied access to social support networks such as friends and family (Narad et al., 2019). This may have been particularly pertinent to parents whose child was admitted to hospital with pTBI during the Covid-19 pandemic (Pollock et al., 2022). At the height of the pandemic, restrictions were applied to parent and family access to hospitals, significantly reducing the availability of social support for parents at times of considerable personal and family trauma (Pollock et al., 2022).

I have found it important to continually refer to the decision that the digital behaviour change intervention will be designed to exist within a wider pathway of care. This is the case whilst specifically supporting parents to adhere to delivering physiotherapy exercises to their child with pTBI (West and Michie, 2016, National Institute for Health and Care Excellence, 2022). The following brief illustration is based on findings from the qualitative studies presented in chapters 4 and 5, and draws attention to some of the different influences on behaviour at different times. For example, within the hospital environment a lot of social support and reassurance (Social opportunity), imparting knowledge (Psychological capability) and involving parents in physiotherapy sessions (Reflective and Automatic motivation) occurs initially. Over time, parents gain expertise and learn how to flexibly integrate physiotherapy into everyday life (Physical and Psychological capability) whilst managing unexpected or challenging situations (Physical opportunity). Parents also progress rehabilitation towards identified goals (Reflective motivation) and seek to have fun with their child and the wider family (Automatic motivation) within the home environment and local community.

In-depth behavioural analysis and diagnosis

Table 6.5 provides an in-depth behavioural analysis and considers each component of the COM-B model, what needs to happen for the target behaviour to occur and whether there is a need for change. In other words, the behavioural analysis summarises what the digital intervention, or personal support, need to address for parental adherence to occur. This is followed by the behavioural diagnosis at the bottom of the table to identify what aspects of capability, opportunity and motivation should be targeted to achieve the desired behaviour change, with focus on the most promising components to target in the intervention.

Table 6.5 - Behavioural analysis and diagnosis

COM-B components	What needs to happen for the target behaviour to occur?	Is there a need for change?
Physical capability	Parents have the physical skills to deliver physiotherapy exercises	Yes, parents need to learn the necessary physical skills to proficiently deliver physiotherapy exercises. This will primarily take place in person with the physiotherapist, therefore outside of the digital intervention
Psychological capability	Parents have the necessary psychological skills to deliver physiotherapy exercises and remember how to do this	Yes, training of psychological skills is required to safely and proficiently deliver physiotherapy exercises
	Parents know about the importance of physiotherapy and the role this plays in their child's rehabilitation following pTBI	Yes, change needed to increase knowledge about the role of physiotherapy
	Parents have sufficient attention to work with the physiotherapist and learn physiotherapy exercises	This needs to be considered by the treating physiotherapist and gauged appropriately as it is influenced by how parents respond to the traumatic event in terms of their emotions and psychological wellbeing
Reflective motivation	Parents have appropriate and meaningful goals to work towards with plans in place to deliver physiotherapy exercises	Yes, goals and plans need to be agreed to support parents to deliver physiotherapy exercises
	Parents have positive beliefs about the value of delivering physiotherapy exercises, and their capability to deliver them	Yes, parents need to be motivated by beliefs in both the value of, and their capability to, deliver physiotherapy exercises
Automatic motivation	Parents have the emotional capacity to deliver physiotherapy exercises and find delivering physiotherapy exercises rewarding	Yes, being mindful of parents' emotional needs and linking physiotherapy with meaningful and enjoyable activities will be important
	Parents establish routines and habits for delivering physiotherapy	This will develop over time through repetition within everyday life
Physical opportunity	Parents have access to suitable equipment within the environment to support physiotherapy delivery	This will need to be considered and provided by the treating physiotherapist, independent of the digital intervention
	Parents have the necessary time to deliver physiotherapy exercises	Yes, this will need to be considered alongside setting goals and planning the delivery of physiotherapy exercises
Social opportunity	Parents have the resources and social support necessary to deliver physiotherapy exercises over time	Yes, having access to social support from physiotherapists will be important across different contexts

Behavioural diagnosis of the relevant COM-B components	Changes in all components of COM-B are required for parents to adhere to delivering physiotherapy exercises. Evidence feeding into this behavioural diagnosis shows that changes in **‘Reflective motivation’, ‘Automatic motivation’** and **‘Psychological capability’** are particularly important components of the COM-B model to target through the digital behaviour change intervention.

These initial four steps effectively conclude stage one of the conceptual behaviour change intervention design process. The behavioural diagnosis of what needs to change will be linked to the selection of intervention functions (Stage 2) and behaviour change techniques (Stage 3) to bring about change.

Stage 2: Identify intervention options

Step 5: Identify intervention functions

The initial steps undertaken in *Stage 1: Understand the behaviour* resulted in the behavioural diagnosis of what needs to change, as presented in Table 6.5 above. The behavioural diagnosis provides the basis for selecting intervention options. This includes intervention functions, defined as the “broad categories of means by which an intervention can change behaviour” (Michie et al., 2014, p.109).

Within this step, I will initially present the nine candidate intervention functions of the BCW according to the APEASE criteria - previously outlined in Table 6.1 - to select which could plausibly be used within the intervention. This is presented in Table 6.6 below. I will then consider the selected candidate intervention functions in relation to their specified COM-B targets – including the behavioural diagnosis and available evidence - to identify which intervention function(s) show promise for inclusion in the digital intervention (see Table 6.7). Finally, I will consider each of the six COM-B components, detail what needs to change for parents to adhere to delivering physiotherapy exercises and how physiotherapists can enable this. Alongside this, I will also assign example intervention functions of how this can be delivered within or outside of the intervention (see Table 6.8).

Table 6.6 - Candidate intervention functions considered against the APEASE criteria

Candidate intervention function	**Description**	**Does the intervention function meet the APEASE criteria in the context of parental adherence to delivering physiotherapy exercises?**
Education	Increasing knowledge and understanding by informing, explaining, showing and providing feedback	Yes
Persuasion	Using words and images to change the way people feel about a behaviour to make it more or less attractive	Yes
Incentivisation	Changing the attractiveness of a behaviour by creating the expectation of a desired outcome or avoidance of an undesired one	Yes
Coercion	Changing the attractiveness of a behaviour by creating the expectation of an undesired outcome or denial of a desired one	No Given the context of having a child with paediatric traumatic brain injury, coercion is deemed to not be acceptable
Training	Increasing the skills needed for a behaviour by repeated practice and feedback	Yes
Restriction	Constraining performance of a behaviour by setting rules	No The intervention is orientated to promoting the desired behaviour (delivering physiotherapy), so restriction is not appropriate
Environmental restructuring	Constraining or promoting behaviour by shaping the physical or social environment	Yes
Modelling	Showing examples of the behaviour for people to imitate	Yes
Enablement	Providing support to improve ability to change in a variety of ways not covered by other intervention types	Yes
Selected candidate intervention functions		Candidate intervention functions for the digital intervention include Education, Persuasion, Incentivisation, Training, Environmental restructuring, Modelling and Enablement

Considering an intervention function against the APEASE criteria is a helpful starting point in identifying whether an intervention function, or several intervention functions, could plausibly be utilised in the intervention itself. The next stage is to consider each intervention function in relation to specified COM-B targets and whether it is likely to be promising, based on the available evidence and behavioural diagnosis. This is summarised in Table 6.7.

Table 6.7 - Promising candidate intervention functions for inclusion in the intervention, considered in relation to their COM-B targets

Candidate intervention functions	**COM-B targets**	**Promising based on the available evidence and behavioural diagnosis**
Education	Capability and motivation	Yes
Persuasion	Motivation	Yes
Incentivisation	Motivation	Yes
Training	Capability, opportunity and motivation	Yes
Environmental restructuring	Opportunity and motivation	Yes
Modelling	Opportunity and motivation	Yes
Enablement	Capability, opportunity and motivation	Yes

Having identified seven candidate intervention functions that meet the APEASE criteria and specified that all seven show promise based on the existing evidence in relation to the COM-B model, I will now expand upon this understanding in relation to the intervention itself. To do this I will consider each of the COM-B components in turn, specifying what needs to change for the parent to adhere to delivering physiotherapy exercises and detail how a physiotherapist might enable this. Finally, I will provide example intervention functions of how this could be delivered, then specify whether this is likely to be delivered within the digital intervention itself, or independent of the digital intervention – please see Table 6.8. These insights help to clarify which intervention functions show most promise for inclusion in the intervention.

Table 6.8 - Influences on parental adherence according to COM-B components linked with intervention functions within the intervention

Influences on behaviour according to COM-B component	**What needs to change for parents to be able to adhere**	**How could physiotherapists enable this**	**Example of promising intervention functions**	**Likelihood of being delivered within or independent to the digital intervention**
Physical capability	Parents need to have the necessary physical skills, strength and stamina to deliver physiotherapy exercises.	Physiotherapists need to train parents with the necessary physical skills.	Training: for example, skills training of physiotherapy exercises taught gradually in line with parents increasing skill levels.	Likely to occur independently of the digital intervention
Psychological capability	Parents require knowledge of the importance of physiotherapy together with the short- and long-term benefits and be able to remember when and how to deliver the exercises.	Physiotherapists need to impart knowledge about the importance and benefit of physiotherapy in a way that is easy to understand.	Education: for example, providing information about the role, importance and benefit of physiotherapy. Enablement: for example, develop the mental strength required to remember when and how to deliver the exercises.	Likely to occur both within and independently of the digital intervention
Physical opportunity	The environment around the parent is important and a parent can be involved in physiotherapy sessions with support from the physiotherapist.	Physiotherapists involve parents in sessions and begin the process of empowering parents to do physiotherapy with their children through modelling exercises and breaking complex tasks down into simpler steps.	Environmental restructuring: for example, setting up a physiotherapy session where a parent can join and learn how to use a piece of equipment.	Likely to occur independently of the digital intervention
Social opportunity	Parents have multiple interpersonal interactions	Physiotherapists offer substantial social support to parents following	Modelling: for example, modelling an example exercise	Likely to occur both within and independently

	with physiotherapists and receive social support, encouragement and feedback.	their child's brain injury. The provision of encouragement and feedback is important in developing parents' confidence.	for a parent to copy, then giving social support through encouragement about a parent's ability to support their child's recovery through physiotherapy.	of the digital intervention
Reflective motivation	It is important for parents to have goals to work towards and plans for delivering physiotherapy; this supports their belief about the positive consequences of physiotherapy.	It is the physiotherapists' role to support the parent to be able to deliver physiotherapy in the hospital, at home and in the community. Helping to establish agreed goals which are meaningful supports this.	Incentivisation and Persuasion: for example, making the behaviour of delivering physiotherapy exercises more attractive by supporting parents' beliefs that their actions will lead to a positive outcome and support achieving goals.	Likely to occur both within and independently of the digital intervention
Automatic motivation	Parents are highly distressed following their child's injury and may find delivering physiotherapy challenging.	Physiotherapists provide advice and recommendations to support parents to deliver physiotherapy. Linking exercises with existing interests may increase reinforcement and motivation to engage.	Incentivisation: for example, linking physiotherapy with existing interests with reinforcement that doing physiotherapy can be enjoyable and fun.	Likely to occur both within and independently of the digital intervention
Summary	Physical skills training and elements of environmental restructuring are likely to take place outside of the digital intervention. The other intervention functions show promise for inclusion within the digital intervention.			

Step 6: Identify policy categories

The intervention aims to target a specific group of people, namely parents of children with pTBI, and support behaviour change at the individual level. The present focus is initial intervention development therefore this step of identifying policy categories sits outside the scope of this PhD research.

An example of a policy category within the BCW is ‘Guidelines’ which is defined as “creating documents which recommend or mandate practice. This includes all changes in service provision” (Michie et al., 2014, p.135). At this stage of development, the intervention is not yet fully established or working, its feasibility and acceptability amongst parents and physiotherapists has not yet been assessed and therefore it is deemed premature to begin to create guidelines about its use (Craig et al., 2008, Croot et al., 2019). Another example of a policy category is ‘Service provision’ defined as “Delivering a service” (Michie et al., 2014, p.135). As above, further research is required to consider how the intervention could be best integrated into services, and what the required service provision will be to support this. Such considerations fall outside the scope of initial intervention development (Croot et al., 2019).

That said, considering policy categories will be an important element of future research focusing on the feasibility, testing and implementation of the intervention (Craig et al., 2008, Brierley et al., 2022).

Stage 3: Identify content and implementation options

Step 7: Identify behaviour change techniques

This step of intervention development is concerned with identifying which BCTs can deliver the identified intervention functions determined during *Step 5: Identify intervention functions*. BCTs are the postulated active ingredients of interventions which are designed to change the behaviour of the target population (Michie et al., 2013, Michie et al., 2014).

This stage involves three different aspects, including the identification of the most frequently used BCTs according to each intervention function (as identified in Table 3.3 of the BCW book; pp.151-155). It is helpful to note that the same BCT may be commonly used across more than one intervention function resulting in possible duplication of BCTs. In addition, it is important to consider whether each BCT meets the APEASE criteria outlined earlier in the chapter (see Table 6.1). Finally, I previously identified the BCTs present in existing interventions within *Chapter 2: Systematic review*, therefore I will also cross-reference identified BCTs against existing interventions supporting parent delivered physiotherapy exercises following pTBI.

Following the identification of BCTs and determining whether they are good candidates to be included within the intervention, I will consider where they could plausibly be delivered as part of the digital intervention. Each of these identified stages are represented within the columns set out in Table 6.9 below. The identification of candidate BCTs will then feed into prototype intervention development as detailed in *Chapter 8: Prototype intervention development*.

Table 6.9 - Linking intervention functions with behaviour change techniques (BCTs) and identifying promising candidates for the digital intervention

Intervention function	**COM-B components**	**Most frequently used BCTs**	**Does the BCT meet the APEASE criteria in the context of parental adherence to delivering physiotherapy exercises?**	**Did the BCT feature in my systematic review?***	**Promising candidate for the intervention? (Yes/No)** **If yes, where could the BCT plausibly feature in the intervention?**
Education	Capability and motivation	5.1 Information about health consequences	Yes	Yes++	Yes Explanation about the benefits of physiotherapy, plus benefits of specific exercises
		5.3 Information about social and environmental consequences	Yes	No	Yes Explanation about the role of family and friends in supporting the injured child or young person, with physiotherapy included a positive aspect of these relationships
		2.2 Feedback on behaviour	Yes	Yes++	Yes Summary feedback from the intervention about delivering the physiotherapy exercises
		2.7 Feedback on outcome(s) of the behaviour	Yes	Yes+	Yes Summary feedback from the intervention about outcomes of delivering the physiotherapy exercises, e.g., changes in physical function
		7.1 Prompts/cues	Yes	No	Yes Digital prompts, for example push notifications delivered by the intervention - adjustable by each parent
		2.3 Self-monitoring of behaviour	Yes	Yes++	Yes

					Checklist of completed exercises, plus the option to add notes within a notes page / diary feature
Persuasion	Motivation	9.1 Credible source	Yes	Yes++	Yes Explanation about the benefits of physiotherapy, plus example exercises using a credible model such as a child that previously suffered a brain injury
		5.3 Information about social and environmental consequences	Yes	No	Yes Explanation about the role of family and friends in supporting the injured child or young person, with physiotherapy included a positive aspect of these relationships
		5.1 Information about health consequences	Yes	Yes++	Yes Explanation about the benefits of physiotherapy, plus benefits of specific exercises
		2.2 Feedback on behaviour	Yes	Yes++	Yes Summary feedback from the intervention about delivering the physiotherapy exercises
		2.7 Feedback on outcome(s) of the behaviour	Yes	Yes+	Yes Summary feedback from the intervention about outcomes of delivering the physiotherapy exercises, e.g., changes in physical function
Incentivisation	Motivation	2.2 Feedback on behaviour	Yes	Yes++	Yes Summary feedback from the intervention about delivering the physiotherapy exercises
		2.7 Feedback on outcome(s) of the behaviour	Yes	Yes+	Yes Summary feedback from the intervention about outcomes of delivering the physiotherapy exercises, e.g., changes in physical function
		2.1 Monitoring of behaviour by others without evidence of feedback	No	Yes++	No Feedback is shown to be an important component of adherence

		2.5 Monitoring outcome of behaviour by others without evidence of feedback	No	No	No Feedback is shown to be an important component of adherence
		2.3 Self-monitoring of behaviour	Yes	Yes++	Yes Checklist of completed exercises, plus the option to add notes within a notes page / diary feature
Training	Capability, opportunity and motivation	6.1 Demonstration of the behaviour	Yes	Yes++	Yes Within example exercises using pictures / videos
		4.1 Instruction on how to perform a behaviour	Yes	Yes++	Yes Within example exercises using instructions
		2.2 Feedback on the behaviour	Yes	Yes++	Yes Summary feedback from the intervention about delivering the physiotherapy exercises
		2.7 Feedback on outcome(s) of behaviour	Yes	Yes+	Yes Summary feedback from the intervention about outcomes of delivering the physiotherapy exercises, e.g., changes in physical function
		2.3 Self-monitoring of behaviour	Yes	Yes++	Yes Checklist of completed exercises, plus the option to add notes within a notes page / diary feature
		8.1 Behavioural practice/rehearsal	Yes	Yes++	Yes As part of example exercises to be practiced
Environmental restructuring	Opportunity and motivation	12.5 Adding objects to the environment	Yes	Yes++	Yes The digital intervention itself as an object
		7.1 Prompt/cues	Yes	No	Yes Digital prompts, for example push notifications delivered by the intervention - adjustable by each parent
		12.1 Restructuring the physical environment	No	No	No Not suitable within the digital intervention

Modelling	Opportunity and motivation	6.1 Demonstration of the behaviour	Yes	Yes++	Yes Within example exercises using pictures / videos
Enablement	Capability, opportunity and motivation	3.1 Social support (unspecified)	Yes	Yes++	Yes Through physiotherapist contact details, plus a general resources page
		3.2 Social support (practical)	Yes	Yes++	Yes Through physiotherapist contact details
		1.1 Goal setting (behaviour)	Yes	Yes++	Yes Collaborative goal setting with the physiotherapist
		1.3 Goal setting (outcome)	Yes	Yes++	Yes Collaborative goal setting with the physiotherapist
		12.5 Adding objects to the environment	Yes	Yes++	Yes The digital intervention itself as an object
		1.2 Problem solving	Yes	Yes++	Yes Identify factors influencing adherence to completing exercises, plus documentation within a notes page / diary feature
		1.4 Action planning	Yes	Yes++	Yes Through collaboration with the physiotherapist, plus linking physiotherapy to existing interests
		2.3 Self-monitoring of behaviour	Yes	Yes++	Yes Checklist of completed exercises, plus the option to add notes within a notes page / diary feature
		12.1 Restructuring the physical environment	No	No	No Not suitable within the digital intervention
		1.5 Review behaviour goal(s)	Yes	Yes++	Yes Review with the physiotherapist
		1.7 Review outcome goal(s)	Yes	Yes++	Yes Review with the physiotherapist

Other less frequently used but potentially promising candidate BCTs		2.4 Self-monitoring of outcome(s) of behaviour	Yes	Yes+	Yes Outcomes of completed exercises, plus the option to self-monitor through adding notes within a notes page / diary feature
		8.3 Habit formation	Yes	Yes+	Yes Through advice about the benefits of repetition to develop habits
		8.6 Generalisation of target behaviour	Yes	No	Yes Through advice about completing physiotherapy in different contexts
		8.7 Graded tasks	Yes	Yes++	Yes Through graded and tailored example exercises
		15.3 Focus on past success	Yes	No	Yes Through reviewing when delivering physiotherapy went well. This could be supported by adding and reviewing notes within a notes page / diary feature
BCTs which represent good candidates for the intervention	Frequently used BCTs (those previously identified in *Chapter 2: Systematic review* are included in **bold**): **1.1 Goal setting (behaviour); 1.2 Problem solving; 1.3 Goal setting (outcomes); 1.4 Action planning; 1.5 Review behaviour goals(s); 1.7 Review outcome goal(s); 2.2 Feedback on behaviour; 2.3 Self-monitoring of behaviour; 2.7 Feedback on outcome(s) of behaviour; 3.1 Social support (unspecified); 3.2 Social support (practical); 4.1 Instructions on how to perform the behaviour; 5.1 Information about health consequences;** 5.3 Information about social and environmental consequences; **6.1 Demonstration of the behaviour;** 7.1 Prompts/cues; **8.1 Behavioural practice/rehearsal; 9.1 Credible source; 12.5 Adding objects to the environment.**				Total number of BCTs which represent good candidates for the intervention: 24

	Less frequently used BCTs (those previously identified in *Chapter 2: Systematic review* are included in **bold**): **2.4 Self-monitoring of outcome(s) of the behaviour; 8.3 Habit formation;** 8.6 Generalisation of target behaviour; **8.7 Graded tasks;** 15.3 Focus on past success.	

*This column considers whether the behaviour change technique (BCT) was featured within *Chapter 2: Systematic review* (yes or no). If yes, additional detail is given about the level of certainty with which the BCT was deemed to be present within existing interventions:
'++' signifies that the BCT was identified as being present beyond all probable doubt.
'+' signifies that the BCT was identified as most likely being present.

As outlined in Table 6.9 above, from the list of 22 frequently used BCTs identified within the BCW guide, I selected 19 as good candidates for the intervention, and 17 of those I had previously identified within *Chapter 2: Systematic review*. The frequently used BCTs that were judged to not meet the APEASE criteria and therefore were deemed to not be good candidates for the intervention were decided on the basis that feedback is an important component of parental adherence. Therefore monitoring behaviour without evidence of feedback is not deemed suitable (BCTs 2.1 and 2.5). In addition, it was deemed incompatible to restructure the physical environment within a digital behaviour change intervention (BCT 12.1).

Five less frequently used BCTs were additionally identified as being good candidates for the intervention. They primarily relate to self-monitoring of outcomes of the behaviour and supporting maintenance of behaviour change over time (BCTs 2.4, 8.3, 8.6, 8.7 and 15.3). I had previously identified three of the five less frequently used candidate BCTs within *Chapter 2: Systematic review*.

Overall, a total of 24 BCTs represent good candidates for the intervention, 20 of which I had previously identified within *Chapter 2: Systematic review*.

Step 8: Identify mode of delivery

The final step in this process is to identify how the intervention is to be delivered. Based on in-depth PPI work, plus public and stakeholder engagement with physiotherapists and professional networks that I undertook in preparation for the NIHR fellowship application, it was decided *a priori* that the intervention would be delivered digitally. During the PhD fellowship research, this intention remained unchanged as research participants, the PPI group and stakeholder groups wanted a digital intervention.

Evidence presented within the thesis chapters, feeding into the conceptual design of the intervention, further supports the use of a digital intervention. This is because the intervention will target behaviour change at an individual level and be used across a range of different contexts. The contexts which were identified during the systematic review and qualitative studies include: acute hospital and rehabilitation settings, the home environment and the local community. Therefore, it is important that the intervention is designed to be accessed remotely by parents and be utilised to support adherence to delivering physiotherapy exercises the self-management of their child's physiotherapy following pTBI across a range of different contexts (Pollock et al., 2022, National Institute for Health and Care Excellence, 2022).

It is acknowledged that participants were recruited digitally and took part in research conducted remotely requiring a level of digital literacy. This means that they may have shown bias towards digital interventions (NHS England, 2024b). Further post-doctoral research should involve a more diverse groups of parents to understand their needs with regards to the intervention and its delivery mode.

6.6 Discussion

This chapter has outlined the in-depth conceptual design of the intervention in granular detail. The conceptual design includes the behavioural diagnosis of what needs to change to support parental adherence to delivering physiotherapy exercises, according to the COM-B model. I have identified seven promising candidate intervention functions for use within the intervention, and all seven were previously identified within *Chapter 2: Systematic review* as being present within existing interventions. The selection of promising intervention functions resulted in the identification of 24 candidate BCTs, 20 of which I previously identified within the *Chapter 2: Systematic review* as being present within existing interventions. To reiterate, the evidence presented within the current chapter represents the conceptual design of the intervention according to BCW guidance (Michie et al., 2014, Sinnott et al., 2015). In the following two chapters I will provide a detailed understanding of the user requirements of the intervention (chapter 7) and detail the prototype intervention itself (chapter 8).

Related to the conceptual design of the intervention, utilising the BCW guide greatly aided my understanding of parental adherence and resulted in a detailed and structured process of developing a conceptual intervention (Michie et al., 2014, Sinnott et al., 2015, McDonagh et al., 2018). The BCW provided an excellent framework for integrating relevant empirical evidence, in keeping with the MRC guidance for developing complex interventions (Craig et al., 2008, Ojo et al., 2019). Having said that, I also encountered some challenges. Despite the detailed step-by-step process provided by the BCW guide, I found it complex to reach the initial behavioural diagnosis which is detailed in Table 6.5 above. This is perhaps because all six of the COM-B components were identified as having important influences on parental adherence within the systematic review and qualitative chapters. Likewise, throughout the various stages multiple judgements were required about the appropriateness and relevance of different content and components which could plausibly be included within the intervention. I found these to be complex and challenging processes which were aided by my structured use of the BCW and the APEASE criteria to inform judgements, as I will consider further below.

Here, the in-depth consideration of the APEASE criteria together with PPI and stakeholder groups were important to inform decision making (Public Health England, 2019, Brierley et al., 2022). This approach was suitable for my PhD research with finite time and resources available to deliver the first conceptual design of the intervention. If more time and resources were available, this approach could have been improved through comprehensively co-producing the conceptual design with end users, including parents and physiotherapists.

I also found that the integration of evidence according to the COM-B model supported the judgements and decision making as it offered a consistent framework to integrate the different sources of evidence (Michie et al., 2011, Sinnott et al., 2015, Atkins et al., 2020). I have found that such a structured, detailed and transparent approach is beneficial when gathering, organising and integrating evidence which is relevant to both physiotherapy-specific interventions as well as wider MDT goals and therapy delivery (Michie et al., 2014, McDonagh et al., 2018, Pritchard-Wiart et al., 2019, Dunford et al., 2020, Ryan et al., 2025). I would certainly recommend such an approach to other clinicians, researchers and intervention developers in the future.

6.6.1 The role of the digital intervention within an existing pathway of care

The digital intervention will be designed for implementation within an existing pathway of care, to complement and enhance what currently happens within clinical practice. From the empirical evidence gathered during this doctoral research, it is clear that some components of the existing pathway of care will not form part of the intervention. However, they are important to consider and acknowledge as influences for parental adherence to delivering physiotherapy. Such components include the rapport and interpersonal relationship which develops between the parent and physiotherapist, beginning from their initial interactions in hospital (Tipping et al., 2010, Harniess et al., 2022, English et al., 2022). Additionally, the physiotherapist physically involving parents in physiotherapy sessions cannot exist within the digital intervention, nor can physically restructuring the environment to facilitate the exercises.

Given the vital role that parents play in their child's physiotherapy and rehabilitation following pTBI, and the importance of adherence to recommended physiotherapy exercises, it is proposed that the intervention has great potential to become an integral component of the pathway of care. This is because it will provide a platform to support guided self-managed rehabilitation; a recommendation included in the NICE guidance for rehabilitation following major trauma (National Institute for Health and Care Excellence, 2022). Consideration needs to be given to when and how the intervention is introduced by the physiotherapist as this will be done on an individual basis according to the physiotherapist’s judgement (Drake et al., 2024).

Irrespective of how comprehensively an intervention is designed to support behaviour change in the desired direction, there remains the possibility that users may not engage with it, thus limiting the intervention’s effectiveness (Kohl et al., 2013). To help optimise the relevance of the intervention and make it meaningful, engaging and acceptable to users, it is important to also consider the views and perspectives of the end-users and other key stakeholders (Technology and Design, 2012). Integrating the perspectives of end-users and key stakeholders throughout the design process is known as co-design (THIS Institute, 2022) which will be the focus of the next chapter.

Stage 5 - Co-designing the prototype intervention

Chapter 7: Developing a detailed understanding of user requirements for the intervention

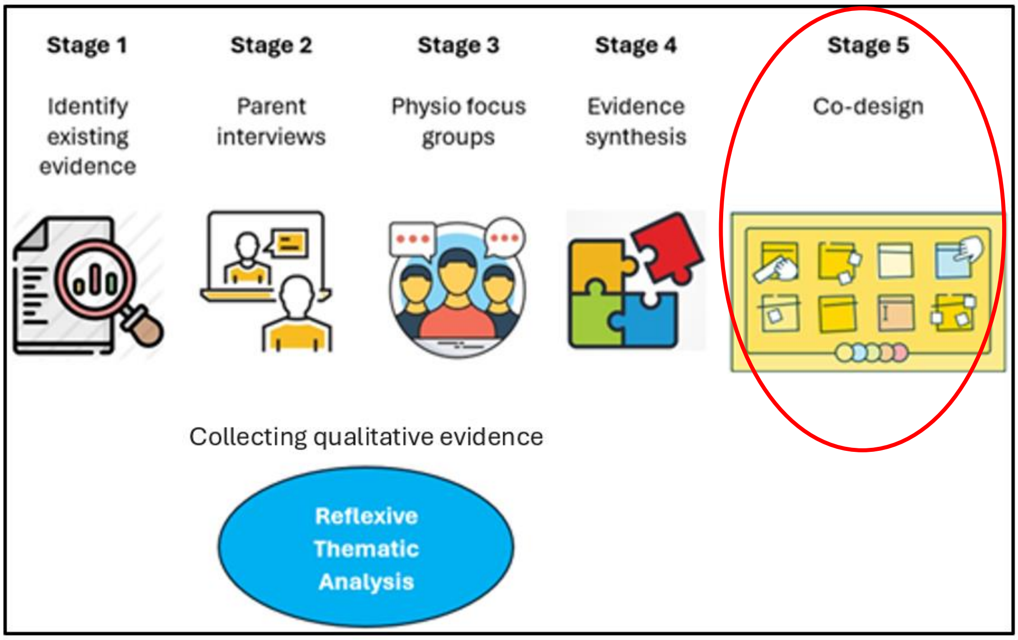
7.1 A brief overview of this chapter

The focus of this chapter is the development of a detailed understanding of user requirements for the intervention. Here, I will present a co-design study which I conducted together with members of a UK-based health-technology company, UBQO Ltd., and a public representative recruited from my PPI group.

Collectively, we acted as workshop facilitators and facilitated a remote workshop with parents, the target end-users of the intervention, and paediatric physiotherapists. Creative approaches, known within intervention development as generative co-design, were used as a framework to structure the process of designing a persona to help detail participants' current needs, experiences and challenges. This was followed by identification of preferences and requirements of the intervention by detailing a future scenario which outlined perceived benefits that the intervention will offer.

Data were analysed to identify important and valued components of the proposed digital intervention. The work presented in this chapter represents Stage 5 of the design process, as detailed in Figure 1.1 below.

Figure 1.1 - Figure providing an overview to the thesis structure



7.2 Introduction

The target behaviour of my proposed digital behaviour change intervention is parental adherence to delivering physiotherapy exercises. The empirical evidence that I have presented in previous chapters has provided new insights and a detailed understanding about the complex and multi-faceted phenomenon that is parental adherence (Heale and Forbes, 2013, Mir, 2023). In addition, I have identified the vital role that physiotherapists play in supporting parents and, more specifically, promoting adherence to delivering physiotherapy exercises. I have comprehensively reviewed and organised the empirical findings according to the COM-B model to inform the conceptual design of the theory- and evidence-based digital intervention, following the design stages of the BCW framework (Craig et al., 2008, Michie et al., 2014, O'Cathain et al., 2019), as specified in *Chapter 6: The conceptual design of the intervention*.

Following a rigorous process such as this is extremely important when designing a digital behaviour change intervention. It provides a clear understanding of behavioural influences, plus intervention components and content, including BCTs (Michie et al., 2013, Michie et al., 2014). This is necessary to maximise the likelihood that the users' behaviour will change in the desired direction (West and Michie, 2016). However, users may not fully engage with a rigorously designed intervention, limiting its effectiveness and possibility for behaviour change (Kohl et al., 2013).

Therefore, alongside an in-depth understanding of the target behaviour and specifying the digital intervention in detail, co-design of the intervention with key stakeholders is an important element of the design process (Skivington et al., 2021). Key stakeholders include those that are targeted by the intervention, also referred to as intervention end-users: parents of CYP with pTBI who will use the intervention (Technology and Design, 2012). Additional key stakeholders include paediatric physiotherapists who support the delivery of the intervention; digital technology developers who develop the intervention; and public representatives and researchers (NHS Digital, 2021, Skivington et al., 2021). From here onwards, parents of CYP with pTBI will be referred to as the 'end-users' of the intervention, with paediatric physiotherapists, digital technology developers, public representatives and researchers referred to as 'key stakeholders'.

Consideration of the needs, goals and preferences of the end-users of the intervention and other key stakeholders during the design process is known as user-centred design (Graham et al., 2021). The purpose of co-designing the intervention in a user-centred way is to make it more meaningful, engaging and acceptable, with the aim of increasing the effectiveness of the intervention (Technology and Design, 2012). This is a complex process which involves the combination of different design elements which are explained in the next paragraph.

Designing effective and engaging digital behaviour change interventions requires specific consideration of the target behaviour alongside the intervention design (West and Michie, 2016). Voorheis and colleagues outline that intervention design should include an in-depth understanding of the target behaviour (termed *behavioural design*) which is combined with specific considerations around the function and design of the intervention itself (termed *design thinking*). Design thinking begins with an in-depth understanding of, and empathy for the needs, preferences and recommendations of end-users and other key stakeholders (Voorheis et al., 2022). Therefore, integrating behavioural design with design thinking is proposed to optimise usability and user engagement with a digital intervention whilst supporting behaviour change (Voorheis et al., 2022).

This chapter reports the use of design thinking within the co-design study. I will provide a background to co-design and its role within healthcare and intervention development. I will then propose that design thinking is a creative process through which intervention end-users and key stakeholders can be supported to outline in detail their requirements of the intervention. This involves structured discussion to define current challenges, followed by imagining possible solutions to these challenges. I will finally introduce two tools which have been utilised in this study to structure and guide the design thinking processes: the Generative Co-Design Framework for Healthcare Innovation (Bird et al., 2021) and the Value Proposition Canvas (Osterwalder et al., 2014).

7.2.1 Background to co-design

Co-design is an approach used to inform the design of a product or service through proactively seeking and integrating end-user and key stakeholder perspectives, including their needs, experiences and preferences within the design process (LeRouge et al., 2013, Voorheis et al., 2022). The origins of co-design can be traced back to the 1970s within the Scandinavian participatory design movement. During this movement, computer scientists and information systems designers took the view that "the people destined to use the system [must] play a critical role in designing it" (THIS Institute, 2022, p.3) (Robert et al., 2022, pp.3).

More recently, co-design has been applied to healthcare through the integration of designers alongside end-users and other key stakeholders during the development and delivery of healthcare systems and interventions (Robert et al., 2021). Within the healthcare context, co-design helps ensure that services and interventions are practicable and deliverable, whilst meeting the needs, preferences and values of those accessing and delivering them (THIS Institute, 2022). Hence, proactively seeking and incorporating the views of end-users and other key stakeholders throughout the design process represents a movement beyond simple consultation to co-design (Agency for clinical innovation, 2019). Instead of asking users to comment on functions and features of products which have already been developed, there is a commitment to partnership and collaboration from sharing initial ideas through to developing the final product (Sanders and Stappers, 2008, Agency for Clinical Innovation, 2019, THIS Institute, 2022).

By its very nature, intervention design is a creative process that helps people to solve problems through creativity (Design Council, 2024). Consequently, in seeking to understand and incorporate the views of end-users and other key stakeholders in the design process, it is necessary to utilise creative approaches (Sanders and Stappers, 2008).

7.2.2 Harnessing creativity to support intervention design

Co-design harnesses creative approaches to understand peoples' experiences and design solutions through a collective commitment to openness, respect and empathy whereby end-users and stakeholders have an equal voice in the design process (Agency for Clinical Innovation, 2019, Vargas et al., 2022). In this sense, design acts as a link between creativity and innovation which is said to be "a structured process that transforms ideas into concrete products" (Hollanders and van Cruysen, 2009, p.3).

When looking to design solutions to peoples' problems, an important prerequisite is to have a thorough understanding of the problems and challenges to be addressed, then to generate ideas to address these (Sanders and Stappers, 2008, Vargas et al., 2022). One such approach to co-designing interventions is to work with small groups of participants to draw on their own lived experience to detail challenges related to how things currently are. Subsequently, to innovatively and creatively imagine a future scenario which enables the expression of participants' latent needs to address these challenges and propose solutions through the generation of stories, artefacts or prototypes, for example (Sanders and Stappers, 2008). This approach is referred to as a generative approach to intervention co-design (Bird et al., 2021).

Alongside this, it is also possible to directly address how users and deliverers of the intervention could benefit from it, and the value that they can expect to gain from using it. The term 'value' originates within the field of business and refers to the range of experiences that a business causes its customers to have (Payne et al., 2017, Sibalija et al., 2021). When applied to a digital intervention to support parent delivered physiotherapy, the concept of value relates to the perceived experiences and benefits that parents and physiotherapists can anticipate having through using the intervention (Sibalija et al., 2021).

7.3 Frameworks used to structure and guide the design thinking process

Through collaboration and partnership with the technology developers, two frameworks were identified to structure and guide the design thinking processes within the co-design workshop. These were the Generative Co-Design Framework for Healthcare Innovation (Bird et al., 2021) and the Value Proposition Canvas (Osterwalder et al., 2014). The purpose of utilising these frameworks was to provide an in-depth understanding of current challenges faced by those with lived experience and explore how to address these challenges through generating solutions. When using these frameworks, it is recommended that researchers, designers and developers adopt the role of *workshop facilitators* to guide participant discussions and provide metaphorical scaffolds to support creative expression (Sanders and Stappers, 2008).

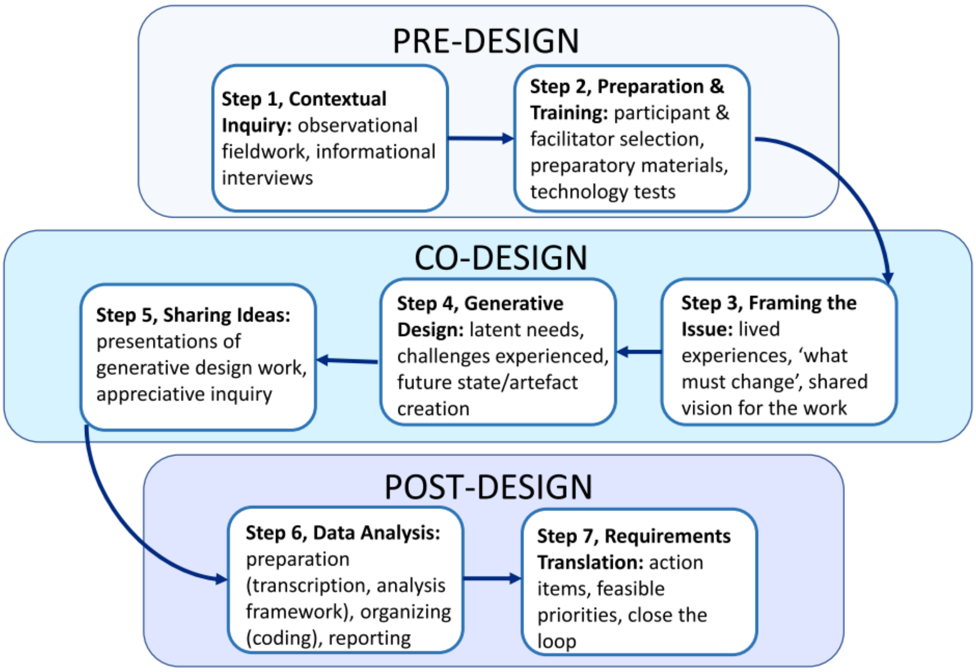
I will now introduce A Generative Co-Design Framework for Healthcare Innovation and the Value Proposition Canvas in turn.

7.3.1 A Generative Co-Design Framework for Healthcare Innovation

A generative co-design framework for healthcare innovation (henceforth referred to as 'the generative co-design framework') has been developed specifically for the healthcare setting whereby creativity can be harnessed to inform healthcare innovations (Bird et al., 2021). Its purpose is to enable participants, including end-users, deliverers of interventions and other key stakeholders, to use their own personal experience to identify problems and challenges related to how things currently are. Creative, or generative, approaches are then used to support participants to propose alternative scenarios which directly addresses these problems and challenges (Bird et al., 2021).

The generative co-design framework consists of seven steps across three stages: pre-design, co-design and post-design, as outlined in Figure 7.1 below.

Figure 7.1 - A Generative Co-Design Framework for Healthcare Innovation, taken from Bird et al. (2021).



The pre-design stage is characterised by initial exploration and enquiry into the current state of things to understand what challenges may exist and what is currently available. This is followed by preparation for the co-design stage through participant recruitment, the identification of workshop facilitators, preparation of materials and testing any technologies that will be required during the co-design process.

The co-design phase commences by bringing participants and workshop facilitators together to informally share experiences and generate a collective vision for co-design, referred to as 'framing the issue'. Through guided discussion it is proposed that participants with lived experience can provide a deep understanding of the problems and challenges they currently face and the impact of the environment in which they are based. Therefore, by taking real-world concerns and challenges as a starting point, it is proposed that participants can harness creativity to solve present day challenges by drawing on their own experiences (Bird et al., 2021). A means by which to do this is to use their creative minds to generate 'alternative future scenarios' which solve present-day challenges and address concerns through the creation of an artefact, persona or an initial prototype, for example (Sanders and Stappers, 2008). The rationale is that creativity enables participants to address both their explicitly stated needs as well as the deeper, or latent, needs which may be more difficult to express (Sanders and Stappers, 2008, Bird et al., 2021).

Finally, the post-design phase involves participant data analysis to distil the most pertinent and relevant topics and ideas. These are then used as a basis to prioritise features of the innovation (i.e., digital intervention) and create design plans based on what can be achieved.

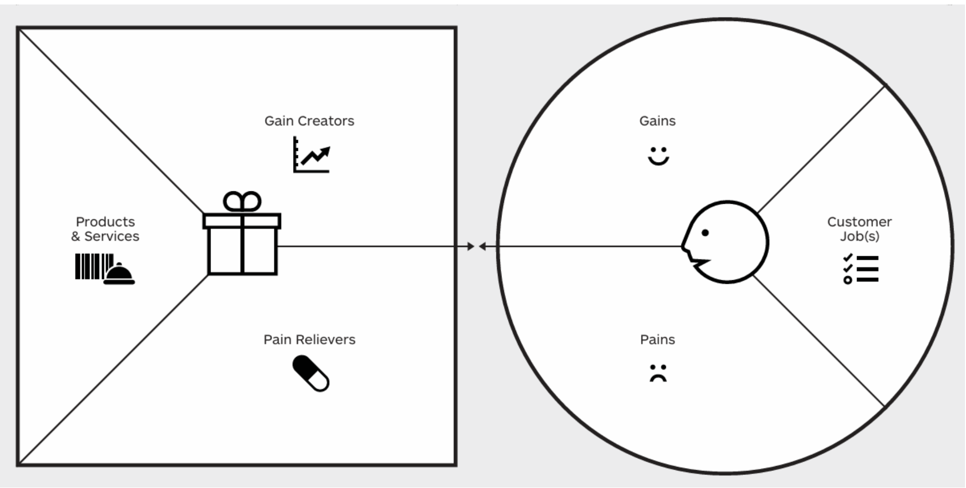
Whilst the generative co-design framework facilitates the identification of problems, challenges and some solutions, it doesn't offer detailed insights into the proposed benefits (or value) that a specific intervention could offer. To this end, the Value Proposition Canvas can be utilised to help articulate what benefits end-users and other key stakeholders of an intervention can expect to have, and how these will be delivered (Osterwalder et al., 2014).

7.3.2 The Value Proposition Canvas

The Value Proposition Canvas originates from the field of business and considers customer needs, whilst attracting customers to use products and services through clearly articulating the *added value* they offer (Osterwalder et al., 2014). Sibalija and colleagues argue that the focus of the Value Proposition Canvas relates closely to patient-centred healthcare, with examples available to illustrate its use in guiding digital health intervention development (Lentferink et al., 2020, Sibalija et al., 2021, Ignat, 2024).

The Value Proposition Canvas is made up of two elements: the customer profile and the value map (see Figure 7.2 below). For the purpose of my co-design study, I will refer to 'users' and the 'user profile' as opposed to 'customers' and the 'customer profile' (Ignat, 2024).

Figure 7.2 - The Value Proposition Canvas, taken from Osterwalder et al. (2014)



On the right-hand side of the Value Proposition Canvas is the user profile. The user profile consists of the jobs that the user is trying to get done on a day-to-day basis, for example delivering physiotherapy exercises to their child as recommended by a physiotherapist. It also includes the pains – annoyances or frustrations – that the users experience when trying to get a job done or the things that prevent them from doing a job. This could include forgetting what the recommended physiotherapy exercises are. Finally, the gains describe the benefits or the outcomes that users specifically want, whether they are required, expected, unexpected, or desired. This could include the desire to feel confident in delivering a recommended physiotherapy exercise (Osterwalder et al., 2014).

On the left-hand side of the Value Proposition Canvas is the value map. The value map consists of the products and services on offer. It also includes pain relievers which outline how a proposed intervention will help to relieve pains that users have identified, for example by providing prompts and written guidance about recommended exercises. Finally, the value map also includes gain creators which describe how the proposed intervention will create gains for users, for example by offering step-by-step guidance to increase confidence in delivering recommended exercises. It is said that one achieves 'fit' when the value proposition addresses important jobs, alleviates important pains and creates important gains that users care about; it is at this point that the value of the intervention can be clearly articulated (Osterwalder et al., 2014).

To support design thinking and the generation of ideas to guide innovation, parents and physiotherapists were brought together to capture relevant data to help guide the design process (Hollanders and van Cruysen, 2009). The aim of this study was to develop a detailed understanding of user requirements for the intervention, achieved through the combined use of the generative co-design framework and the Value Proposition Canvas within an intervention co-design workshop.

7.4 Aim & Objectives

The study aim was to:

- Develop a detailed understanding of user requirements for the intervention.

To achieve this study aim, the following objective was defined:

1) To generate descriptions of users' current challenges, difficulties and needs together with possible solutions for these to understand the user requirements for the intervention.

7.5 Method

7.5.1 Design

This co-design study involved a remote workshop with parents (intervention end-users), together with physiotherapists, technology developers, a public representative and myself as a doctoral researcher (key stakeholders). As recommended by Sanders and Stappers (2008) the technology developers, public representative and myself acted as workshop facilitators to help guide participant discussions according to the workshop facilitator notes (Appendix 21). Within the workshop, the parent participants were included within a breakout room for the discussion, facilitated by one technology developer plus support from the PPI representative. Within a separate breakout room, the physiotherapy participants' discussion was facilitated by one technology developer plus support from myself. For additional details please see below within section 7.5.3 '*Patient and Public Involvement and the role of workshop facilitators*'.

During the workshop, generative co-design approaches were utilised to identify the main user-centred requirements for the intervention. The purpose of the workshop was to explore the current challenges, difficulties and needs of participants and to identify possible solutions to these, whilst outlining the proposed value of the digital intervention. Please see '7.6 Procedures and process of analysis' section below for a detailed breakdown of the process.

The co-design workshop was held in November 2023 and ethical approval for this study was received from the University of East Anglia Faculty of Medicine and Health Sciences Research Ethics Committee, Ref: ETH2324-1044 (see Appendix 22).

7.5.2 Participants

I recruited two groups of participants for the co-design workshop: parents and physiotherapists. It was a priority that representation of parents and physiotherapists was equally balanced so that one group was not more heavily represented than another. This supported equal power sharing within the workshop with all participants having an equal voice (THIS Institute, 2022).

I decided prior to commencing recruitment that up to four parents and up to four physiotherapists would participate in the workshops, providing an equal balance between each of the participant groups and facilitators. Additionally, eight workshop participants represents an average sample size for such discussions, allowing all participants to contribute (Carlsen and Glenton, 2011).

Parents

Parents were recruited if they met the following inclusion criteria:

- The parent of a child affected by pTBI (or acquired brain injury), having been discharged from hospital at the time of participation.
- Have access to suitable technology to allow them to join an online workshop.
- The ability to communicate verbally in English.

Parent participants were recruited to the study using two approaches. Firstly, participants were parents of CYP with pTBI who had previously participated in parent interviews as part of *Chapter 4: Qualitative study involving parent interview* and given consent to being contacted about the co-design study. One parent did not meet the inclusion criteria within *Chapter 4: Qualitative study involving parent interview* as their child received a non-traumatic brain injury, however required physiotherapy after leaving hospital. They specifically expressed an interest in taking part in the co-design workshop and were deemed eligible to participate based on discussion with academic supervisors and the PPI group. This decision is reflected in the parent participant inclusion criteria above.

Additionally, parents were newly recruited to the study via snowball sampling whereby existing participants nominated others that met the inclusion criteria (Naderifar et al., 2017). Where this was the case, a pre specified research email address and/or research telephone number was given to the prospective participant and an eligibility questionnaire was sent to them for completion to confirm eligibility (see Appendix 23).

All eligible participants were required to complete an online consent form to provide informed consent prior to participation (see Appendix 24).

Physiotherapists

Physiotherapists were recruited if they met the following inclusion criteria:

- A qualified physiotherapist with relevant experience of working with children and young people following pTBI, and their parents, currently based within the acute hospital environment, community settings, charitable organisations or private practice.
- Have access to suitable technology to allow them to join online workshops.

All physiotherapy participants were qualified physiotherapists who had previously participated in focus groups as part of *Chapter 5: Qualitative study involving physiotherapy focus groups* and given consent to being contacted about the co-design study. Eligible participants were required to complete an online consent form and provide informed consent prior to participation in the co-design study (see Appendix 24).

7.5.3 Patient and Public Involvement and the role of workshop facilitators

One public representative from the PPI group who was involved in my doctoral research from its inception was recruited to co-facilitate the co-design workshop. The rationale for this was to place the parents' voices at the very centre of the design process, and to help create a relaxed, inclusive and supportive atmosphere for parents where their voices were valued (National Institute for Health and Care Excellence, 2025).

Two technology developers employed by UBQO Ltd. co-facilitated workshop discussions and acted as scribes to document participants' thoughts, ideas and suggestions. The public representative and both technology developers were named study team members within the ethics application. Their individual roles were reviewed and approved by the research ethics committee prior to commencing the workshop.

7.6 Procedures and process of analysis

The procedures outlined below were designed to meet the study aim by providing a detailed understanding of user requirements for the intervention using a remote workshop.

I hosted the remote workshop using Microsoft Teams, with small group activities completed within breakout rooms. I chose Microsoft Teams as opposed to Zoom for this study due to the functionality of break out rooms to support small group discussions. Alongside accessing Microsoft Teams for group discussions, all participants accessed a shared Miro whiteboard: a digital whiteboard for anonymously documenting ideas and discussion summaries. Participants were free to add digital sticky notes to an online canvas - an online equivalent of sticky notes on an A3 piece of paper.

As this study concerns intervention co-design work and not a qualitative study, it was not appropriate to utilise qualitative analysis methods (e.g., thematic analysis) as has been undertaken previously within the qualitative studies. Rather, participants completed a persona-scenario activity which imagined the requirements of a future intervention according to the Value Proposition Canvas (see Figure 7.2 above). Analysis involved identifying the fit between the user profile and value map of the Value Proposition Canvas to identify important user requirements for the intervention. Please see below for further details which are structured according to the three defined phases of the generative co-design framework, divided into seven steps: *Pre-design* (steps 1-2), *Co-design* (steps 3-5) and *Post design* (steps 6-7).

Pre-design

Extensive preliminary research was undertaken through the systematic review, qualitative studies with parents and physiotherapists and the conceptual design of the intervention (step 1). Prior to undertaking the co-design workshop, participants were recruited and consent forms signed. Workshop materials including the participant persona template (see Appendix 25) and the Value Proposition Canvas template (see Appendix 26) were prepared. I additionally undertook technology testing of Microsoft Teams, including breakout rooms, and use of the Miro whiteboard (step 2). Participants were sent research summaries of the parent interview study and physiotherapy focus group study via email: I prepared these summaries without the involvement of the PPI group (see Appendix 27). I encouraged them to review the summaries and become familiar with the research insights from the studies in preparation for the workshop (see Appendix.

Co-design workshop

The co-design phase involved a remote co-design workshop which lasted three hours and was structured around the workshop facilitator notes (Appendix 21). The purpose of the workshop was to bring parents and physiotherapists together to develop a shared vision of the co-design task and reflect on their own experiences of supporting and delivering physiotherapy. This provided a focus for the workshop and a shared understanding of what must change to better support parents to adhere to delivering physiotherapy exercises (step 3).

Participants were divided into two small groups within Microsoft Teams breakout rooms. One small group included parents, the PPI representative and one technology developer. The other small group consisted of physiotherapists, one technology developer and myself. A starting point was to generate a fictional persona – a fictional character which represents a typical member of that group - through guided discussions and populating the template (Valaitis et al., 2014). Parents generated a parent persona, and physiotherapists generated a physiotherapist persona. Personas included a name, age and some background information, plus details about the context within which they were based, some highlights of their role and other important information about them (Valaitis et al., 2014).

Each small group's persona then provided the basis for participants to populate the 'User Profile' of the Value Proposition Canvas (see Figure 7.2 above) from the perspective of the fictional persona (Valaitis et al., 2014). Discussions were documented as digital sticky notes on the user profile as 'Jobs' (things they are trying to get done), 'Pains' (bad outcomes, risks and obstacles related to jobs) and 'Gains' (outcomes they want to achieve or concrete benefits they wanted to seek). For the parent group this related to delivering physiotherapy exercises to their child, for the physiotherapist group this related to supporting a parent to deliver physiotherapy exercises to their child.

Each small group continued the task and created a future scenario which detailed requirements of the digital intervention and detailed proposed or imagined solutions to current challenges (Sanders and Stappers, 2008, Valaitis et al., 2014). Discussions were documented on the 'Value Map' of the Value Proposition Canvas as 'Pain Relievers' (descriptions of how the intervention could alleviate user pains) and 'Gain Creators' (descriptions of how the intervention could create user gains). Please note, at the time of the workshop the intervention did not exist, therefore the 'Products and Services' section of the value map was not relevant. Throughout group discussions, a scribe added digital sticky notes to the Miro whiteboard to document ideas and suggestions, and participants were free to add their own anonymous sticky notes.

By completing the Value Map and ideating possible solutions to user Jobs, Pains and Gains, participants collectively described a future scenario detailing the requirements of the digital intervention to support parent delivered physiotherapy (Valaitis et al., 2014). The outputs from this step of the process were the two completed Value Proposition Canvases: one for the parent group and the second for the physiotherapist group (step 4).

Both participant groups were then brought back together to feedback about their fictional persona and the generative small group discussions according to their Value Proposition Canvas (step 5). The outputs from the workshop were the textual comments, ideas and suggestions posted on digital sticky notes on: i) the parent group's completed Value Proposition Canvas, and ii) the physiotherapist group's completed Value Proposition Canvas. The textual data were taken forward for analysis in the post-design phase.

Post-design

Following the workshop, I remotely accessed the Miro whiteboard and extracted the relevant textual data from the digital sticky notes (step 6). The parent specific textual data was kept separate to the physiotherapist specific textual data, and the analysis process was undertaken as follows. Participant ideas and suggestions from the Value Map (Pain Relievers and Gain Creators) were grouped together according to similar features, for example, the gains that can be created through collaboration between parents and physiotherapists. I then cross-referenced these against the User Profile (Jobs, Pain and Gains) to identify where there was alignment, for example, recognising that parents are an integral part of the process of delivering physiotherapy, relating to collaboration. These were organised into two separate columns along the same row of a table, and the process was repeated for all data relating to the delivery of physiotherapy exercises (please see Table 7.1 for parent data and Table 7.2 for physiotherapist data).

The purpose of this process was to ascertain where the proposed digital intervention would meet users' needs by addressing important jobs, alleviating important pains and creating important gains – termed 'fit' – according to the Value Proposition Canvas (Osterwalder et al., 2014). I initially completed the above process for the parent specific data, then repeated the same process for the physiotherapist specific data. During this analysis phase I met regularly with the technology developers and PPI representative to discuss and agree about insights gained from the workshop, and summary notes from meetings were documented (see Appendix 28).

The output from this stage of the process was the alignment of data from the Value Proposition Canvas for the parent group and physiotherapist group. I then integrated the two sets of findings to identify the key essential elements for the intervention which took the form of a list of prioritised intervention components (O'Cathain et al., 2010, Heale and Forbes, 2013) (step 7).

7.7 Findings

Prior to the co-design workshop in November 2023, four parents and four physiotherapists were invited to participate, and all were recruited. Amongst the parents, three had a child who was hospitalised after sustaining a pTBI and required physiotherapy, and one had a child who suffered a non-traumatic brain injury requiring hospitalisation and physiotherapy. All four physiotherapists were employed within acute NHS Trusts.

In this section I will initially present the fictional persona and the results of the Value Proposition Canvas for the parent group (Table 7.1), and then the physiotherapist group (Table 7.2). Finally, I will present an overall summary of findings from parents and physiotherapists which are integrated within a matrix detailing the main user-centred requirements for the intervention (Table 7.3).

7.7.1 Findings from the Value Proposition Canvas – parents

Parents developed the persona of a 35-year-old mother called Ally. Ally had a child that had sustained a pTBI and she was ‘advised by the hospital and community physiotherapists to do exercises with my child to help their movement difficulties’. It was said that a highlight of Ally’s role as a parent related to her children and seeing ‘siblings getting along again’.

The table below presents of the data captured through the parents’ Value Proposition Canvas and organised according to where ‘fit’ was deemed to exist between the user profile and value map.

Table 7.1 - Parents' Value Proposition Canvas: identifying fit between user profile and value map

The focus of small group discussion and data according to the Value Proposition Canvas	**Persona-based user profile**	**Corresponding scenario-based value map**
Acknowledging the role of parents and fostering collaboration	Parent as part of the team [Gains] Recognition that the parent is an integral part of the process [Gains]	Sense of collaboration whilst enabling independence [Gain creators]
Engaging in goal setting and relating goals to existing interests	Clinicians asking what our goals are when parents don't know what is available, possible etc. [Pains]	Goals the child can set themselves in line with their interests [Gain creators] Find out what the child's passion is [Pain relievers] Identifying unique motivators (e.g., brother etc) [Pain relievers]
Building confidence and addressing anxieties related to delivering physiotherapy exercises	Deal with anxiety to do with rehab [Jobs] Every day is totally different [Pains]	Build confidence [Gain creators] Get right information at the right time [Gain creators]
Connecting physiotherapy recommendations with existing interests and having guidance to deliver physiotherapy exercises	Facilitating therapy [Jobs]	Activities related to the child and their interests [Pain relievers] Videos of the exercises that could be repeated at home [Pain relievers] Personalised videos [Pain relievers] Ability to "look back" to show progress [Gain creator] Make it meaningful - game based [Pain relievers]

		Prompts and reminders the child can set themselves [Pain relievers]
Understanding new terminologies	Lack of understanding of professional terminology [Pains] Understanding of what the different terminologies are [Gains] What does this all mean (terminology) [Gains]	Get right information at the right time [Gain creators]
Coordinating with the physiotherapist	Coordinate with physio [Jobs]	Coordinate between MDT [multi-disciplinary team] and family [Gain creator]

The important insights reported in Table 7.1 are that parents emphasised the need for the digital intervention to enable their collaboration with the physiotherapist in setting meaningful goals. Parents additionally focused on the exploration of what the child's passions are, and what unique motivators could be identified to support them to engage in physiotherapy. They also emphasised the importance of being supported to confidently deliver the physiotherapy exercises through personalised physiotherapy recommendations, which included video demonstrations.

Alongside this, parents deemed that being able to 'look back' and see the progress that the child had made was a helpful way to monitor and review their child's improvements. In addition, receiving the right information at the right time was deemed to be important, due to the identified lack of understanding about professional terminology.

7.7.2 Findings from the Value Proposition Canvas – physiotherapists

Physiotherapists developed the persona of a 40-year-old female physiotherapist called Georgie; a paediatric physiotherapist working in an acute major trauma centre in England. They identified a range of highlights of Georgie's role as a paediatric physiotherapist, including 'getting to know the young people and family' and to be 'one of the people that sees them from PICU through' whilst offering 'continuity and relationship' during this time. Additional highlights for Georgie were that she could help by 'joining the dots between different aspects of care' and be 'someone to help problem solve'.

The table below presents of the data captured through the physiotherapists' Value Proposition Canvas, organised according to where 'fit' was deemed to exist between the user profile and value map.

Table 7.2 - Physiotherapists' Value Proposition Canvas: identifying fit between user profile and value map

The focus of small group discussion and data according to the Value Proposition Canvas	**Persona-based user profile**	**Corresponding scenario-based value map**
Establishing rapport and getting to know the child and parents in their 'own words'	Rapport building [Jobs] Getting to know the child in their 'own words'. Who are they? [Gains] Subjective info [information] [Jobs] Improved communication between families and teams [Gains] Non-threatening opportunity to gain feedback [Gains]	Terminology not negative for families, e.g., goals not achieved - can have a positive slant to increase motivation [Pain relievers] PT [physiotherapist] can be more efficient - will know what drives the patient/their passion to help with treatment planning [Pain relievers]
Supporting goal setting	Goal setting – e.g., to achieve safe discharge [Jobs]	Terminology not negative for families, e.g., goals not achieved - can have a positive slant to increase motivation [Pain relievers]
A space for parent-led documentation to self-monitor progress	A space to have questions / queries / wonderings when not in sessions, e.g., parents' queries on how to facilitate [their] child [Gains]	Record of videos shows progress - may help motivation also [Gain creators] Award/success/progress board that families can populate themselves with pictures or comments [Gain creators]

Recommending and personalising physiotherapy exercises	Generating HEP [home exercise programme] [Jobs] Catalogue of resources (exercises, accessibility ideas - sports/hydrotherapy) [Gains] Age and condition appropriate exercise catalogue [Gains] Tailored/personalisation of programmes and advice, e.g., filming of handling guidance, splint donning, exercise prescriptions [Gains] Voice recording instructions [Gains] Someone completing the exercises who presents with a comparable disability - rather than a generalised exercise list of tools [Gains]	Make exercises which are tailored to the child [Gain creators] Record of videos shows progress - may help motivation [Gain creators] List of exercises to choose from [Pain relievers] Opportunity to edit text or complete voice overs [Pain relievers] Option to upload child video - more meaningful [Pain relievers] Equipment section of app - including picture of each of child's equipment, e.g., splints, stander, wheelchair and brief information on this for others, e.g., how to don splints, picture set up in the stander - ensure tailored to the child, i.e. pictures of the child in the equipment (or option for generic one if picture of child may not be appropriate). [Pain relievers]

The above table highlights that physiotherapists deemed goal setting and providing personalised physiotherapy exercises plus activity recommendations to be a priority for the intervention. Physiotherapists identified that written explanations and pictorial/video demonstrations of exercises, which can be personalised and sent to parents, were required. These were not deemed to be beneficial in isolation, but rather through the process of rapport building and getting to know the child and parents in their 'own words', whilst identifying any existing passions and drivers to encourage physiotherapy and improve efficiency. In addition, physiotherapists deemed a space for parents important where they could document thoughts and ideas as well as add notes, pictures and videos to monitor progress and celebrate success.

7.7.3 Parent and physiotherapist matrix

After analysing the above data from parent and physiotherapy Value Proposition Canvases separately, I integrated the data within a matrix, together with rationale and perceived value of different features of the intervention (Table 7.3). The purpose of this was to identify the collective user-centred requirements and core components for the intervention. This process was undertaken through collaborative discussions with the technology developers and PPI representative (Appendix 28).

Table 7.3 – Matrix representing proposed core features of the intervention

Parents	**Physiotherapists**	**Rationale and perceived value for this feature within the intervention**
Acknowledging the role of parents and fostering collaboration Coordinating with the physiotherapist	Establishing rapport and getting to know the child and parents in their 'own words'	Providing a basis for collaboration between parents and physiotherapists. Providing children and parents with a means by which to express themselves in their 'own words'. Such collaboration provides a starting point for additional features of the intervention such as goal setting and physiotherapy recommendations, as outlined below.
Engaging in goal setting and relating goals to existing interests	Supporting goal setting	Supporting goal setting and linking physiotherapy goals with existing interests and passions
Connecting physiotherapy recommendations with existing interests and having guidance to deliver physiotherapy exercises	Recommending and personalising physiotherapy exercises	Providing personalised physiotherapy recommendations, related to existing interests and rehabilitation goals
Building confidence and addressing anxieties related to delivering physiotherapy exercises	A space for parent-led documentation to self-monitor progress	A means of self-monitoring physiotherapy exercises and progress, plus a mechanism to rate and track changes in confidence and/or anxieties
Understanding new terminologies		Offering a way for parents to understand unfamiliar terms, e.g., a glossary of medical terms

The above table provides support in addressing the study aim as it clarifies the main user requirements for the intervention. Firstly, rapport building, communication and collaboration between the parent and physiotherapist was expressed as being an important function of the intervention. Parents and children need to have the ability to share existing passions and interests, whilst physiotherapists must get to know parents and children in their 'own words'. From there, supporting collaboration through joint goal setting and relating physiotherapy goals to existing interests is identified to be another core component of the intervention.

Insights from the co-design workshop additionally show that the intervention should offer a way to connect physiotherapy recommendations with existing interests and passions in a personalised way. It was expressed by both sets of participants that having guidance and pictorial or video demonstrations of exercises which provide personalised recommendations would be important. Following on from that, a means by which parents could grow in confidence in delivering physiotherapy exercises, document anxieties related to rehabilitation and track changes in confidence over time was said to be important. Furthermore, a complimentary component of the intervention was said to be a space whereby parents can self-monitor progress and add documentation related to questions and queries, and a space to for monitoring and celebrating progress. Finally, parents expressed that the intervention should help them to understand unfamiliar terms and new terminologies following the pTBI.

7.8 Discussion

This co-design study aimed to develop a detailed understanding of user requirements for the intervention to inform the design of a prototype digital intervention. Design is a creative process through which innovative solutions to problems can be identified and developed (Hollanders and van Cruysen, 2009). Generative approaches were employed to facilitate small groups of parents and physiotherapists to identify current challenges, difficulties and needs, together with identifying perceived valued components of the intervention (Sanders and Stappers, 2008, Bird et al., 2021). The following discussion will consider participants' agreed core priorities for the intervention in greater detail.

Firstly, both parent participants and physiotherapy participants agreed that goal setting and the provision of personalised physiotherapy recommendations should be core features of the intervention. In many respects, this is unsurprising given that every intervention analysed within the *Chapter 2: Systematic review* included goal setting and the provision of exercises (Young et al., 2024a). Moreover, goal setting and supporting parents to become involved in physiotherapy and learn to deliver physiotherapy exercises themselves were findings from both

Chapter 4: Qualitative study involving parent interviews and *Chapter 5: Qualitative study involving physiotherapy focus groups*.

Going above and beyond the findings of the previous chapters is the need for physiotherapists to get to know the CYP and parents in their 'own words' and for the intervention to support collaboration. Related to this, parents spoke of the importance of physiotherapists understanding existing passions and motivations for CYP prior to the injury and relating goals to existing interests. Similarly, physiotherapists spoke about the benefits of getting to know the child and parents in their 'own words' and using this understanding to guide goal setting and treatment planning in a personalised and more efficient way.

This finding is in keeping with the insights of Melin and colleagues who reviewed goal setting in physiotherapy (Melin et al., 2021). Analysis from their literature review revealed that goal setting between patients and physiotherapists is a collaborative process built on an underlying partnership whereby a mutual understanding on what is meaningful to the patient is sought. Here, goals are considered as "aspirations, hopes and dreams" (Melin et al., 2021, p.872) from which smaller, short-term goals can be formulated. This process is also true for goal setting within the wider MDT which needs to focus on specific areas of daily life that are meaningful to the child and family (Pritchard-Wiart et al., 2019, Dunford et al., 2020). Time is required to listen to the child and not only their parents to ensure that it is a truly inclusive and collaborative endeavour (Ryan et al., 2025).

In collaborative goal setting specific to paediatric rehabilitation following brain injury, it is said that the F-words of child development can be a useful resource to structure and support the discussions around goals (Jenkin et al., 2022a). In *Chapter 5: Qualitative study involving physiotherapy focus groups* it was focus group participants themselves that identified the F-words of child development, mapped on to the WHO's ICF (Rosenbaum and Gorter, 2011), as a user-centred way to structure discussions about goals. The insights from the co-design workshop suggests that the F-words of child development could have a novel and potentially useful role to play within the intervention. If used to structure background information related to the child and the family prior to the pTBI, this could be mutually beneficial for both parents and physiotherapists (Jenkin et al., 2022a).

In this way, using the F-words as a starting point could offer the context from which other essential elements of the intervention can flow. For example, the final F-word is 'Future' and this concept could be expanded to include 'Future hopes' which are 'the things that children want to work towards' (Melin et al., 2021). There is potential that considering 'Future hopes' in this manner could support collaborative goal setting between the child, parent and physiotherapist in a way that is deemed meaningful and accessible for families (Young and

Gravett, 2025). Furthermore, the exercises which are recommended by the physiotherapist can relate more closely to existing interests and passions, as well as the goals which have been collaboratively set.

Workshop participants also identified that a component of the intervention should be to help build parent confidence and address anxieties related to delivering physiotherapy, whilst facilitating parents to self-monitor progress. Importantly, developing confidence, together with gaining knowledge and skills, are shown to be key elements of self-managing a long-term health condition (NHS England, 2024c).

7.8.1 Understanding unfamiliar terminology

There are also features of the intervention that only the parents identified. This includes the need for parents to understand new professional terminologies which are unfamiliar to them. This relates to parents' perceived lack of understanding and needing to receive the right information at the right time.

7.8.2 My experience of utilising the generative co-design framework and Value Proposition Canvas

The generative co-design framework and Value Proposition Canvas provided the structure with which to navigate participants through the co-design workshop. Combined use of the generative framework and the Value Proposition Canvas also enabled participants to take part in a persona-scenario which is an approach adopted in intervention co-design (Valaitis et al., 2014).

My overall experience of utilising these novel and creative approaches were positive, although there were some challenges associated with using them. Both approaches were unfamiliar to me prior to conducting the co-design workshop and it required close partnership and planning with the technology developers and PPI representative to plan and facilitate the workshop. In addition, there was a balance to be struck between facilitating participants' free expression related to their experiences and trying to guide the conversation too closely. For example, some participants spoke of challenges related to a child's return to school following the pTBI and teachers not understanding the difficulties that their child faced with learning in the classroom environment. This is not related to parental adherence to delivering physiotherapy, or the design of a digital intervention, however, it was important that participants felt able and supported to express themselves during the workshop (Bird et al., 2021).

Overall, the workshop was a very positive experience and demonstrated the value of bringing together a range of stakeholders with a shared objective of discussing the intervention. In this way, it was of great benefit to bring the technology developers together with parents, the end-users of the intervention, and physiotherapists. NHS Digital specifically emphasises the need for technology experts and developers in the modern healthcare system to work alongside stakeholders when iteratively developing and refining patient-centred technologies (NHS Digital, 2021).

7.8.3 Strengths and limitations

There are several strengths and limitations of this co-design study which should be acknowledged. The aim of the study was to develop a detailed understanding of user requirements for the intervention, and the study succeeded in bringing end-users and other key stakeholders together within the workshop. This meant that a range of different perspectives, voices and types of expertise were brought together to discuss the issue of parent delivered physiotherapy (Bird et al., 2021, Young and Gravett, 2025).

Having the technology developers, the PPI representative and myself as identified workshop facilitators followed best practice guidance for co-design (Sanders and Stappers, 2008). This meant that the technology developers themselves were personally present during discussions with parents and physiotherapists to hear from them firsthand. In addition, having a public representative with personal experience of having a child with pTBI and delivering physiotherapy was felt to be very supportive for the parent participants when they explored what was required of the intervention (National Institute for Health and Care Excellence, 2025).

A further strength was that generative approaches were used to harness participant creativity in designing solutions to current problems. The use of a persona-scenario through combined utilisation of the generative co-design framework and the Value Proposition Canvas was a novel approach which focused on the user requirements for the intervention (Valaitis et al., 2014) (Valaitis et al., 2014). It is possible that without these generative design approaches the latent wants and needs of participants would not have been expressed in the same way during the workshop (Sanders and Stappers, 2008, Bird et al., 2021). That said, the workshop was hosted remotely using Microsoft Teams which limited the opportunity for the participants to interact outside of the specific workshop discussions. This may have impacted upon the rapport building within the participant groups.

A potential limitation was that not all parents had children who had suffered a pTBI. One parent had a child that had suffered a non-traumatic brain injury. However, it was determined prior to recruitment that this participant was able to provide complimentary and valuable insights given that they were a parent who was required to deliver physiotherapy to their child following a brain injury.

As outlined in the introduction to this chapter, there is a need to integrate design thinking with behavioural design when developing digital behaviour change interventions which are acceptable, engaging and likely to support behaviour change in the intended direction (Voorheis et al., 2022). This study has delved into the design thinking processes for end-users and key stakeholders of the intervention which now needs to be integrated with the behavioural design.

The next chapter will detail the integration of design thinking and behavioural design including a detailed logic model of the intervention from which the prototype intervention was developed.

7.9 Conclusions

Co-designing interventions with end-users and key stakeholders is an important element of making interventions usable and acceptable. Parents and physiotherapists agreed that a digital intervention designed to support parent delivered physiotherapy must include aspects of goal setting and guidance on delivering the exercises themselves, alongside other core features. Moving forwards, the insights provided through the co-design workshop should be used to inform intervention development.

Chapter 8: Prototype intervention development

8.1 A brief overview of this chapter

The focus of this chapter is the triangulation of findings from the conceptual design of the intervention, presented in Chapter 6: The conceptual design of the intervention, with the co-design workshop, presented in Chapter 7: Developing a detailed understanding of user requirements for the intervention.

The purpose of this triangulation of data is to identify where convergence (agreement) or divergence (disagreement) exists between the different data sets. The rationale for combining co-design with an in-depth understanding of the target behaviour is to increase the intervention's acceptability, engagement and user-centredness, whilst also delivering the specified active ingredients to support behaviour change. The ultimate aim of this process is to increase the intervention's uptake and effectiveness.

The integration of findings from the preceding chapters guided the development of a detailed logic model of how the intervention is proposed to function, upon which the prototype intervention is based. The prototype is the initial version of the digital intervention 'Physio Together' which has been designed to be accessed using a mobile phone application and via a web application, hosted by the health-technology company, UBQO Ltd.

By the end of this chapter, I will present the detailed logic model and key features of 'Physio Together', accompanied by a summary of component BCTs and intervention functions.

8.2 Introduction

In Chapter 7, I presented the rationale for the importance of combining behavioural design with design thinking when developing digital behaviour change interventions (West and Michie, 2016, Voorheis et al., 2022). Related directly to this, in *Chapter 6: The conceptual design of the intervention* I characterised parental adherence and the behavioural requirements of the intervention. This was followed by the co-design study using a workshop presented in *Chapter 7: Developing a detailed understanding of user requirements for the intervention*.

Combining behavioural design with design thinking is a creative process whereby content and features of an intervention can be created on the basis that they meet users' requirements, needs and preferences whilst supporting behaviour change (Voorheis et al., 2022). In accordance with best practice guidance, data related to behavioural influences has been integrated from a range of different sources (Michie et al., 2014) with different stakeholders brought together to contribute to the generative co-design process (Sanders and Stappers, 2008, Bird et al., 2021). Within the co-design study this included parents and physiotherapists, facilitated by technology developers, a public representative and myself within an online workshop.

The aim of this chapter is to present the co-designed prototype digital intervention 'Physio Together'. To achieve this, I have triangulated the identified user requirements from the co-design workshop (design thinking) with the conceptual design of the intervention (behavioural design). Underpinning the design of 'Physio Together' is a one-page summary of the intervention in the form of a detailed logic model. A logic model is simplified and accessible summary commonly used to represent how complex interventions or systems create outcomes, including their causal processes (Mills et al., 2019).

8.3 Aim & Objectives

The aim of this chapter is to:

- Co-design a prototype digital behaviour change intervention based on design thinking and behavioural design.

To achieve this aim, the following objectives were defined:

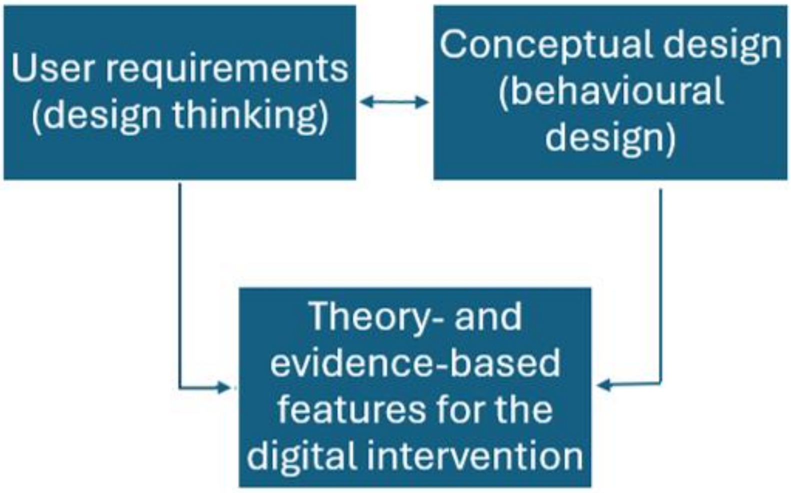
1) Identify core components of the intervention through triangulation of user requirements taken from the co-design workshop (design thinking) with the conceptual design of the intervention (behavioural design).
2) Develop a detailed logic model representing how the intervention is proposed to work.
3) Develop a prototype digital intervention based on the detailed logic model.

8.4 Methods

8.4.1 Data triangulation

Triangulation of data involved bringing together the key findings from the conceptual design (*Chapter* 6) with the co-design study (*Chapter 7*) and interpreting where the findings from each source converged (O'Cathain et al., 2010). This process involved integrating the user-centred features with specified behaviour change content, thereby combining design thinking and behavioural design, as presented in Figure 8.1 below.

Figure 8.1 - Combining design thinking with behavioural design to inform intervention development



Data triangulation was completed by integrating data presented within the two key summary tables from the respective chapters (Voorheis et al., 2022). This process commenced with the summary table of data relating to behavioural design, namely ‘Table 6.9 - Linking intervention functions with behaviour change techniques (BCTs) and identifying promising candidates for the digital intervention’. This comprehensive summary table provided a starting point to then integrate the data from the design thinking matrix 'Table 7.3 - Matrix representing proposed core features of the intervention' which represented the integrated core design features from the parent and physiotherapist generative design discussions.

In turn, I considered how each of the 24 candidate BCTs could be delivered within the intervention in a way which also met the specified user requirements for the intervention. For example, within the conceptual design I determined that the BCT '6.1 Demonstration of the behaviour' was a promising candidate for the intervention, to be delivered through training and modelling. I also identified that this BCT could plausibly be delivered via example exercises using pictures or videos within the intervention. In terms of the specified user requirements, participants in the co-design workshop stated that the intervention needed to support physiotherapists to provide personalised physiotherapy recommendations. Physiotherapists suggested example exercises which are selected from a list of exercises, or an exercise library, to choose from and personalise for an individual child. In this example, there is convergence of the different data sets: the intervention will deliver BCT '6.1 Demonstration of the behaviour' through personalised physiotherapy recommendations using pictures or videos.

The above process was repeated for each promising candidate BCT for the intervention. Using this process I explicitly linked the user-centred features with specified behaviour change content, combining design thinking and behavioural design (Voorheis et al., 2022) (see Table 8.1 below for details).

This resulted in a long list of triangulated data which I took forward into discussions with the technology developers and PPI representative. From these discussions the core components of the theory- and evidence-based digital intervention were selected (see Appendix 28) (O'Cathain et al., 2010, Heale and Forbes, 2013, Michie et al., 2014, West and Michie, 2016, Voorheis et al., 2022). The core components were based on their perceived importance, design time and available resources within the context of an NIHR funded PhD and are summarised in Table 8.2 below.

Perceived importance was judged by the alignment of data from the different data sets which fed into the co-design workshop (data from research reported in Chapters 2, 4 and 5) and the workshop discussions themselves (Chapter 7). For example, goals and goal setting were deemed to be highly important ingredients of interventions which support parents delivered physiotherapy following pTBI which was consistent across the systematic review (Chapter 2) and qualitative studies (Chapters 4 and 5). Within the co-design workshop, relevant data which reflected participant perspectives included 'Goals a child can set themselves in line with their interests' and therefore goal setting was perceived to be important. During the workshop discussions, there was an additional emphasis on 'getting to know the child in their own words, who are they?' which reflected the importance of incorporating a framework such as the F-Words of child development (Rosenbaum and Gorter, 2011, Young and Gravett, 2025). Furthermore, the data feeding into the co-design workshop (presented within Chapters 2, 4 and 5) also emphasised the role of example exercises provided by a physiotherapist to support parents with the delivery of exercises themselves. Echoing this within the workshop was participant data such as 'Activities related to the child and their interests' plus 'Videos of the exercises that could be repeated at home' which further emphasised the need for a range of example exercises. As a result, exercise recommendations have become a feature within the digital intervention.

Table 8.2 below provides a summary of the triangulated data and contains three columns, which are: 'User-centred intervention features', alongside this is 'Rationale for the inclusion of this feature', and finally 'Associated behaviour change content'. I utilised the content of Table 8.2 to form the basis of a detailed logic model, as I will outline further below.

8.4.2 Development of the logic model

I mentioned above that the core features for the intervention included within Table 8.2 formed the basis of the detailed logic model (Figure 8.2 below). To be more specific, I designed the logic model to include the list of required core components of the intervention, as outlined in Table 8.2, as the central column of the logic model named 'Proposed intervention components'. To the left of this column, I included the context, behavioural problem, determinants and proposed strategies/BCTs as elements contextualising and feeding into the intervention. To the right of the 'Proposed intervention components' column, I included the short-, medium-, and long-term outcomes which I anticipate being achieved as a result of parents engaging with and utilising the intervention.

I chose to present this complex flow of inputs, content of the intervention and outputs as a logic model because it provided a one-page overview and shared understanding of how the intervention is proposed to work (NHS England, 2021). The logic model also represents a summary of 'Modelling process and outcomes' which is the third and final stage of developing a complex intervention according to the 2008 MRC guidance (Craig et al., 2008).

The primary audience for the logic model were the technology developers upon which the prototype version of 'Physio Together' was based (Basu et al., 2017). Beyond the developers, the audience included researchers and clinicians to provide a shared understanding of what the intervention aims to do and how it is proposed to work. The purpose of the logic model was also to inform my post-doc research with regards the focus of a future feasibility study and randomised controlled trial. To elaborate further, the feasibility and short-term outcomes can be measured in a subsequent feasibility trial, and medium-term outcomes and long-term impacts within a large scale randomised controlled trial (Skivington et al., 2021). The content of the logic model can additionally be updated as new data becomes available for incorporation into the logic model, and indeed the intervention itself (Skivington et al., 2021).

8.4.3 Prototype intervention development

I worked in collaboration with the technology developers to design an initial prototype version of the digital intervention ‘Physio Together’. The intervention is based on the proposed core intervention components, as reflected in the logic model. This is a recognised way of working and has been utilised previously within paediatric rehabilitation. For example, the Early Therapy in Perinatal Stroke (eTIPS) programme was developed to be implemented amongst parents of children at risk of developing cerebral palsy following a unilateral perinatal stroke (Basu et al., 2017). The eTIPS intervention was designed based on a detailed logic model and underwent iterative refinement following review and feedback from parents and health professionals (Basu et al., 2017).

The main aim of prototype intervention development within the PhD was to get to the point that we can begin alpha testing in post-doctoral research. Alpha testing involves examining the functionality of a digital product to determine whether it can perform its intended purpose, with feedback informing the iterative design of the product and the requirement for new features (Wilson et al., 2018). Within this initial testing and feedback phase, consideration should also be given to the product’s perceived acceptability, usefulness and ease of use (Hamideh Kerdar et al., 2023). To this end, models such as the Technology Acceptance Model (TAM) can be useful in structuring user-testing and feedback focussing on the users’ perceived sense of usefulness and ease of use of the intervention (Davis, 1985).

8.5 Findings

8.5.1 Data triangulation

As described above under 8.4.1 Data triangulation, I have triangulated the 24 BCTs included within Table 6.9 with the design thinking matrix as presented in Table 7.3. Below you can see each of the 24 promising BCTs included alongside their relevant intervention functions and COM-B targets, where the BCT could plausibly fit in the intervention, the corresponding user-centred feature, plus the feature to be included in the intervention.

Table 8.1 - Data triangulation: bringing together promising behaviour change techniques, intervention functions, user-centred features and intervention features

Promising behaviour change technique	**Intervention function (including COM-B components targeted)**	**Where the behaviour change technique could plausibly feature in the intervention**	**User-centred features**	**Feature to be included in the intervention**
1.1 Goal setting (behaviour)	Enablement (C O M)	Collaborative goal setting with the physiotherapist	Supporting goal setting and linking physiotherapy goals with existing interests and passions	Collaborative goal setting with the physiotherapist which links goals with existing interests and passions, with a focus on the behaviour of delivering physiotherapy Utilising the F-words of childhood development to contextualise and help frame the goal setting discussions
1.2 Problem solving	Enablement (C O M)	Identify factors influencing adherence to completing exercises, plus documentation within a notes page / diary feature	A space for parent-led documentation to self-monitor progress with goals	Confidence rater plus notes facility for parents to populate after completing recommended exercises. Subsequently, consider/discuss with the physiotherapist strategies through which parents could overcome barriers and/or increase facilitators to delivering exercises Parent documentation within a notes page / diary feature
1.3 Goal setting (outcome)	Enablement (C O M)	Collaborative goal setting with the physiotherapist	Supporting goal setting and linking physiotherapy goals with existing interests and passions	Collaborative goal setting with the physiotherapist which links goals with existing interests and passions, with a focus on the outcomes to be achieved through physiotherapy

				Utilising the F-words to contextualise and help frame the goal setting discussions
1.4 Action planning	Enablement (C O M)	Through collaboration with the physiotherapist, plus linking physiotherapy to existing interests	Physiotherapy recommendations related to existing interests and rehabilitation goals	Linking physiotherapy with existing interests, passions and goals – specifying the context, frequency, duration or intensity of the exercise
1.5 Review behaviour goal(s)	Enablement (C O M)	Review with the physiotherapist	Collaboratively review goals with the physiotherapist	Collaboratively review (behavioural) goals with the physiotherapist and update as deemed appropriate
1.7 Review outcome goal(s)	Enablement (C O M)	Review with the physiotherapist	Collaboratively review goals with the physiotherapist	Collaboratively review (outcome) goals with the physiotherapist and update as deemed appropriate
2.2 Feedback on behaviour	Education (C M) Persuasion (M) Incentivisation (M) Training (C O M)	Summary feedback from the intervention about delivering the physiotherapy exercises (e.g., frequency of delivering the recommended exercises)	Feedback to support building parents' confidence related to delivering physiotherapy exercises	Summary feedback from the intervention - related to the behaviour of delivering physiotherapy exercises
2.3 Self-monitoring of behaviour	Education (C M) Incentivisation (M) Training (C O M) Enablement (C O M)	Checklist of completed exercises, plus the option to add notes within a notes page / diary feature	Self-monitoring physiotherapy exercises and progress	Checklist for self-monitoring of completed exercises and the option to document within a Notes page / diary feature
2.4 Self-monitoring of outcome(s) of behaviour	Education (C M)	Monitor outcomes of completed exercises, plus within a notes page / diary feature	Self-monitoring physiotherapy exercises and progress	Self-monitor outcomes of completed exercises and the option to document within a Notes page / diary feature

	Incentivisation (M) Training (C O M) Enablement (C O M)			
2.7 Feedback on outcome(s) of the behaviour	Education (C M) Persuasion (M) Incentivisation (M) Training (C O M)	Summary feedback from the intervention about outcomes of delivering the physiotherapy exercises, e.g., changes in physical function	Feedback to support building parents' confidence related to delivering physiotherapy exercises	Summary feedback from the intervention - related to outcomes or functional progress towards agreed goals
3.1 Social support (unspecified)	Enablement (C O M)	Through physiotherapist contact details, plus a general resources page	Physiotherapist contact details to support coordination with the physiotherapist	Physiotherapist contact details to aid coordination with the physiotherapist and access social support. Also, a resources page of additional sources of support
3.2 Social support (practical)	Enablement (C O M)	Through physiotherapist contact details	Physiotherapist contact details to support coordination with the physiotherapist	Physiotherapist contact details as a means of accessing practical social support
4.1 Instruction on how to perform a behaviour	Training (C O M)	Within example exercises using instructions	The provision of personalised physiotherapy recommendations	Personalised physiotherapy recommendations including instructions
5.1 Information about health consequences	Education (C M) Persuasion (M)	Explanation about the benefits of physiotherapy, plus benefits of specific exercises	Information about benefits of physiotherapy and specific exercises within personalised physiotherapy recommendations	General educational information about the benefits of physiotherapy Information about the benefits of specific exercises

5.3 Information about social and environmental consequences	Education (C M) Persuasion (M)	Explanation about the role of family and friends in supporting the injured child or young person, with physiotherapy included a positive aspect of these relationships	Acknowledging the role of parents whilst fostering collaboration between parents and physiotherapists	Education about the role of parents, plus family and friends relating to physiotherapy
6.1 Demonstration of the behaviour	Training (C O M) Modelling (O M)	Within example exercises using pictures / videos	The provision of personalised physiotherapy recommendations	Personalised physiotherapy recommendations including pictures or videos
7.1 Prompts/cues	Education (C M) Environmental restructuring (O M)	Digital prompts, for example push notifications delivered by the intervention - adjustable by each parent	Prompts to support the delivery of physiotherapy exercises	Digital prompts delivered by the intervention which can be individually tailored or adjusted
8.1 Behavioural practice / rehearsal	Training (C O M)	As part of example exercises to be practiced	The provision of personalised physiotherapy recommendations	Personalised physiotherapy recommendations including example exercises to be practiced
8.3 Habit formation	Training (C O M)	Through advice about the benefits of repetition to develop habits	Information about benefits of physiotherapy	Education about the benefits of physiotherapy and advice regarding repetition to develop habits
8.6 Generalisation of target behaviour	Enablement (C O M)	Through advice about completing physiotherapy in different contexts	Physiotherapy related to existing interests	Personalised guidance about completing physiotherapy in different contexts (e.g., outside the hospital or home environment)
8.7 Graded tasks	Training (C O M) Enablement (C O M)	Through graded and tailored example exercises	Personalised physiotherapy recommendations	Personalised physiotherapy recommendations which are graded and tailored by the physiotherapist, including making exercises increasingly difficult
9.1 Credible source	Persuasion (M)	Explanation about the benefits of physiotherapy, plus example exercises using a credible model	Personalised physiotherapy recommendations	Education about the benefits of physiotherapy from a credible source (i.e., physiotherapist)

		such as a child that previously suffered a brain injury		Example exercises using a credible model
12.5 Adding objects to the environment	Environmental restructuring (O M) Enablement (C O M)	The digital intervention itself as an object		
15.3 Focus on past success	Persuasion (M) Enablement (C O M)	Through reviewing when delivering physiotherapy went well	Building confidence related to delivering physiotherapy exercises	Utilise intervention to reflect on when delivering physiotherapy went well Parent documentation within a notes page / diary feature (e.g., to list when delivering physiotherapy went well)

Related to the COM-B components: C = Capability, O = Opportunity, M = Motivation.

Table 8.1 provided a comprehensive description of how the 24 BCT identified within the conceptual design of the intervention have been integrated with the findings of the user-centred design workshop (O'Cathain et al., 2010). It was then through collaborative discussions with the technology developers and PPI representative that the following six core intervention components were identified:

- Standardised information and education materials for all users
- Getting to know the child and parents in their 'own words'
- Exercise recommendations from the physiotherapist
- Features to support access to social support
- Notes page to aid self-monitoring and support problem solving
- Glossary of terms to aid understanding of new medical terms

In Table 8.2 below I expand upon the six core intervention components, each of which are shaded in grey. Below each intervention component I have provided a breakdown of the user-centred feature(s) upon which each is based, a clear rationale for the inclusion of each feature within the intervention and the associated behaviour change content which I propose will be delivered. Table 8.2 helped to inform the development of the detailed logic model (see Figure 8.2) upon which the technology developers and I designed the first prototype of the intervention.

Table 8.2 - User-centred features, rationale, and behaviour change content for the six core intervention components

User-centred intervention features	**Rationale for the inclusion of this feature**	**Associated behaviour change content (behaviour change technique and intervention functions)**
Standardised information and education materials for all users		
Information about 'What is physiotherapy and how does it help?'.	This offers written and video-based explanation of what physiotherapy is and the role that it plays in the child's rehabilitation.	5.1 Information about health consequences [Education – C.M / Persuasion – M] 8.3 Habit formation [Training – C.O.M] 8.6 Generalisation of target behaviour [Enablement – C.O.M] 9.1 Credible source [Persuasion – M]
Information about 'The role of family and friends'.	This offers written and video-based information about the role that family and friends can play in the child's rehabilitation.	5.3 Information about social and environmental consequences [Education – C,M / Persuasion - M]
Getting to know the child and parents in their 'own words'		
Gaining background information using the F-words of childhood development, and using Future hopes to structure discussions about meaningful goals (linking physiotherapy with existing and new interests).	The F-words provides a structured, standardised and evidence-based way to capture background information and help to contextualise physiotherapy for that family. Using the responses provided within the F-words of child development, particularly 'Future hopes' to structure goal setting discussions. These goals can then be reviewed with the physiotherapist and updated during subsequent reviews.	1.1 Goal setting (behaviour) [Enablement – C.O.M] 1.3 Goal setting (outcomes) [Enablement – C.O.M] 1.4 Action planning [Enablement – C.O.M] 1.5 Review behaviour goals(s) [Enablement – C.O.M] 1.7 Review outcome goal(s) [Enablement – C.O.M]
Exercise recommendations from the physiotherapist		
Exercise recommendations with written instructions plus picture or video examples to be checked off once completed. These also include the option to add a rating of confidence	These exercise recommendations can be selected from within 'exercise libraries' and be sent to parents and children within the intervention to support their rehabilitation.	1.2 Problem solving [Enablement – C.O.M] 2.3 Self-monitoring of behaviour [Education C.M / Incentivisation – M / Training – C.O.M / Enablement – C.O.M]

and/or note to support problem solving.	The exercise recommendations can be personalised and adapted to support more fun and participation-based activities, plus the use of prompts and reminders set by the family.	2.4 Self-monitoring of outcome(s) of the behaviour [Education C.M / Incentivisation – M / Training – C.O.M / Enablement – C.O.M] 4.1 Instructions on how to perform the behaviour [Training – C.O.M] 5.1 Information about health consequences [Education – C.M / Persuasion – M] 6.1 Demonstration of the behaviour [Training – C.O.M / Modelling – O.M] 7.1 Prompts/cues [Education – C,M / Environmental Restructuring – O,M] 8.1 Behavioural practice/rehearsal [Training – C.O.M] 8.6 Generalisation of target behaviour [Enablement – C.O.M] 8.7 Graded tasks [Training C.O.M / Enablement – C.O.M] 9.1 Credible source [Persuasion – M]
Summary feedback and reports	Summary feedback and reports for parents to clarify what physiotherapy has been delivered and the outcomes achieved. Professional reports for physiotherapists to include in clinical notes and communication with other professionals.	2.2 Feedback on behaviour [Education – C.M / Persuasion – M / Incentivisation – M / Training – C.O.M] 2.7 Feedback on outcome(s) of behaviour [Education – C.M / Persuasion – M / Incentivisation – M / Training – C.O.M]
Features to support access to social support		
Physiotherapist contact details	Physiotherapist contact details can help to improve communication between parents and the physiotherapist between reviews or appointments.	3.1 Social support (unspecified) [Enablement – C.O.M] 3.2 Social support (practical) [Enablement – C.O.M]

Resources page	The resources page provides information about local or national organisations that can support children, parents and their families following paediatric traumatic brain injury. For example, signposting to the Child Brain Injury Trust resources page and family support group.	3.1 Social support (unspecified) [Enablement – C.O.M]
Notes page to aid self-monitoring and support problem solving		
Notes page (also termed diary).	This was deemed to be a useful feature to support self-monitoring and facilitate problem solving. The notes page is designed to be a blank and flexible space for parents to document questions, thoughts, ideas or reflections, for example. Also, a place where they can upload comments or pictures/videos to celebrate success or achievements their child has made.	1.2 Problem solving [Enablement – C.O.M] 2.3 Self-monitoring of behaviour [Education C.M / Incentivisation – M / Training – C.O.M / Enablement – C.O.M] 2.4 Self-monitoring of outcome(s) of the behaviour [Education C.M / Incentivisation – M / Training – C.O.M / Enablement – C.O.M] 15.3 Focus on past success [Persuasion – M / Enablement – C.O.M]
Glossary of terms to aid understanding of new medical terms		
Glossary of terms	The glossary of terms provides a list of common medical terms and gives an accessible explanation to aid understanding. This can help to act as a 'jargon buster'.	No specific behaviour change techniques or intervention functions associated with this feature, however it was an important feature identified within the co-design workshop.
Summary of included behaviour change content		
Summary of included behaviour change techniques within the intervention	1.1, 1.2, 1.3, 1.4, 1.5, 1.7, 2.2, 2.3, 2.4, 2.7, 3.1, 3.2, 4.1, 5.1, 5.3, 6.1, 7.1, 8.1, 8.3, 8.6, 8.7, 9.1, 15.3	
Summary of included intervention functions within the intervention	Education, Persuasion, Incentivisation, Training, Modelling, Environmental Restructuring, Enablement	

8.5.2 Development of the logic model

Table 8.2, containing the co-designed user-centred components of the intervention, formed the basis for the detailed logic model presented in Figure 8.2 below. This process is described in more detail above in section *8.4.2 Development of the logic model*.

Figure 8.2 Logic model outlining how the intervention is proposed to work, including proposed intervention components, short, medium and long term outcomes

Context	Behavioural Problem	Determinants	Proposed strategies / Behaviour change techniques	Proposed intervention components	Short term outcomes	Medium term outcomes	Long term impact
Following their child's admission to hospital with a traumatic brain injury, parents are in an emotionally traumatised state and experience severe emotional distress (*Brown et al., 2013*). Physios involve parents and gradually empower parents to deliver physio activities (*physio focus groups*). This process starts in hospital then following discharge continues both inside and outside the home environment. In many cases, long-term adherence to physio is required (*parent interviews and physio focus groups*). Children benefit from family-supported rehabilitation delivered in the home environment (Braga et al., 2005, *systematic review*).	Initially, parents feel overwhelmed with information overload, however they need to learn to complete physio exercises with their child (*parent interviews*). With many competing demands, parental adherence to physio recommendations and integrating physio into everyday life is challenging (*parent interviews*). Parental confidence, skills acquisition and expertise increase with practice, time and support (*physio focus groups*). Currently parental engagement with physio recommendations, habits and/or technology is unclear.	**Behavioural determinants** Capability, opportunity, motivation. Collaboratively setting and reviewing meaningful goals is essential. Having a clear plan in place with the allowance of flexibility is important. Structured support to acquire skills through instructions, demonstration and practice.	**Goal setting and review (informed by F-words and 'Future hopes')** e.g., 1.1 'Goal setting (behaviour)'; 1.3 'Goal setting (outcomes)'; 1.5 'Review behavioural goal(s); 1.7 'Review outcome goal(s). **Gradually acquiring the skills and planning physio delivery** e.g., 1.4 'Action planning'; 5.1 'Information about health consequences'; 4.1 'Instruction on how to perform the behaviour'; 6.1 'Demonstration of the behaviour'; 8.1 'Behavioural practice/rehearsal'; 8.7 'Graded tasks'; 9.1 'Credible source'. **Develop routines and integrate physio into everyday life** e.g., 8.3 'Habit formation'; 8.6 'Generalisation of target behaviour'; 1.2 'Problem solving'.	**Standardised information materials for all users** Educational materials that all users can access. **Getting to know child and parents in their 'own words'** Completed F-words and identification of 'Future hopes' as the basis for collaborative goal setting. **Exercise recommendations** Linking tailored physio exercise recommendations with existing interests, focussing on participation. Having clear explanations of activities together with pictures and video demonstrations. **Supporting access to social support** Physio contact details and a structured resources page. **Notes page** Function to support self-monitoring and problem solving. **Glossary of terms**	Response to collaborative goal setting and physio recommendations: do they make sense; did the parent take part in setting them; are they meaningful to the parent, child and family? Acceptability of the structured process and engagement with intervention. Is the process meaningful? Increased awareness, understanding and perceived value of physio recommendations. Gaining skills and confidence to integrate physio within everyday life.	Engagement with physio recommendations on a regular basis (frequency not mandated to allow for flexibility). Understand meaning, purpose and role of physio recommendations. Evidence of working towards goals. Strengthening physical activity habits, problem solving and generalisation of behaviours. Evidence of basis for communication with physio. Specifying progress and learning. Evidence of integrating physio into everyday life and participation in meaningful activities, including those outside the hospital or home.	**Child with brain injury** Increased motor function of child with a traumatic brain injury. Accessing appropriate pre-school, school or employment opportunities. Engaging with previous, modified or new interests and passions. **Parent and family** Engagement with intervention. Reports of utility of the intervention. Growing self-reported confidence and self-efficacy. Working towards goals with child and family participating in life situations. Better 'self-management' of the child's health needs. Increased perceived capacity to cope with the situation and navigate daily challenges. Improved mental health and well-being (child, parent, family).
		Additional component Ability to track progress and receive feedback. Social support and communication with physio. Space for note taking and personal reflection.	**Additional component** **Monitoring progress and receiving feedback** e.g., 2.2 'Feedback on behaviour'; 2.3 'Self-monitoring behaviour'; 2.4 'Self-monitoring outcomes of behaviour'; 2.7 'Feedback on outcomes of behaviour'. **Social support** e.g., 3.1 & 3.2 'Social support' **Personal reflection** Notes page for parent.	**Additional component** Parent inputting information related to the delivery of physio exercises Summary reports on parent behaviour (adherence) and outcomes. Messages to strengthen motivation, capability, and behaviour change. Intervention: easy to activate, simple screen, user control over frequency of support.	**Additional component** Increased capability, opportunity, and motivation. Increased engagement with the intervention and physio recommendations.		

8.5.3 Prototype intervention development

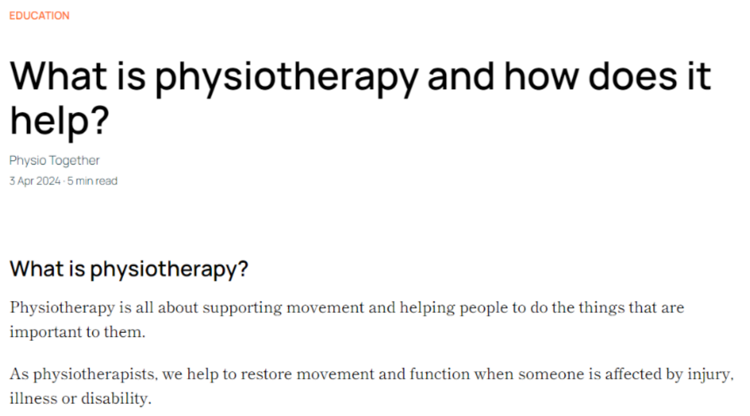
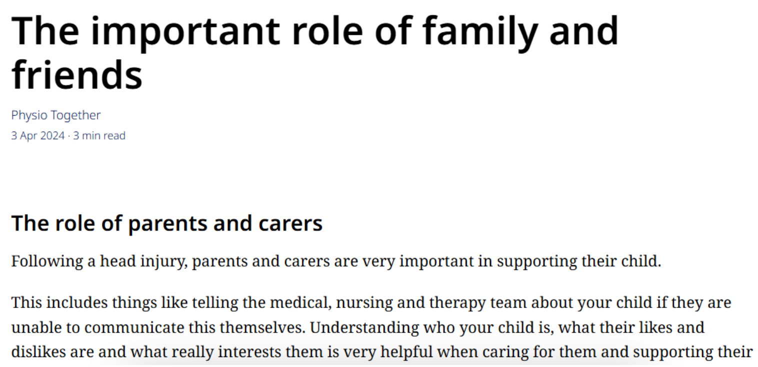
From the above detailed logic model, I worked collaboratively with the technology developers and public representative through a series of online meetings (January to March 2024) and email contact to develop the intervention prototype which is detailed below. During this collaborative working via multiple design discussions with the developers and public representative we decided to name the intervention 'Physio Together'. The name emphasises the need for collaborative working and the need for child with pTBI, their parent and the physiotherapist to work together to support parental adherence to delivering physiotherapy exercises.

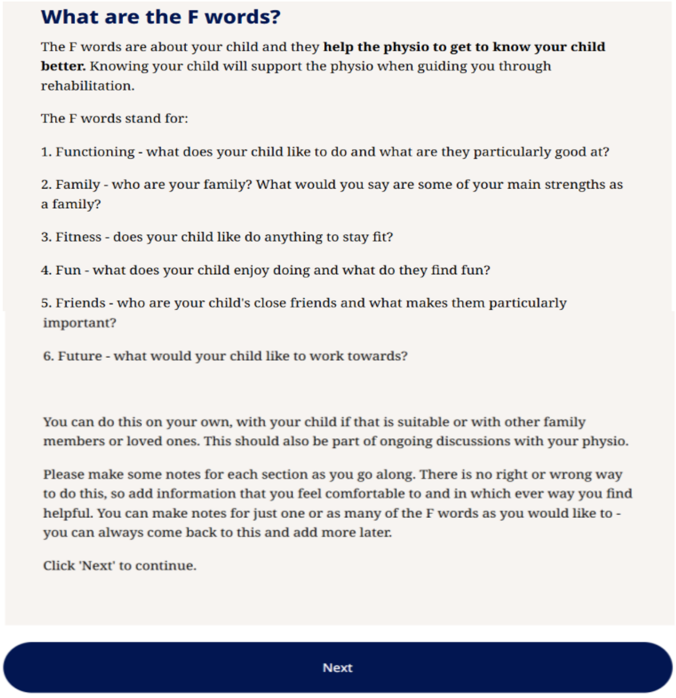
Insights from the co-design workshop (*Chapter 7*) particularly emphasised the need for parents, and CYP with pTBI, to express themselves in their 'own words' and for this to provide the basis for goal setting discussions. This family-centred approach enables the physiotherapist to provide exercise recommendations based on agreed goals which represent meaningful activities for a child related to their interests, passions and participation in life situations (Jenkin et al., 2022a, Drake et al., 2024). Collectively we agreed that without those involved working together, this process had the potential to lack meaning and may hinder a parents' ability to adhere to physiotherapy recommendations (Young and Gravett, 2025). Such was the mutual strength of feeling about this that the PPI representative and I co-authored an evidence-based reflective commentary for the Association of Paediatric Chartered Physiotherapists Journal entitled 'When is a goal not a goal?' (Young and Gravett, 2025). Please find a copy of the reflective commentary in Appendix 29.

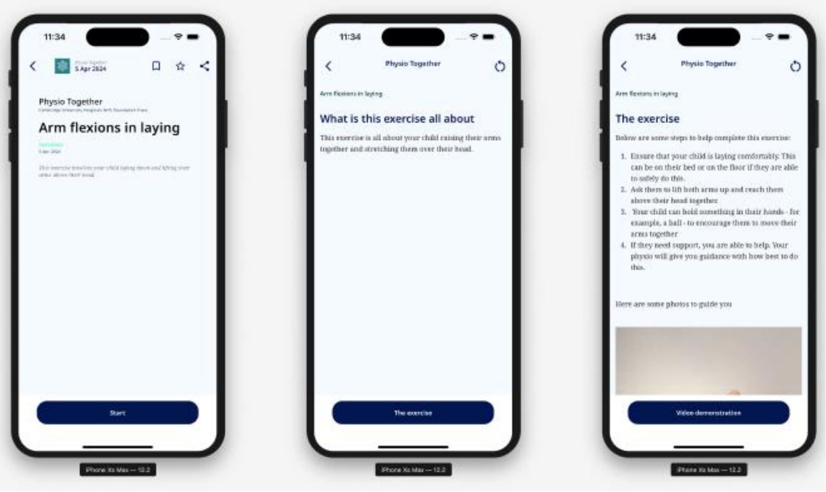
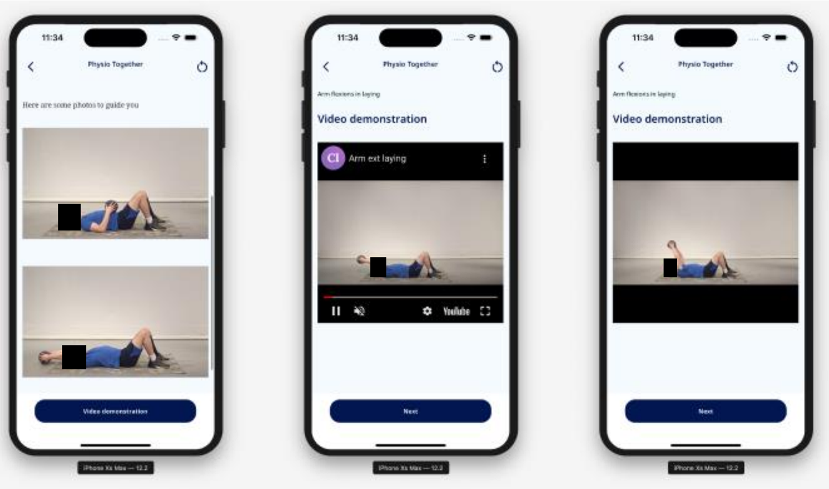
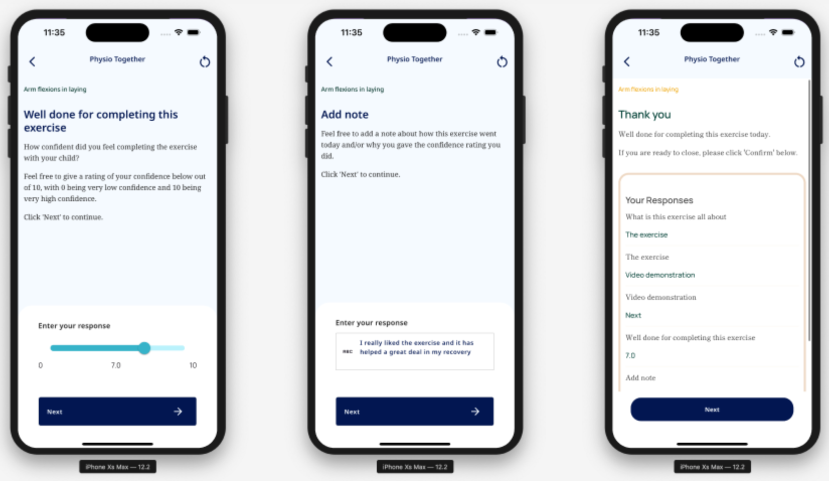
A comprehensive overview of the prototype intervention is presented in Table 8.3 below. I have included illustrative screenshots of different components and features of the intervention together with the associated behaviour change content. For larger versions of the illustrative exercise recommendations, please see Appendix 30.

Table 8.3 – The components and features of the intervention ‘Physio Together’: screenshots and associated behaviour change content

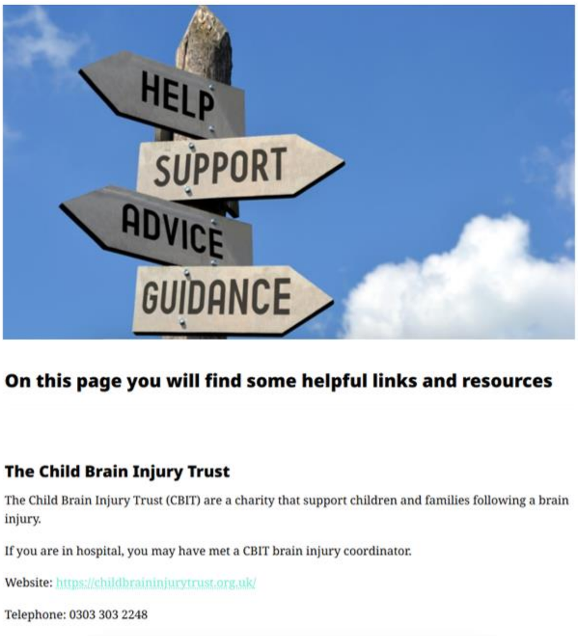
Intervention components and features with illustrative screenshots	**Associated behaviour change content, including intervention functions and behaviour change techniques**
Intervention front page	
Welcome to the digital behaviour change intervention ‘Physio Together’  	

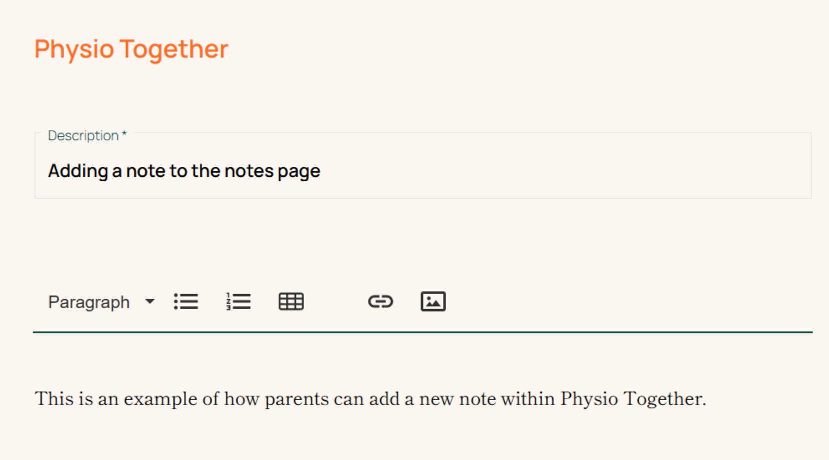
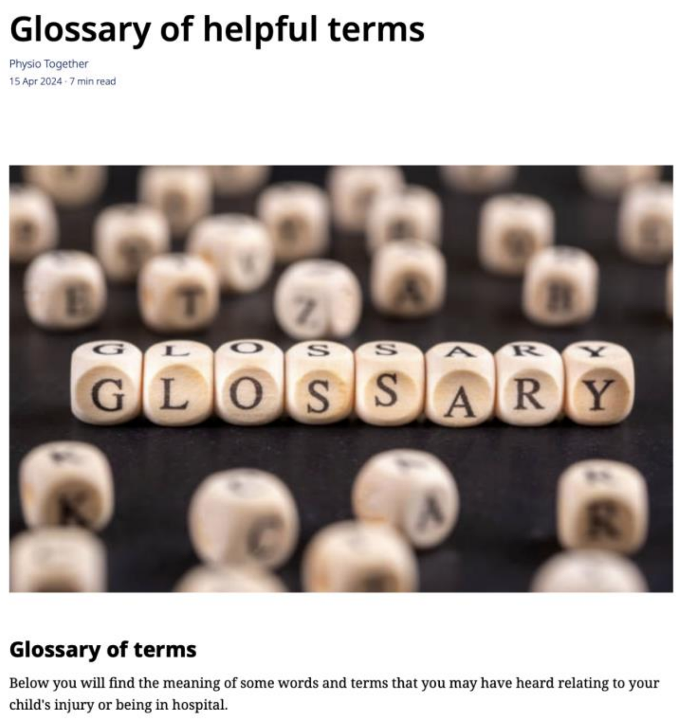
Standardised information and education materials for all users	
What is physio and how does it help?  EDUCATION What is physiotherapy and how does it help? Physio Together 3 Apr 2024 · 5 min read What is physiotherapy? Physiotherapy is all about supporting movement and helping people to do the things that are important to them. As physiotherapists, we help to restore movement and function when someone is affected by injury, illness or disability.	5.1 Information about health consequences [Education – C.M / Persuasion – M] 8.3 Habit formation [Training – C.O.M] 8.6 Generalisation of target behaviour [Enablement – C.O.M] 9.1 Credible source [Persuasion – M]
The important role of family and friends  The important role of family and friends Physio Together 3 Apr 2024 · 3 min read The role of parents and carers Following a head injury, parents and carers are very important in supporting their child. This includes things like telling the medical, nursing and therapy team about your child if they are unable to communicate this themselves. Understanding who your child is, what their likes and dislikes are and what really interests them is very helpful when caring for them and supporting their	5.3 Information about social and environmental consequences [Education – C,M / Persuasion - M]

Getting to know the child and parents in their 'own words'	
Gaining background information using the F-words of childhood development, including Future hopes (linking physiotherapy with interests)  **What are the F words?** The F words are about your child and they **help the physio to get to know your child better.** Knowing your child will support the physio when guiding you through rehabilitation. The F words stand for: 1. Functioning - what does your child like to do and what are they particularly good at? 2. Family - who are your family? What would you say are some of your main strengths as a family? 3. Fitness - does your child like do anything to stay fit? 4. Fun - what does your child enjoy doing and what do they find fun? 5. Friends - who are your child's close friends and what makes them particularly important? 6. Future - what would your child like to work towards? You can do this on your own, with your child if that is suitable or with other family members or loved ones. This should also be part of ongoing discussions with your physio. Please make some notes for each section as you go along. There is no right or wrong way to do this, so add information that you feel comfortable to and in which ever way you find helpful. You can make notes for just one or as many of the F words as you would like to - you can always come back to this and add more later. Click 'Next' to continue. Next	1.1 Goal setting (behaviour) [Enablement – C.O.M] 1.3 Goal setting (outcomes) [Enablement – C.O.M] 1.4 Action planning [Enablement – C.O.M] 1.5 Review behaviour goals(s) [Enablement – C.O.M] 1.7 Review outcome goal(s) [Enablement – C.O.M]

<table>
<tr><th colspan="2">Exercise recommendations from the physiotherapist</th></tr>
<tr><td>Exercise recommendations with written instructions plus picture or video examples to be checked off once completed. These also include the option to add a rating of confidence and/or comments

11:34
5 Apr 2024
Physio Together
Arm flexions in laying
Start
Physio Together
Arm flexions in laying
What is this exercise all about
This exercise is all about your child raising their arms together and stretching them over their head.
The exercise
Physio Together
Arm flexions in laying
The exercise
Below are some steps to help complete this exercise:
1. Ensure that your child is laying comfortably. This can be on their bed or on the floor if they are able to safely do this.
2. Ask them to lift both arms up and reach them above their head together.
3. Your child can hold something in their hands - for example, a ball - to encourage them to move their arms together
4. If they need support, you are able to help. Your physio will give you guidance with how best to do this.
Here are some photos to guide you
Video demonstration

Physio Together
Here are some photos to guide you
Video demonstration
Physio Together
Arm flexions in laying
Video demonstration
Arm ext laying
Next
Physio Together
Arm flexions in laying
Video demonstration
Next

11:35
Physio Together
Arm flexions in laying
Well done for completing this exercise
How confident did you feel completing the exercise with your child?
Feel free to give a rating of your confidence below out of 10, with 0 being very low confidence and 10 being very high confidence.
Click 'Next' to continue.
Enter your response
0 7.0 10
Next
Physio Together
Arm flexions in laying
Add note
Feel free to add a note about how this exercise went today and/or why you gave the confidence rating you did.
Click 'Next' to continue.
Enter your response
I really liked the exercise and it has helped a great deal in my recovery
Next
Physio Together
Arm flexions in laying
Thank you
Well done for completing this exercise today.
If you are ready to close, please click 'Confirm' below.
Your Responses
What is this exercise all about
The exercise
The exercise
Video demonstration
Video demonstration
Next
Well done for completing this exercise
7.0
Add note
Next</td>
<td>1.2 Problem solving [Enablement – C.O.M]
2.3 Self-monitoring of behaviour [Education C.M / Incentivisation – M / Training – C.O.M / Enablement – C.O.M]
2.4 Self-monitoring of outcome(s) of the behaviour [Education C.M / Incentivisation – M / Training – C.O.M / Enablement – C.O.M]

4.1 Instructions on how to perform the behaviour [Training – C.O.M]
5.1 Information about health consequences [Education – C.M / Persuasion – M]
6.1 Demonstration of the behaviour [Training – C.O.M / Modelling – O.M]
7.1 Prompts/cues [Education – C,M / Environmental Restructuring – O,M]
8.1 Behavioural practice/rehearsal [Training – C.O.M]
8.6 Generalisation of target behaviour [Enablement – C.O.M]
8.7 Graded tasks [Training C.O.M / Enablement – C.O.M]
9.1 Credible source [Persuasion – M]</td></tr>
</table>

Features to support access to social support	
Physiotherapist contact details  Contact Us For any queries relating to physiotherapy please contact the main switchboard on **01234 123456** or request that a member of staff contact the physio team on **bleep 4321**. **Physiotherapy team include** Physio Together	3.1 Social support (unspecified) [Enablement – C.O.M] 3.2 Social support (practical) [Enablement – C.O.M]
A resources page with helpful information and links to local and national organisations that may be able to offer support. For example, information about the Child Brain Injury Trust with contact details  **On this page you will find some helpful links and resources** **The Child Brain Injury Trust** The Child Brain Injury Trust (CBIT) are a charity that support children and families following a brain injury. If you are in hospital, you may have met a CBIT brain injury coordinator. Website: https://childbraininjurytrust.org.uk/ Telephone: 0303 303 2248	3.1 Social support (unspecified) [Enablement – C.O.M]

Notes page to aid self-monitoring and support problem solving	
Notes page, also termed diary, providing a flexible and relatively blank space for parents to add information in their own time. This includes the ability to add textual information, upload pictures, videos or links. This feature supports parents with self-monitoring of their behaviour and outcomes, the identification of problems and facilitate problem solving, and reflect and focus on past success  Physio Together Description * Adding a note to the notes page This is an example of how parents can add a new note within Physio Together.	1.2 Problem solving [Enablement – C.O.M] 2.3 Self-monitoring of behaviour [Education C.M / Incentivisation – M / Training – C.O.M / Enablement – C.O.M] 2.4 Self-monitoring of outcome(s) of the behaviour [Education C.M / Incentivisation – M / Training – C.O.M / Enablement – C.O.M] 15.3 Focus on past success [Persuasion – M / Enablement – C.O.M]
Glossary of terms to aid understanding of new medical terminologies	
Glossary of terms  Glossary of helpful terms Physio Together 15 Apr 2024 · 7 min read Glossary of terms Below you will find the meaning of some words and terms that you may have heard relating to your child's injury or being in hospital.	No specific behaviour change techniques or intervention functions associated with this feature, however it was an important feature identified within the co-design workshop.

Summary of included behaviour change content	
Summary of included behaviour change techniques within the intervention	1.1, 1.2, 1.3, 1.4, 1.5, 1.7, 2.2, 2.3, 2.4, 2.7, 3.1, 3.2, 4.1, 5.1, 5.3, 6.1, 7.1, 8.1, 8.3, 8.6, 8.7, 9.1, 15.3
Summary of included intervention functions within the intervention	Education, Persuasion, Incentivisation, Training, Modelling, Environmental Restructuring, Enablement

8.6 Discussion

This chapter has detailed the integration of user-centred design thinking with behavioural design to inform the development of the digital intervention 'Physio Together' for use by parents of CYP affected by pTBI (O'Cathain et al., 2010, Voorheis et al., 2022). Underpinning the design of the intervention is a detailed logic model.

The strength of this intervention is that a comprehensive understanding of the influences on parental behaviour (behavioural design) has been combined with user-centred co-design (design thinking). Consequently, Physio Together is an intervention designed to be acceptable and engaging for parents, whilst delivering evidence-based BCTs to increase adherence to delivering physiotherapy exercises through strengthening user capability, opportunity and motivation (Michie et al., 2011, Michie et al., 2014, West and Michie, 2016).

The ultimate goal of the intervention is for the injured CYP's functional skills to improve as a result of parent-delivered physiotherapy. The intervention will capture data such as the individual exercises which parents record that they have delivered, plus the frequency, intensity and duration of their delivery. The intervention will provide the basis for parents to self-monitor their own behaviour and record improvements that they identify in the child's motor function, for example, independence with mobility or progressing with complex balance exercises. This can be very motivating as it enables parents to monitor what they have delivered, how their child's motor function is changing and provides a basis for enhancing self-efficacy (Ley and Putz, 2024). In addition, other intervention features will encourage parents to reflect on the process of delivering exercises and enter a confidence rating which can be reviewed over time to see how confidence, and thus self-efficacy, has changed over time (Pinto et al., 2025).

The intervention Physio Together builds on the foundational understanding that parents experience severe emotional distress following their child's hospitalisation following pTBI, however they play a crucial role in delivering physiotherapy exercises to their child to support their recovery (Braga et al., 2005, Young et al., 2024a). The intervention has the potential to enhance parents' involvement in rehabilitation and ability to adhere to recommended physiotherapy exercises which aid their child's recovery. As it is a digital intervention, users will be able to access the Physio Together remotely through a range of different devices and in different contexts, including in the hospital setting, as early as the PICU or ward setting. For example, features such as the background information may help to provide parents with clear and easily understood information about the role of physiotherapy from an early stage in the rehabilitation journey and physiotherapists will initially introduce parents to the intervention.

The intervention utilises novel approaches to contextualising physiotherapy within the context of the child and family unit. The co-design workshop revealed that a priority for the intervention should be for physiotherapists to get to know the child and parents in their 'own words'. Through the integration of the F-words of child development as a core feature, parents will have the opportunity to provide background information about their child and family in their own words (Rosenbaum and Gorter, 2011, Jenkin et al., 2022a). This information then provides the basis and the context for other key intervention features to function: collaborative goal setting and the provision of recommended physiotherapy exercises. This is a different approach to that already used within digital interventions supporting physiotherapy via the intervention Physitrack™ and draws upon my understanding that motivation is a key element for influencing parents' adherence (Johnson et al., 2020). Additionally, the F-words provide a basis for connecting physiotherapy with existing interests. Keeping the child and their interests at the centre of the process means that recommended exercises relate to exiting interests and passions, and the exercises have a meaning. Without doing this, it may be that physiotherapy goals and exercises could feel somewhat arbitrary, or even counter to the priorities of the child and family (Young and Gravett, 2025).

Another feature which I would not have considered without the insights from the co-design workshop is the notes function. By design this is a flexible space for parents to access and utilise as they deem appropriate. The feature is designed to aid self-monitoring and the ability to track and celebrate progress. It has the potential to support parents by documenting physiotherapy input and meaningful outcomes that their child has achieved. It also has the potential to facilitate behaviour change through focussing on past success and enabling parents to keep track of examples of where they have succeeded in delivering physiotherapy to their child, and the outcomes that have been achieved. In addition to this, there is the potential for parents to use the notes function to support problem solving by documenting and analysing factors which influence their behaviour, then generate and document strategies to overcome barriers or increase facilitators to support their behaviour (Michie et al., 2014).

In this sense, there is an acknowledgement of the need for parents to gain new skills to support their child following pTBI and adapt to the new roles and responsibilities which are required (Tyerman et al., 2017, Brandt et al., 2022, Young and Gravett, 2025). Parents are highly likely to need to adopt a degree of dual parent and carer roles as their child will have a greater level of health and care needs following the pTBI (Farquhar, 2022, Patty et al., 2024). This change in roles is reflected in the intervention under section 'The important role of family and friends', subsection 'The role of parents of carers' (see Table 8.3 above). This section of the intervention acknowledges both the parent role and the carer role whilst providing specific information for those supporting a CYP following pTBI (Patty et al., 2024, Young et al., 2024a).

8.6.1 Reflecting on the intervention design process

The intervention design process as reported in this chapter has been complex and detailed, leading to the design of a prototype intervention whereby the active ingredients and behaviour change content are transparently laid out alongside the features. This means that future research can focus on user engagement, perceived acceptability and the effectiveness of the intervention, including the ability of specified features of the intervention to deliver BCTs and influence behaviour as proposed. Clear reporting on intervention content and the delivery of BCTs allows for greater understanding about how an intervention influences behaviour. Due to the well-defined theory- and evidence-base informing the intention, there is also greater potential for the intervention to be adapted and delivered within different contexts, widening the potential impact of Physio Together (O'Cathain et al., 2019, Skivington et al., 2021). For further discussion and reflection of the design process, please see section *9.4.4 Combining behaviour change and intervention co-design* which can be found within the general discussion below.

Chapter 9: General Discussion

9.1 A brief overview of this chapter

This final chapter will discuss the main findings of the studies reported in this thesis relating to their contributions to knowledge, their implications for research and for clinical practice. Consideration will be given to the overall strengths and limitations of this programme of research, and the chapter will close with some personal reflections and concluding remarks.

9.2 Overview of the thesis and research aims

This thesis describes the co-design of the theory- and evidence-based digital behaviour change intervention ‘Physio Together’ which has undergone development as a prototype. The intervention has been designed to support parents of CYP with pTBI to adhere to delivering recommended physiotherapy exercises.

The theory and evidence presented in the various chapters of this thesis informed the prototype intervention. Collectively the thesis chapters have addressed the following research aims:

- To identify the active ingredients of existing interventions designed to support parents to deliver rehabilitation exercises aimed at improving motor function of their child following a pTBI.
- To explore first-hand experiences of delivering physiotherapy exercises and identify factors which influence parental adherence to the delivery of recommended physiotherapy, from the perspective of parents and physiotherapists.
- To specify the conceptual design of a theory- and evidence-based intervention utilising Behaviour Change Wheel guidance.
- To develop a detailed understanding of user requirements for the intervention, then co-design a prototype digital intervention.

The above research aims have been addressed as follows. Initially, the active ingredients of existing interventions designed to support parents to deliver rehabilitation exercises following pTBI were identified using a systematic review (*Chapter 2*). Two qualitative studies were conducted, involving one-to-one interviews with parents and focus groups with physiotherapists (*Chapter 4* and *Chapter 5*, respectively). These studies explored participants' first-hand experiences and identified underlying behavioural influences on parental adherence to delivering physiotherapy exercises.

The key findings from these chapters were mapped against the COM-B model to inform the behavioural diagnosis, followed by a detailed conceptual design of the intervention which included BCTs and intervention functions (*Chapter 6*). A subsequent co-design study involved a workshop with parents and physiotherapists, and other key stakeholders, to identify key user-centred features to increase acceptability and engagement with the intervention (*Chapter 7*). Finally, the findings of the co-design study were triangulated against the conceptual design, which informed the design of the prototype digital behaviour change intervention 'Physio Together' (*Chapter 8*).

9.3 Contributions to knowledge

Across the chapters of this thesis, the various studies have contributed to knowledge in a range of different ways through key findings. These will be discussed in detail within the following sub-sections, but can be summarised into four main areas as follows:

1. The importance of getting to know the child and family on an individual basis and making individualised recommendations about physiotherapy.
2. It is vitally important for physiotherapists to consider the emotional toll of pTBI on parents and the role that physiotherapy, and physiotherapists, can play in supporting parents following their child's pTBI.
3. It is important to consider not only the initiation of behaviour but also the need to maintain behaviour over time. The integration of physiotherapy into everyday life and aligning physiotherapy with current and evolving interests are important influences of the maintenance of behaviour.
4. Combing an in-depth understanding of influences on parental adherence together with user-centred design has been invaluable in informing the design of the intervention 'Physio Together'. Co-designing the intervention with target end-users and other key stakeholders offered valuable insights alongside the in-depth understanding of parental adherence.

9.3.1 Getting to know the child and family

The findings of the *Chapter 2: Systematic review* revealed that goal setting and supporting the delivery of physiotherapy exercises are key aspects of physiotherapy practice and components of existing interventions following pTBI (Braga et al., 2005, Young et al., 2024a). The qualitative and co-design studies presented in this thesis have highlighted that goal setting alone is not sufficient. Physiotherapy goals may not be considered relevant or meaningful to the child and parent, or may reflect health professional priorities as opposed to the CYP's and family's priorities (Young and Gravett, 2025). Instead, it is important to get to know the CYP, parent and family, then work collaboratively to ensure that goal setting and physiotherapy are collaborative endeavours which support therapy to be embedded into everyday life activities (Tipping et al., 2010, Pritchard-Wiart et al., 2019, Dunford et al., 2020, Melin et al., 2021, Harniess et al., 2022, Jenkin et al., 2022a).

Physiotherapists who participated in *Chapter 5: Qualitative study involving physiotherapy focus groups* spoke of the importance of asking what the child likes to do for fun, then building physiotherapy around their interests. Likewise, making physiotherapy fun, engaging children and young people with pTBI in enjoyable and meaningful activities and seeing physiotherapy as 'a family affair' were key elements of the final theme within the *Chapter 4: Qualitative study involving parent interviews*. These findings were further reiterated in *Chapter 7: Developing a detailed understanding of user requirements for the intervention*. Here parents and physiotherapists agreed upon collaborative working and use of the F-words of child development playing an important role within the digital intervention to help inform goal setting and contextualise physiotherapy within a family unit (Jenkin et al., 2022a). Such an approach is proposed to help to structure physiotherapy activities and exercise recommendations around the interests and goals of the child in a more holistic way (Young and Gravett, 2025).

These are new insights in the context of this target group. Although the F-words have been used to support rehabilitation and goal setting with a view to motivating and engaging children in rehabilitation, to date this has primarily focussed on cerebral palsy and childhood disability more broadly (Bayon et al., 2018, Soper et al., 2019). The integration of the F-words within the digital intervention 'Physio Together' demonstrates that such an approach is not only applicable to pTBI but may have an important role to play in physiotherapy from as early as the acute hospital setting. This also begins to address the identified evidence gap in the development of a holistic understanding of the child and family in paediatric rehabilitation following brain injury, as identified by Jenkin and colleagues (Jenkin et al., 2022b).

This new evidence underscores the importance of goal setting in rehabilitation, reflecting the collaborative process between the physiotherapist, the CYP with pTBI and their parent. This involves establishing a mutual basis and understanding of what is most meaningful to the individual, then supporting them to express their desired future state and how physiotherapy can support them to get there (Melin et al., 2021). Collaborative and holistic goals which link directly to the recommended physiotherapy exercises are likely to lead to improved clinical outcomes through increased engagement in rehabilitation across different settings (Swann et al., 2023). A recent consensus study has shown that parental involvement in truly collaborative goal setting and rehabilitation focussing on child participation are important to physiotherapists and rehabilitation professionals alike, as it has relevance across the rehabilitation pathway (Gmelig Meyling et al., 2023b).

It is therefore of utmost importance that physiotherapists be trained in the application of collaborative goal setting practices and using the F-words of child development at all stages of rehabilitation (Young and Gravett, 2025). There is great potential for this approach to influence parental behaviour change in a positive direction through increasing parental motivation via holistic goal setting and review (‘Reflective motivation’), and by structuring physiotherapy around existing interests and what the child finds fun (‘Automatic motivation’). Such an approach also helps to structure information about the health consequences of physiotherapy by linking collaborative goals with personalised recommendations (‘Psychological capability’).

9.3.2 Considering the emotional needs of parents

A second key finding is the importance of physiotherapists considering the emotional toll of pTBI on parents and seeking to support their emotional needs. This was particularly evident within the qualitative studies: parents initially encountered physiotherapists within acute hospital settings following their child’s pTBI when they were at a heightened and intense emotional state (Brown et al., 2013). Both parents and physiotherapists expressed that the initial encounters and inter-personal interactions were important for establishing rapport and relationship which developed during rehabilitation (English et al., 2022, Jenkin et al., 2022b).

During *Chapter 4: Qualitative study involving parent interviews*, parents eloquently described their experience of shock and fear related to attending hospital following their child’s pTBI. These experiences were said to continue when commencing physiotherapy and when parents themselves were becoming involved in physiotherapy delivery. Likewise, during *Chapter 5: Qualitative study involving physiotherapy focus groups*, physiotherapists spoke about gradually involving parents in physiotherapy and training them by increasing their physical and psychological skills to support their child in a graded way (Tipping et al., 2010). It is evident that this is a very flexible process which must be based around the needs of the parent as they gain new and additional skills as an informal carer for their injured child (Brandt et al., 2022).

These in-depth findings related to parents' initial emotional needs were not reflected in the findings presented in *Chapter 2: Systematic review*. This may be due to the interventions identified by the systematic review being based in primarily outpatient or community settings delivered months after the pTBI itself, and not considering the initial emotional response of parents (Young et al., 2024a). Through collecting and analysing data which considered parents' initial response to their child's pTBI and their involvement in physiotherapy on PICU and in the acute hospital setting, I generated new knowledge which contributes to the existing evidence base. It is evident that physiotherapists play an active role in supporting parents in this initial stage following their child's pTBI and provided parents with a purpose and a means by which to support their child in a proactive and purposeful way (Hobfoll et al., 2007).

Similarly, physiotherapists reflected upon their experiences and identified that they proactively sought opportunities to involve parents and enable them to help their child. This involvement is an extremely important starting point, following on from rapport building, emotional support and coming to understand the context of the family when delivering physiotherapy (Rosenbaum and Gorter, 2011).

The parent interview study additionally demonstrated that emotional needs are not limited to the initial period following the pTBI. Similar needs continued over time and ongoing social support was required from physiotherapists as parents returned home and sought to integrate physiotherapy into daily life. These findings are reflected in Physio Together as it includes educational materials about the role of physiotherapy and the role of parents in supporting their child's rehabilitation through physiotherapy. The intervention also includes a resources page with links to regional and national organisations where additional social support can be sought.

These findings are important as they highlight that physiotherapists require educational provision to better understanding the crucial role that they can play in helping to meet the emotional needs of parents following pTBI. Training contextualised within the Hobfoll five essential needs of humans following trauma may be valuable in helping physiotherapists to understand the role they play through providing safety, calm, connection, self-efficacy and hope (Hobfoll et al., 2007). In addition, this could help to inform clinical practice through training physiotherapists in structuring conversations and looking to make physiotherapy as collaborative as possible with injured CYP and their parents (Melin et al., 2021, Jenkin et al., 2022a).

9.3.3 Supporting behaviour change over time

A third key finding from the research is the need to influence behaviour change (parental delivery of physiotherapy exercises) over the longer term. It was evident from *Chapter 2: Systematic review* that a number of active ingredients commonly included in existing interventions are vital in influencing the initiation of behaviour, for example goal setting, instruction, demonstration and practice (Young et al., 2024a). The additional evidence gathered across the qualitative and co-design studies highlights the role of influences such as habit formation, focussing on past success and generalisation of the target behaviour to support the maintenance of behaviour change. Novel behaviours require conscious processing and planning when initially enacted (Gardner et al., 2023). Following familiarisation with the behaviour, repetition and the formation of habits, the behaviours can shift from being enacted primarily through 'Reflective motivation' towards 'Automatic motivation' requiring less cognitive effort (Hankonen, 2021, Gardner et al., 2023).

Using their own words and means of expression, both parents and physiotherapists spoke about physiotherapy exercises not being limited to a single context or environment. An important finding is that physiotherapy moves beyond a parent delivering a pre-specified set of physiotherapy exercises to their child at a pre-determined and agreed time, to a much broader application of physiotherapy within the context of daily life. A theme of *Chapter 4: Qualitative study involving parent interviews* is 'learning how to integrate physiotherapy into everyday life'. This theme speaks to the need for parents to gradually learn and adapt to the varying challenges of daily life following pTBI and the role that physiotherapy plays in supporting families to navigate these challenges. Similarly, a theme from *Chapter 5: Qualitative study involving physiotherapy focus groups* is 'supporting parents to adapt to life following pTBI'. These findings are important because they emphasise the need for parents to actively engage in physiotherapy within the context of daily life, focusing the proactive aspect of parental adherence as opposed to mere compliance with physiotherapy recommendations (Mir, 2023). In keeping with this, there is potential for parents to become experts of their child's needs and, with support, become proficient in self-management and problem solving through daily life challenges (Wong Chung et al., 2021, National Institute for Health and Care Excellence, 2023b).

The insights from this doctoral research reaffirm the need for physiotherapy to be approached in a holistic way around the strengths and needs of individual families to best support parental adherence and recovery trajectories of the injured CYP (Schwellnus et al., 2020). The concept of participation, defined as one's 'involvement in life situations' is of particular importance when considering physiotherapy following pTBI (World Health Organization, 2001). Whilst full participation in daily life situations may be challenging within a hospital or specialist rehabilitation setting, this remains an important focus throughout the rehabilitation pathway (Gmelig Meyling et al., 2023a). Again, the F-words of childhood development offer a holistic and accessible way to consider the family context and provide a consistent framework for contextualising and informing physiotherapy, particularly when considering a child and family's future hopes and their future participation in life situations (Rosenbaum and Gorter, 2011, Young and Gravett, 2025). It is proposed that utilising the F-words of child development as a core feature within Physio Together will help in focusing on the child and family in a holistic way across the rehabilitation pathway and support parental adherence over time (Novak-Pavlic et al., 2023).

9.3.4 Combining behaviour change and intervention co-design

A final key finding are the novel insights which have been gained through in-depth consideration of parental adherence and co-designing the intervention with parents, physiotherapists and other key stakeholders.

The prototype digital behaviour change intervention 'Physio Together' exists within a complex intersection of physiotherapy as part of post-traumatic rehabilitation, behavioural science and technology design (Graham et al., 2021, Lievesley et al., 2022, Voorheis et al., 2022). Therefore, alongside a comprehensive and detailed understanding of influences upon parents' adherence to delivering physiotherapy exercises, co-designing the intervention with target end-users and other key stakeholders has provided additional insights and value to the design process (Robert et al., 2021). My research represents a far more detailed and comprehensive approach to intervention design than what is currently available within clinical practice (Johnson et al., 2020, Young et al., 2024a). For example, Johnson and colleagues identified that use of the online exercise prescription platform is Physitrack™ was no more effective at supporting adherence to a home exercise programme than conventional paper-based methods for exercise prescription (Johnson et al., 2020). The authors proposed that using a behaviour change approach incorporating theory and evidence offered a new and potentially efficacious approach to intervention design. My research has addressed this evidence gap.

I have utilised a range of novel approaches within paediatric physiotherapy to identify behavioural influences on parental adherence, and integrated the views and insights of parents and physiotherapists through creative approaches and co-design (Michie et al., 2014, Bird et al., 2021). These creative approaches supported participant engagement and offered participants accessibility to innovation and the design process by focussing first and foremost on the challenges and difficulties that they currently face (Hollanders and van Cruysen, 2009, Bird et al., 2021).

The findings have particularly highlighted that it is crucial to understand the family environment and the child prior to the head injury. Subsequently, associating recommended physiotherapy exercises with existing, or indeed new, interests, together with providing clear individualised explanations of the benefits of each given exercise (Young and Gravett, 2025). These have been important insights from the research which were only generated by following the complex intervention development guidance (Craig et al., 2008) and co-designing the intervention with users and other key stakeholders (Skivington et al., 2021). The co-design workshop focussed a great deal on the need to understand the child and family in their 'own words' and the utilisation of the F-words of child development as an evidence-based tool to support this reflecting these important priorities.

It has also been beneficial to involve the technology developers as group facilitators throughout the co-design workshop and design process. This allowed them to have first-hand insights into what actually happens for parents and physiotherapists (NHS Digital, 2021). These valuable insights fed into the intervention design process with the aim of increasing the usability and acceptability of the intervention for both the end-users of the intervention and other key stakeholders (NHS Digital, 2021). Future research needs to include user testing and feedback to inform the refinement of 'Physio Together', whilst further developing key features of the intervention such as goal setting and feedback (Basu et al., 2017).

9.4 Implications for research

There are a range of implications for research which come from this thesis. These include the robust and transparent development of physiotherapy interventions based on theory and evidence, the ongoing development and refinement of 'Physio Together', and the use of technology as a means for recruiting and conducting research. These will be considered further below.

9.4.1 Use of the Behaviour Change Wheel to guide intervention development

A known limitation of many interventions for healthcare is the lack of transparency related to what they include and how they are proposed to work (Michie et al., 2011, Young et al., 2024a). This results in a limited ability to evaluate the effectiveness of interventions, adapt and replicate them in different contexts (Skivington et al., 2021). Moreover, there may be limited prospects to gain insights into how users engage with the intervention or perceive its acceptability (Davis, 1985, Wade et al., 2020). It is recommended that complex interventions are based on theory and evidence (O'Cathain et al., 2019).

The Behaviour Change Wheel provides a detailed framework for intervention development, offering clinicians, researchers and developers a step-by-step guide (Michie et al., 2014). *Chapter 6: The conceptual design of the intervention* provides a fully detailed and specified example of how BCW can be utilised in relation to physiotherapy intervention development (Michie et al., 2014). I have also demonstrated how the COM-B model can be successfully utilised as the central framework to organise and synthesise different sources of evidence when developing an intervention (Michie et al., 2011).

It is recommended that clinicians, researchers and intervention developers utilise the COM-B model and BCW when developing interventions in the future to provide a theoretical basis for intervention development and evaluation. Moreover, it is also recommended that combining behavioural design with design thinking can enhance the usability and acceptability of new interventions when co-designed together with intervention users and key stakeholders (Voorheis et al., 2022).

Careful development of behaviour change interventions provides a rigorous basis for feasibility testing by informing process measures and understanding causal mechanisms, plus assessing the impact of contextual influences which have been identified (Skivington et al., 2021, Pinto et al., 2025). Then going beyond feasibility testing, assessments of the interventions efficacy within the context of a randomised controlled trial can be combined with economic evaluation and cost-effectiveness analysis prior to seeking to implement the intervention into everyday practice (Blatch-Jones et al., 2018, Perski and Short, 2021, Pinto et al., 2025).

9.4.2 Refining the intervention through user-testing and feedback

Having undergone the initial stage of development of ‘Physio Together’ as a prototype digital behaviour change intervention, future research should seek to refine the intervention through rounds of user-testing and feedback with parents and physiotherapists. In this sense, adopting an agile approach to iterative software development and refinement as recommended (West and Michie, 2016).

To this end, the application of a model such as the Technology Acceptance Model can be helpful in informing the refinement of interventions. The Technology Acceptance Model considers users’ perceived usefulness and perceived ease of use as being key determinants of their acceptance, and therefore use, of technology (Davis, 1985, Perski and Short, 2021). Such a model could provide the basis for undertaking rounds or user-testing and feedback with the aim of iteratively refining the intervention in preparation for a future feasibility study (Craig et al., 2008, Basu et al., 2017, Drehlich et al., 2020, Creaser et al., 2022).

Future research should also seek to better understand the experiences and perspectives amongst parents who are non-English speaking and represent a diversity of perspectives not captured within this research. Although I went to great lengths to include non-English speaking parents within *Chapter 4: Qualitative study involving parent interviews*, only fluent English speakers were recruited. Those conducting future research in this area are recommended to consult with diverse communities and community leaders and follow best practice recommendations about how best to engage parents from diverse backgrounds in research (Ray Chaudhuri et al., 2023, Health Research Authority, 2025). Integrating additional important insights from a diverse range of perspectives will be important when refining the intervention to ensure that it is accessible to a diverse range of users (National Health Service, 2019). There should also be consideration given to creating an online community of parents using ‘Physio Together’.

Future research should additionally seek the views of physiotherapists working in different clinical contexts such as acute hospital care, specialist rehabilitation and community settings to further explore the potential utility of the intervention across the rehabilitation pathway. In doing so, Skivington and colleagues emphasise the importance of updating the logic model upon which an intervention is based as new evidence us generated and incorporated (Skivington et al., 2021).

9.4.3 Technology to support online recruitment and conduct of remote interviews, focus groups and a co-design workshop

The Covid-19 pandemic forced researchers to review methods of recruitment and data collection then swiftly adopt remote methodologies (Keen et al., 2022). I commenced my doctoral research in July 2021 which coincided with periods of increased or decreased restrictions on human interaction and social distancing. I conducted all aspects of participant recruitment and data collection remotely including parent interviews, physiotherapy focus groups and the co-design study. Alongside adhering to the national and university guidance on remote working and social distancing, I also worked closely with the PPI group supporting my doctoral research that advised remote data collection due to existing pressures on parents of CYP with pTBI.

The use of technology and remote data collection impacted positively upon my research by supporting recruitment across a wide geography spanning the UK and Northern Ireland (Carter et al., 2021). The same is true for participant recruitment for physiotherapy focus groups which also minimised the impact and disruption to work commitments, as focus groups were conducted remotely.

It must be acknowledged that I put considerable thought and planning into designing studies which facilitated the establishment of rapport with participants when conducting online as opposed to face-to-face data collection (Bukamal, 2022, Keen et al., 2022). In addition, considerable time and effort also went into preparing research protocols which directly addressed dealing with participants' heightened emotion and distress, adverse events and the disclosure of sensitive information during data collection (Carter et al., 2021). In the interests of completeness, I encountered no adverse events during data collection for any of the studies, and participants experienced heightened emotions which were in keeping with the subject matter and research topic. Moreover, participants were provided time to debrief following data collection and were signposted through the participant information sheets and verbally to appropriate support such as the Child Brain Injury Trust counselling service (Carter et al., 2021, Child Brain Injury Trust, 2025).

There is potential for bias in the findings as participants were only recruited digitally and took part in research conducted remotely (Keen et al., 2022). The findings may mainly reflect the perspectives of participants who are already familiar with digital technology and its utilisation, meaning that the perspectives of those with lower digital literacy are reflected less well (Digital Poverty Alliance, 2026). The bias towards a digital intervention could have steered the findings towards digital solutions, whereas not all future users of the intervention will be familiar with technology, potentially reinforcing digital exclusion (Digital Poverty Alliance, 2026). Future research should seek to recruit a more diverse range of participants to explore their first-hand experiences and contribute to intervention development.

Overall, online recruitment and the use of remote data collection have been extremely successful, and it is recommended that these approaches are at least considered as viable alternatives to face-to-face qualitative date collection and co-design in the future.

9.5 Implications for clinical practice

My research has a range of implications for clinical practice. These implications include supporting the initial interactions between parents and physiotherapists to enhance social support, and potential implications for a more diverse range of patient populations beyond pTBI. These will be considered below.

9.5.1 Initial interactions with parents following their child's traumatic brain injury

Participants in *Chapter 4: Qualitative study involving parent interviews* and *Chapter 5: Qualitative study involving physiotherapy focus groups* identified that the initial interactions between parents and physiotherapists were important in laying the foundations for parental adherence to delivering physiotherapy. During the initial interactions, physiotherapists gave explanations about physiotherapy and its role within the recovery of the CYP following pTBI (Tipping et al., 2010). This was also an opportunity for physiotherapists to provide parents with reassurance about the initiation of physiotherapy and to set the scene for parental involvement in delivering physiotherapy themselves (Harniess et al., 2022).

Parents are in an emotionally traumatised state following their child's admission to hospital with pTBI (Brown et al., 2013, Kirk et al., 2014), therefore physiotherapists need to sensitively and compassionately tailor their communication to each parent individually. Participants in *Chapter 5: Qualitative study involving physiotherapy focus groups* described their flexible approaches to communicating with parents and the importance of not overwhelming them further (Tipping et al., 2010). An important implication for clinical practice is that more training and education should be provided for physiotherapists to confidently and consistently approach these initial interactions and discussions: in my experience such specialist training and education are not currently standard practice for physiotherapists. Further support should also be established to help physiotherapists determine suitable opportunities to introduce parents to their new role in supporting their child's rehabilitation through physiotherapy. Likewise, consideration needs to be given to how and when they approach the important topic of parental adherence to physiotherapy delivery, and how such discussions are revisited across the rehabilitation pathway following the pTBI (Keetley et al., 2021).

This relates closely to supporting physiotherapists to know when and how to introduce an intervention such as 'Physio Together' to a parent. In this sense, physiotherapists have been described as 'gatekeepers' in healthcare settings who control and guide parents' access to available knowledge, resources and services (Collyer et al., 2017, Drake et al., 2024). Throughout the thesis it has been identified that the intervention 'Physio Together' is designed to exist alongside an existing pathway of care, supporting important elements of inter-personal interaction and communication, as opposed to replacing them.

In this sense, the digital intervention ‘Physio Together’ may better be described as a resource which offers greater support to parents than is currently offered, and which can be used by physiotherapists, parents and CYP with pTBI. The intervention itself could be a broadened out to include not only the resource ‘Physio Together’, but also how physiotherapists introduce ‘Physio Together’ in clinical practice and encourage its utilisation by parents. The co-production of these other intervention components will require greater exploration within post-doctoral research. Therefore, establishing when and how ‘Physio Together’ is most effectively integrated and utilised within healthcare will be an important ongoing consideration within clinical practice (Clark et al., 2020).

Moreover, considerations around the initial uptake and ongoing implementation of innovations by physiotherapists within routine clinical practice are key considerations for clinical practice and implementation research moving forward (Hassett and Wolfenden, 2022).

9.5.2 Getting to know the child and family in their own words

Across the qualitative and co-design studies (*Chapters 4, 5 and 7, respectively*) there has been a focus on getting to know the child and family in their ‘own words’. This has important implications for clinical practice.

In the first instance, that taking the time to get to know someone on an individual basis and connecting as human beings is an important element of establishing rapport and trust with patients and families (English et al., 2022). When considering parent delivered physiotherapy more specifically, I propose that getting to know a child and family in their own words can provide reciprocal benefits for parents and physiotherapists alike. It can support physiotherapists to actively listen to the needs and important priorities of parents, which is an important aspect of developing a therapeutic relationship (Jenkin et al., 2022b). It can support collaborative and agreed goal setting and concurrently consider the bigger picture through longer-term goals that children and families may identify, whilst also considering the shorter-term goals which can change and adapt over time (Jenkin et al., 2022a, Young and Gravett, 2025).

An important implication from my research is that the F-words of child development provides an established, holistic and evidence-based way to get to know the child and family in their own words (Rosenbaum and Gorter, 2011). Moreover, I propose that the F-words of child development can be utilised as early as the PICU and acute hospital setting, and then offer continuity throughout the rehabilitation pathway (Rosenbaum and Gorter, 2011, Soper et al., 2019, Rosenbaum, 2022, Young et al., 2024b, Young and Gravett, 2025). The standardised implementation of the F-words of child development within rehabilitation services across the continuum of care is an important implication for clinical practice (Young et al., 2024b). This includes, but is not limited to, its important role within the 'Physio Together' intervention, as well as beyond the intervention.

9.5.3 Implication for paediatric rehabilitation beyond paediatric traumatic brain injury

The focus of this thesis and intervention development has been within pTBI sustained following a physical trauma. That said, new knowledge and insights regarding influences on parental adherence to delivering physiotherapy across a range of contexts have been provided. These could have important implications for family-centred rehabilitation services more broadly, given the importance of involving parents and supporting family-centred services are considered best practice across acquired brain injury, pTBI, cerebral palsy and childhood disability alike (Lord et al., 2018, Wong Chung et al., 2021, Jenkin et al., 2022b, Gmelig Meyling et al., 2023b, Novak-Pavlic et al., 2023, Young et al., 2024a, Young et al., 2024b, Young and Gravett, 2025).

Moving forwards, consideration will be needed with regards to the maintenance, roll out, scalability and sustainability of 'Physio Together'. These are well known considerations and potential challenges facing all digital health innovations whereby adherence to policy guidelines and regulations are essential alongside developing robust financing arrangements (LeFevre et al., 2021, Ebenso et al., 2025, World Health Organization, 2026). Potential funding opportunities in the short- to medium-term may include research grants to support initial refinement, user-testing and iterative development of the intervention (World Health Organization, 2026). Following this, exploration of commissioning options to help ensure the maintenance and sustainability of 'Physio Together' will be key to supporting the long-term success of the intervention (National Health Service, 2019, LeFevre et al., 2021, Ebenso et al., 2025).

9.6 Strengths and limitation of the research

The strengths and limitations pertinent to each study have been addressed within the individual chapters. Within this section, the overall strengths and limitations of the body of research will be summarised.

9.6.1 Strengths

The key strengths of my research relate to the robust and consistent application of behaviour change theory and frameworks throughout the various studies that were conducted. Unlike other interventions such as Physitrack™ which support parent-delivered physiotherapy following pTBI, my intervention is based on a theoretical underpinning of behaviour with a comprehensive consideration of influences upon adherence (Michie et al., 2011, Johnson et al., 2020).

Related to this, another strength is the combined use of the BCW and MRC complex intervention framework to develop a theory- and evidence-based intervention (Sinnott et al., 2015, O'Cathain et al., 2019, Ojo et al., 2019). As a result of this detailed and transparent process, I have detailed each stage of the conceptual design according to the BCW together with supporting evidence. I have been able to develop a fully specified intervention whereby each component of 'Physio Together' includes a comprehensive summary of the purpose of that component in relation to supporting parental adherence, including the relevant BCTs and intervention functions included within it. Consequently, there is a very clear rationale behind how the intervention, including its component parts, is proposed to work, and there is greater potential for evaluation, transferability and replication of the intervention into different settings (Skivington et al., 2021).

As part of this process, I utilised the COM-B model to map the behavioural influences on parental adherence within the systematic review and qualitative studies (*Chapters 2, 4 and 5, respectively*). I have successfully utilised the COM-B model to triangulate the findings from the different sources of evidence feeding into the behavioural diagnosis and conceptual design of the intervention (Michie et al., 2014). Alongside this, I have also developed a detailed logic model summarising how the intervention is proposed to work, which can be reviewed and updated as additional evidence is integrated into the design of the intervention (West and Michie, 2016, Skivington et al., 2021).

Another strength has been the combined use of inductive and deductive qualitative analysis to generate new evidence related to participant experience and their collective construction of reality, together with exploring underlying influences of behaviour (Alderson, 2021). The rigorous application of reflective thematic analysis enabled me to address different research objectives within the qualitative studies. These contributed new evidence to the limited evidence base which is parental adherence to delivering physiotherapy exercises following pTBI (Braun and Clarke, 2022).

A further strength of my research is the important role that co-design with parents, physiotherapists and other key stakeholders has played in intervention design. This has meant that a wide range of perspectives and experiences fed into the design of the intervention, utilising innovative and creative approaches to do this (Sanders and Stappers, 2008, Hollanders and van Cruysen, 2009, Bird et al., 2021, Robert et al., 2021, THIS Institute, 2022). My research represents an example of proactively seeking to empower parents and engage physiotherapists in an attempt to make a positive change to the health service, namely parent delivered physiotherapy. This is an approach consistent with recommendations from the recent Darzi report on the current state of the NHS (Department of Health and Social Care, 2024).

A final strength is the vital role that committed and passionate members of the PPI group have played in this research. Members of the group consistently informed and guided the research through the different studies and have been crucial in informing the development of the intervention itself. The highly valued role of the PPI group is epitomised by the fact that one parent co-facilitated the co-design workshops.

9.6.2 Limitations

There are also several limitations to acknowledge and consider. One limitation relates to participant recruitment within the qualitative studies. Considerable efforts were made in *Chapter 4: Qualitative study involving parent interviews* which respected and welcomed the value of cultural diversity and the recruitment of participants who were non-English speaking, or unable to communicate fluently in English (Squires et al., 2023). Whilst this was the case, only fluent English speakers were recruited for the study. This meant that only the experiences of native English speakers or those with a high command of the English language were considered within the analysis and ultimately contributed to the design of the digital intervention (Squires et al., 2023).

Additionally, within *Chapter 5: Qualitative study involving physiotherapy focus groups* the vast majority of participants were based in acute NHS hospitals with many of those working in regional major trauma centres. Whilst the data reflected considerable expertise related to the acute management of CYP following pTBI and supporting parents to adhere to delivering physiotherapy, participants provided fewer community-based perspectives (Jenkin et al., 2022b). Likewise, physiotherapists working in private practice or the third sector charitable organisations were not represented. This is a limitation as the findings may reflect the acute phases of care as opposed to including a more diverse range of perspectives.

Within digital intervention development, there is growing emphasis on importance of adopting user-centred design and incorporating lived experience perspectives throughout the design process (Morton et al., 2020, Voorheis et al., 2022). Due to the nature of the limited evidence base identified through the systematic review, I followed the MRC guidance and prioritised qualitative studies to generate new evidence related to influences on parental adherence (Craig et al., 2008). I made this decision to inform my theoretical understanding of the process of change prior to conducting the co-design workshop (Craig et al., 2008, Bird et al., 2021). Whilst this is not a limitation, per se, it should be acknowledged that my research illustrates a process of development whereby behavioural design proceeded design thinking (Voorheis et al., 2022). This meant that a great deal of prior thinking and consideration had gone into understanding the behavioural influences upon parental adherence in a detailed and fine-grained fashion before conducting co-design. This occurred to the extent that a comprehensive conceptual design of the intervention was developed prior to the co-design study (Michie et al., 2014). If there was a more expansive evidence base to draw upon from the outset, without the need to undertake new primary research, there is potential that design thinking and behavioural design could have been more closely aligned during the design process (Craig et al., 2008, Morton et al., 2020, Voorheis et al., 2022).

9.7 Personal reflections

9.7.1 Reflections on utilising conceptual frameworks and theories

From the inception of the initial idea to develop a digital intervention to support parents to adhere to delivering physiotherapy following pTBI, it was always my intention to develop an intervention based on theory and evidence. As outlined by O’Cathain and colleagues, combining the MRC framework with the BCW provides the basis for developing theory- and evidence-based interventions (O'Cathain et al., 2019), as has been done before (Sinnott et al., 2015, Ojo et al., 2019).

The first step in developing a complex behaviour change intervention is to identify the available evidence, following by undertaking new primary research to supplement the evidence base where required. I undertook the systematic review first and made the decision to make the database searches broad and sensitive given the varied ways in which physiotherapy and rehabilitation following pTBI can be described. I found the process of coding intervention descriptions using BCTs and mapping this against the COM-B model to be a very detailed process but one which was useful and provided an important reference point moving forwards with the qualitative studies.

When it came to generating new evidence, it was a priority for me to explore how participants constructed meaning, whilst also coding findings against the COM-B model. By adopting the epistemological lens of critical realism and combining inductive and deductive analysis in distinct but sequential phases, I addressed two separate research objectives within each of the qualitative studies. That said, it has been a very involved, complex and time-consuming process.

Having the COM-B model as a consistent component of the systematic review and qualitative studies has greatly supported the integration of different sources of data and was extremely helpful when it came to working through the Behaviour Change Wheel. I found it to be particularly helpful when informing the behavioural diagnosis in step 4 of the process: 'Identify what needs to change' (Michie et al., 2014). From a methodological perspective, this approach is one that I would certainly recommend to other clinicians, researchers and intervention developers as a detailed and accessible way to structure the process. The APEASE criteria were also very accessible and helpful when informing decision making about the intervention content.

9.7.2 Conducting qualitative research

I worked closely with the Child Brain Injury Trust who were very supportive in recruiting parents for the parent interview study. The interest in the study amongst parents was excellent and I interviewed five parents in total. The study remained open for over six months, and I learned that requesting multiple means of contact – for example, email and phone number - was important in case the incorrect details were provided. Likewise, the Association of Chartered Physiotherapists were very supportive in recruiting physiotherapists for focus groups and participant recruitment went extremely well.

Prior to this doctoral research, I had never conducted a formal research interview or focus group. I found the interviews to be a highlight of the doctoral research, and an eye-opening process. I also found that my style of communication had to change within the context of a research interview as opposed to a clinical consultation. Regular support from the PPI group was particularly valuable during this time and I became more comfortable with providing time for participants to respond to questions and exploring points further through follow up questioning. That said, I found that I was naturally quite comfortable with establishing an initial rapport with participants and helping them to feel at ease prior to the interview.

In addition, I had never completed such comprehensive qualitative data analysis prior to this doctoral research. I can really relate to the description that Braun and Clarke use in their book about the tendency of inexperienced qualitative researchers to be fearful / weighed down by the magnitude of the process (Braun and Clarke, 2022). Two things that I will certainly take away from this research are i) to take time to think carefully about the research question(s), and ii) always come back to the research question(s) when analysing the data. The latter point was sage advice that I have heard countless times during supervisions over the past four years.

9.7.3 Reflections on the important role of parents

During the introductory chapter, *Chapter 1: Introduction to the thesis,* I introduced the concept that heterogeneity is the hallmark of traumatic brain injury (Covington and Duff, 2021). I have found this sentiment to be very true throughout the various aspects of my doctoral research. Each study that I have completed has reinforced the individualised nature and impact of pTBI on the CYP, as well as the individualised reaction that parents have to their child being injured. It has become very evident to me that physiotherapists must be flexible and adaptable in their approach to supporting parents, and that additional training is required to help physiotherapists to achieve this confidently and in an effective and consistent way.

Looking back to before I started my PhD, I was able to appreciate the role and importance of parents in their child's physiotherapy from the bedside in hospital through to continuing rehabilitation in the community. However, the lack of formal guidance or interventions to help was a very real challenge that I faced on a daily basis in clinical practice. This meant that I had to rely on my clinical judgement, clinical reasoning skills and 'common sense' to guide me through this process. Having completed the various studies of the PhD, I can now appreciate the far greater insight that I have gained into human behaviour and influences on parental adherence to physiotherapy following pTBI.

Reflecting further, prior to undertaking this doctoral research I was fairly sure, now I am convinced, that physiotherapists together with professional colleagues within the multi-disciplinary team, have a unique opportunity to better support parents from the very beginning of the rehabilitation journey. There is potential that with evidence-based support, physiotherapists can better empower parents to support their children through rehabilitation, as well as to begin the process of adjustment.

One discussion with my supervisory team in Spring 2024 really stands out to me as the occasion that the ‘penny dropped’ about the role that physiotherapy has in supporting children, their parents and the wider family following pTBI. The following section is paraphrased from the supervisory discussion, however, illustrates this point well. When discussing involving parents early on in physiotherapy sessions I reflected that ‘When first working with a child and their parent(s) in hospital, I knew that it was important to begin to get parents involved in the rehabilitation, even if it is in a small, very discreet way. However, I didn’t really know why it was so important, but I do now. Involving parents early starts to build their self-efficacy by contributing to their child’s care and helping their child. This helps parents to see and understand the role that they themselves can play in supporting their child’s recovery. This is the starting point and over time it changes to parents being able to manage the child at home, and everything else that follows.’

Whilst conducting the qualitative studies and analysing the data, two particularly powerful quotes immediately stood out to me as being truly insightful. These are the following:

- Parent: ‘it’s confidence…as times gone on, it gets to some point when you think, OK, I know my child better than anyone else’ (Parent-3)
- Physiotherapist: ‘transferring your skills and [parents] being able to become proficient in a different place, in a different environment, different context…that's what we're all trying to do. It isn't just about being at home, being in hospital and being able to do it, you need to be in different environments, you need to be doing what you want to be doing’ (Physiotherapist-7)

For me, both quotes focus on the life-changing impact that a pTBI has on CYP, parents and families. The latter quote also emphasises to me the pragmatic role that physiotherapists play in supporting parents (and families) to begin the process of adjusting to life following the pTBI. It emphasises that parent delivered physiotherapy isn’t only being able to complete a physiotherapy programme, but that delivering physiotherapy to their child is one aspect supporting parents to become the experts, once again, of their child. Additionally, incorporating physiotherapy exercises and recommendations into daily life can also support how a family adjusts and interacts with their environment following the pTBI, which are the ultimate aims of rehabilitation (World Health Organization, 2024).

Another reflection is that when I was analysing the data from the qualitative studies and planning for the co-design study, I became very interested in the family context within which the CYP exists. I was previously aware of the F-words of child development from training courses and comments from colleagues over the years, however I had never considered the role of the F-words in the acute setting following pTBI. The way in which Rosenbaum and Gorter (2011) describe parents being the 'main contextual factor' for children was a transformational shift in understanding for me (Rosenbaum and Gorter, 2011). Considering the context of the family prior to the injury can help to inform the approach to rehabilitation and involving parents following the injury. Therefore, I now understand that utilising the F-words can provide the basis for effective, meaningful and timely communication between physiotherapists and parents, whilst helping to inform physiotherapy goals and planning (Young and Gravett, 2025).

9.7.4 Reflections on co-designing 'Physio Together'

I will start this section with an old African proverb (original source uncertain): 'If you want to travel fast, go alone. If you want to travel far, go together'.

This proverb holds a great deal of truth for me and for my experience of this doctoral research for a range of different reasons. Firstly, it encapsulates the enormous value and benefit of working together with end-users and a range of stakeholders to co-design Physio Together. Co-design can be a complicated and resource intensive process, however, it provides a great deal of new insights. This is certainly my experience of co-design, as well as working so closely with the amazing PPI group throughout this doctoral research.

Another reason that this proverb holds a great deal of meaning is that, without being consciously aware of the proverb, we decided to name the digital intervention 'Physio Together'. Over the course of multiple PPI discussions, one of the PPI group members spoke so powerfully of her experience and perception that physiotherapy was 'done to' rather than 'done with' her child following their admission to hospital following pTBI. Therefore, in complete contrast to her own experience, the aim of 'Physio Together' is to be an intervention to support collaboration and change behaviour whereby parents, physiotherapists and indeed the child are *working together*.

The final reflection that I wish to add is that it has been a great privilege to conduct this doctoral research. I am extremely grateful to all the participants and the PPI group for their openness and generosity in sharing their experiences – thank you.

9.8 Concluding remarks

In conclusion, despite the important role that parents play in their child's rehabilitation following pTBI, and considering that parents are the central 'contextual factor' in their child's lives, little support currently exists in clinical practice enabling parents to deliver physiotherapy. Parental adherence to physiotherapy delivery following pTBI is a complex process which goes beyond simple compliance to a set of pre-specified exercises. Parents must play an active role in supporting their child's recover following pTBI and the F-words of child development offers an accessible way to contextualise physiotherapy, and rehabilitation more broadly.

The research presented in this thesis has focussed on the development of a digital behaviour change intervention and combined insights from existing interventions, qualitative research and co-design. One of the key findings is that parental motivation, both reflective and automatic, are vital influences of parental adherence together with psychological capability supported through increasing knowledge and understanding. Alongside this, physiotherapists play a critical role in supporting parents through social support and increasing their physical capability through physical skills acquisition.

Whilst the prototype digital intervention 'Physio Together' has been developed and goes some way to addressing the need for theory- and evidence-based support for parents, a stand-alone digital intervention is not sufficient. Physiotherapists provide crucial support to parents through face-to-face interactions which cannot be replicated or replaced by a digital intervention. Further research is required to guide the iterative refinement of 'Physio Together', plus evaluating its feasibility, effectiveness and cost-effectiveness. Such research should precede the exploration of how best to integrate the intervention into the current pathway of care, from the hospital bedside to the community, and beyond.

Appendixes

Appendix 1: Information about the primary and secondary phases of injury following traumatic brain injury

Please see Figures 1 and 2 below for a pictorial overview of the primary and secondary phases of injury following traumatic brain injury (taken from Lui et al., 2022)

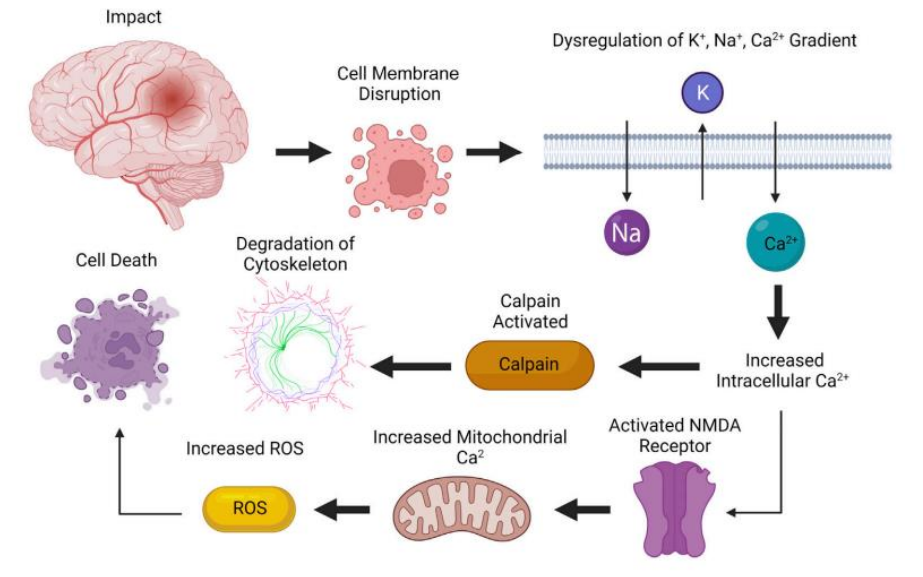


FIGURE 1 | Primary phase of injury from TBI. The primary phase of injury occurs during impact, leading to disruption of cellular membranes. Increased intracellular calcium levels activates calpain, leading to degradation of cytoskeleton. Calcium also activates NMDA receptors, causing increased mitochondrial calcium levels, which increases the concentration of reactive oxygen species (ROS), leading to cell death. Created with BioRender.com.

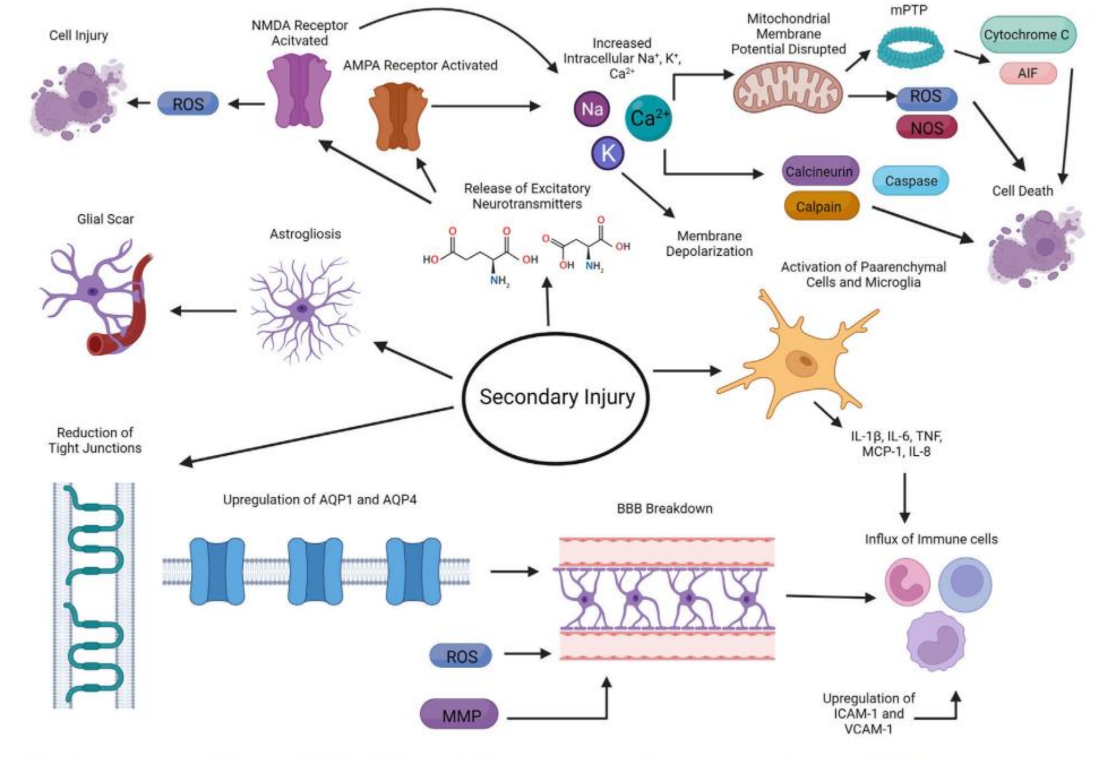


FIGURE 2 | Secondary delayed phase of injury from TBI. The second delayed phase of injury consists of the breakdown of the blood brain barrier (BBB), induction of neuroinflammation, excitotoxity, oxidative stress, apoptosis, and mitochondria dysfunction. Created with BioRender.com.

Appendix 2: Systematic review - Search strategy

Search strategy	
MEDLINE (EBSCO)	
S98	S43 AND S67 AND S97
S97	S68 OR S69 OR S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77 OR S78 OR S79 OR S80 OR S81 OR S82 OR S83 OR S84 OR S85 OR S86 OR S87 OR S88 OR S89 OR S90 OR S91 OR S92 OR S93 OR S94 OR S95 OR S96
S96	(MH "Neuronal Plasticity+")
S95	(MH "Regeneration+")
S94	(MH "Recovery of Function")
S93	(MH "Human Body")
S92	(MH "Physical Functional Performance+")
S91	(MH "Health Behavior+")
S90	neuro* plastic*
S89	neuroplastic*
S88	“outcome measur*”
S87	dexter*
S86	mobili*
S85	balanc*
S84	neck
S83	trunk
S82	leg*
S81	arm*
S80	limb*
S79	recover*
S78	enact*
S77	competen*
S76	perform* N3 (exercise* OR rehab* OR activit* OR action* OR task* OR test* OR strateg*)
S75	strength
S74	movement*
S73	motor*
S72	behavior*
S71	behaviour*
S70	complian*
S69	adherence
S68	physical N2 function*
S67	S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S64 OR S65 OR S66
S66	(MH "Biofeedback, Psychology+")
S65	(MH "Exercise+")
S64	(MH "Activities of Daily Living+")
S63	(MH "Neurological Rehabilitation+")
S62	(MH "Exercise Therapy+")
S61	strateg* N3 (adherence OR perform* OR rehab* OR deliver* OR behaviour OR behavior OR enact* OR promot*)
S60	class N2 exercise*
S59	group N2 therap*
S58	intervention
S57	strength*
S56	fitness
S55	aerobic
S54	biofeedback
S53	“virtual realit*”
S52	“video game*”
S51	exercise*
S50	neuro* N2 rehab*
S49	rehabilitation
S48	OT
S47	“occupational therap*”

S46	PT
S45	“physical therap*”
S44	physiotherap*
S43	S11 AND S29 AND S42
S42	S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41
S41	(MH "Nuclear Family+")
S40	(MH "Caregivers")
S39	famil*
S38	guardian*
S37	caregiver*
S36	carer*
S35	dad
S34	father*
S33	mom
S32	mum
S31	mother*
S30	parent*
S29	S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28
S28	(MH "Carotid Artery Diseases+")
S27	(MH "Hematoma+")
S26	(MH "Intracranial Hemorrhage, Traumatic+")
S25	(MH "Cerebrovascular Trauma+")
S24	(MH "Craniocerebral Trauma+")
S23	(MH "Brain Injuries+")
S22	“carotid artery-cavernous sinus fistula”
S21	“vascular dissection”
S20	haemorrhage N3 (subarachnoid OR intraventricular OR intracerebral)
S19	hemorrhage N3 (subarachnoid OR intraventricular OR intracerebral)
S18	haematoma N3 (epidural OR extradural OR subdural OR intracerebral)
S17	hematoma N3 (epidural OR extradural OR subdural OR intracerebral)
S16	DAI
S15	"diffuse axonal injur*"
S14	brain N2 damage
S13	head N2 injur*
S12	"brain injur*"
S11	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10
S10	(MH "Adolescent")
S9	(MH "Infant+")
S8	(MH "Child+")
S7	youth*
S6	teen*
S5	adolescen*
S4	paediatric*
S3	pediatric*
S2	infan*
S1	child*
b) AMED (EBSCO)	
S79	S35 AND S54 AND S78
S78	S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S64 OR S65 OR S66 OR S67 OR S68 OR S69 OR S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77
S77	neuro* plastic*
S76	neuroplastic*
S75	“outcome measur*”
S74	dexter*
S73	mobili*
S72	balanc*

S71	neck
S70	trunk
S69	leg*
S68	arm*
S67	limb*
S66	recover*
S65	enact*
S64	competen*
S63	perform* N3 (exercise* OR rehab* OR activit* OR action* OR task* OR test* OR strateg*)
S62	strength
S61	movement*
S60	motor*
S59	behavior*
S58	behaviour*
S57	complian*
S56	adherence
S55	physical N2 function*
S54	S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53
S53	strateg* N3 (adherence OR perform* OR rehab* OR deliver* OR behaviour OR behavior OR enact* OR promot*)
S52	class N2 exercise*
S51	group N2 therap*
S50	intervention
S49	strength*
S48	fitness
S47	aerobic
S46	biofeedback
S45	“virtual realit*”
S44	“video game*”
S43	exercise*
S42	neuro* N2 rehab*
S41	rehabilitation
S40	OT
S39	“occupational therap*”
S38	PT
S37	“physical therap*”
S36	physiotherap*
S35	S8 AND S23 AND S34
S34	S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33
S33	famil*
S32	guardian*
S31	caregiver*
S30	carer*
S29	dad
S28	father*
S27	mom
S26	mum
S25	mother*
S24	parent*
S23	S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22
S22	“carotid artery-cavernous sinus fistula”
S21	“carotid artery-cavernous sinus fistula”
S20	“vascular dissection”
S19	“vascular dissection”
S18	haemorrhage N3 (subarachnoid OR intraventricular OR intracerebral)
S17	hemorrhage N3 (subarachnoid OR intraventricular OR intracerebral)
S16	haematoma N3 (epidural OR extradural OR subdural OR intracerebral)

S15	hematoma N3 (epidural OR extradural OR subdural OR intracerebral)
S14	DAI
S13	"diffuse axonal injur*"
S12	brain N2 damage
S11	head N2 injur*
S10	"brain injur*"
S9	TBI
S8	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7
S7	youth*
S6	teen*
S5	adolescen*
S4	paediatric*
S3	pediatric*
S2	infan*
S1	child*
c) CINAHL (EBSCO)	
S94	S45 AND S67 AND S93
S93	S68 OR S69 OR S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77 OR S78 OR S79 OR S80 OR S81 OR S82 OR S83 OR S84 OR S85 OR S86 OR S87 OR S88 OR S89 OR S90 OR S91 OR S92
S92	(MH "Neuronal Plasticity")
S91	(MH "Human Body")
S90	neuro* plastic*
S89	neuroplastic*
S88	“outcome measur*”
S87	dexter*
S86	mobili*
S85	balanc*
S84	neck
S83	trunk
S82	leg*
S81	arm*
S80	limb*
S79	recover*
S78	enact*
S77	competen*
S76	perform* N3 (exercise* OR rehab* OR activit* OR action* OR task* OR test* OR strateg*)
S75	strength
S74	movement*
S73	motor*
S72	behavior*
S71	behaviour*
S70	complian*
S69	adherence
S68	physical N2 function*
S67	S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S64 OR S65 OR S66
S66	(MH "Exercise+")
S65	(MH "Activities of Daily Living+")
S64	(MH "Rehabilitation+")
S63	strateg* N3 (adherence OR perform* OR rehab* OR deliver* OR behaviour OR behavior OR enact* OR promot*)
S62	class N2 exercise*
S61	group N2 therap*
S60	intervention
S59	strength*
S58	fitness
S57	aerobic
S56	biofeedback
S55	“virtual realit*”
S54	“video game*”

S53	exercise*
S52	neuro* N2 rehab*
S51	rehabilitation
S50	OT
S49	“occupational therap*”
S48	PT
S47	“physical therap*”
S46	physiotherap*
S45	S11 AND S30 AND S44
S44	S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43
S43	(MH "Family Functioning+")
S42	(MH "Nuclear Family+")
S41	(MH "Caregivers")
S40	famil*
S39	guardian*
S38	caregiver*
S37	carer*
S36	dad
S35	father*
S34	mom
S33	mum
S32	mother*
S31	parent*
S30	S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29
S29	(MH "Carotid Artery Diseases+")
S28	(MH "Hematoma+")
S27	(MH "Intracranial Hemorrhage+")
S26	(MH "Head Injuries+")
S25	(MH "Brain Injuries+")
S24	“carotid artery-cavernous sinus fistula”
S23	“carotid artery-cavernous sinus fistula”
S22	“vascular dissection”
S21	haemorrhage N3 (subarachnoid OR intraventricular OR intracerebral)
S20	hemorrhage N3 (subarachnoid OR intraventricular OR intracerebral)
S19	haematoma N3 (epidural OR extradural OR subdural OR intracerebral)
S18	hematoma N3 (epidural OR extradural OR subdural OR intracerebral)
S17	DAI
S16	"diffuse axonal injur*"
S15	brain N2 damage
S14	head N2 injur*
S13	"brain injur*"
S12	TBI
S11	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10
S10	(MH "Infant+")
S9	(MH "Child+")
S8	(MH "Adolescence+")
S7	youth*
S6	teen*
S5	adolescen*
S4	paediatric*
S3	pediatric*
S2	infan*
S1	child*
d) PsycINFO (EBSCO)	
S90	S40 AND S64 AND S89
S89	S65 OR S66 OR S67 OR S68 OR S69 OR S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77 OR S78 OR

	S79 OR S80 OR S81 OR S82 OR S83 OR S84 OR S85 OR S86 OR S87 OR S88
S88	DE "Motor Processes" OR DE "Activity Level" OR DE "Animal Locomotion" OR DE "Gait" OR DE "Grasping" OR DE "Jumping" OR DE "Licking" OR DE "Locomotion" OR DE "Motor Control" OR DE "Motor Coordination" OR DE "Motor Performance" OR DE "Motor Skills" OR DE "Physical Activity" OR DE "Physical Agility" OR DE "Physical Mobility" OR DE "Posture" OR DE "Range of Motion" OR DE "Rotational Behavior" OR DE "Sucking" OR DE "Swallowing" OR DE "Swimming" OR DE "Tonic Immobility" OR DE "Tool Use" OR DE "Wandering Behavior"
S87	neuro* plastic*
S86	neuroplastic*
S85	“outcome measur*”
S84	dexter*
S83	mobili*
S82	balanc*
S81	neck
S80	trunk
S79	leg*
S78	arm*
S77	limb*
S76	recover*
S75	enact*
S74	competen*
S73	perform* N3 (exercise* OR rehab* OR activit* OR action* OR task* OR test* OR strateg*)
S72	strength
S71	movement*
S70	motor*
S69	behavior*
S68	behaviour*
S67	complian*
S66	adherence
S65	physical N2 function*
S64	S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63
S63	DE "Biofeedback" OR DE "Biofeedback Training" OR DE "Neurotherapy"
S62	DE "Activities of Daily Living"
S61	DE "Occupational Therapy"
S60	DE "Neurorehabilitation"
S59	DE "Physical Therapy"
S58	strateg* N3 (adherence OR perform* OR rehab* OR deliver* OR behaviour OR behavior OR enact* OR promot*)
S57	class N2 exercise*
S56	group N2 therap*
S55	intervention
S54	strength*
S53	fitness
S52	aerobic
S51	biofeedback
S50	“virtual realit*”
S49	“video game*”
S48	exercise*
S47	neuro* N2 rehab*
S46	rehabilitation
S45	OT
S44	“occupational therap*”
S43	PT
S42	“physical therap*”

S41	physiotherap*
S40	S9 AND S26 AND S39
S39	S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38
S38	DE "Nuclear Family"
S37	DE "Caregivers"
S36	famil*
S35	guardian*
S34	caregiver*
S33	carer*
S32	dad
S31	father*
S30	mom
S29	mum
S28	mother*
S27	parent*
S26	S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25
S25	DE "Brain Injuries" OR DE "Traumatic Brain Injury"
S24	DE "Head Injuries" OR DE "Brain Concussion"
S23	“carotid artery-cavernous sinus fistula”
S22	“carotid artery-cavernous sinus fistula”
S21	“vascular dissection”
S20	“vascular dissection”
S19	haemorrhage N3 (subarachnoid OR intraventricular OR intracerebral)
S18	hemorrhage N3 (subarachnoid OR intraventricular OR intracerebral)
S17	haematoma N3 (epidural OR extradural OR subdural OR intracerebral)
S16	hematoma N3 (epidural OR extradural OR subdural OR intracerebral)
S15	DAI
S14	"diffuse axonal injur*"
S13	brain N2 damage
S12	head N2 injur*
S11	"brain injur*"
S10	TBI
S9	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8
S8	DE "Pediatrics" OR DE "Lennox Gastaut Syndrome"
S7	youth*
S6	teen*
S5	adolescen*
S4	paediatric*
S3	pediatric*
S2	infan*
S1	child*
e) Embase (Ovid)	
1	child*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
2	infan*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
3	pediatric*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
4	paediatric*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]

5	adolescen*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
6	teen*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
7	youth*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
8	exp adolescent/
9	exp child/
10	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9
11	TBI.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
12	brain injur*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
13	(head adj3 injur*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
14	(brain adj3 damage).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
15	diffuse axonal injur*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
16	DAI.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
17	(hematoma adj4 (epidural or extradural or subdural or intracerebral)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
18	(haematoma adj4 (epidural or extradural or subdural or intracerebral)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
19	(hemorrhage adj4 (subarachnoid or intraventricular or intracerebral)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
20	(haemorrhage adj4 (subarachnoid or intraventricular or intracerebral)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]

21	vascular dissection.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
22	carotid artery-cavernous sinus fistula.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
23	exp head injury/
24	exp brain hemorrhage/
25	exp brain hematoma/
26	11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25
27	parent*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
28	mother*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
29	mum.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
30	mom.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
31	father*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
32	dad.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
33	carer*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
34	caregiver*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
35	guardian*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
36	famil*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
37	exp caregiver/
38	exp nuclear family/
39	27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38
40	10 and 26 and 39
41	physiotherap*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]

42	physical therap*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
43	PT.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
44	occupational therap*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
45	OT.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
46	rehabilitation.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
47	(neuro* adj3 rehab*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
48	exercise*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
49	video game*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
50	virtual realit*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
51	biofeedback.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
52	aerobic.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
53	fitness.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
54	strength*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
55	intervention.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
56	(group adj3 therap*).mp. [mp=title, abstract, heading word, drug trade name, original title, device

	manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
57	(class adj3 exercise*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
58	(strateg* adj4 (adherence or perform* or rehab* or deliver* or behaviour or behavior or enact* or promot*)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
59	exp physiotherapy/
60	exp neurorehabilitation/
61	exp occupational therapy/
62	exp biofeedback/
63	41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62
64	(physical adj3 function*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
65	adherence.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
66	complian*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
67	behaviour*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
68	behavior*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
69	motor*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
70	movement*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
71	strength.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
72	(perform* adj4 (exercise* or rehab* or activit* or action* or task* or test* or strateg*)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
73	competen*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]

74	enact*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
75	recover*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
76	limb*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
77	arm*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
78	leg*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
79	trunk.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
80	neck.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
81	balanc*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
82	mobili*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
83	dexter*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
84	outcome measur*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
85	neuroplastic*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
86	neuro* plastic*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
87	exp motor performance/
88	exp brain regeneration/
89	exp nerve cell plasticity/
90	64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or 81 or 82 or 83 or 84 or 85 or 86 or 87 or 88 or 89
91	40 and 63 and 90
f) Scopus	
78	#34 AND #53 AND #77
77	#54 OR #55 OR #56 OR #57 OR #58 OR #59 OR #60 OR #61 OR #62 OR #63 OR #64 OR #65 OR #66 OR #67 OR

	#68 OR #69 OR #70 OR #71 OR #72 OR #73 OR #74 OR #75 OR #76
76	neuro* AND plastic*
75	neuroplastic*
74	"outcome measur*"
73	dexter*
72	mobili*
71	balanc*
70	neck
69	trunk
68	leg*
67	arm*
66	limb*
65	recover*
64	enact*
63	competen*
62	perform* W/3 (exercise* OR rehab* OR activit* OR action* OR task* OR test* OR strateg*)
61	strength
60	Movement*
59	Motor*
58	behavior*
57	behaviour*
56	complian*
55	adherence
54	physical W/2 function*
53	#35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR #47 OR #48 OR #49 OR 50 OR #51 OR #52
52	strateg* W/3 (adherence OR perform* OR rehab* OR deliver* OR behaviour OR behavior OR enact* OR promot*)
51	class W/2 exercise*
50	group W/2 therap*
49	intervention
48	strength*
47	fitness
46	aerobic
45	biofeedback
44	"virtual realit*"
43	"video game*"
42	exercise*
41	neuro* W/2 rehab*
40	rehabilitation
39	ot
38	"occupational therap*"
37	pt
36	"physical therap*"
35	physiotherap*
34	#9 AND #22 AND #33
33	#23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32
32	famil*
31	guardian*
30	caregiver*
29	carer*
28	Dad
27	father*
26	Mom
25	Mum
24	mother*
23	parent*
22	#9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20
21	“carotid artery-cavernous sinus fistula”
20	“vascular dissection”

19	haemorrhage W/3 (subarachnoid OR intraventricular OR intracerebral)
18	hemorrhage W/3 (subarachnoid OR intraventricular OR intracerebral)
17	haematoma W/3 (epidural OR extradural OR subdural OR intracerebral)
16	hematoma W/3 (epidural OR extradural OR subdural OR intracerebral)
15	DAI
14	"diffuse axonal injur*"
13	brain W/2 damage
12	head W/2 injur*
11	"brain injur*"
10	TBI
9	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7
8	young
7	youth*
6	teen*
5	adolescen*
4	paediatric*
3	pediatric*
2	infan*
1	child*
g) Cochrane library	
#1	(child*):ti,ab,kw (Word variations have been searched)
#2	(infan*):ti,ab,kw (Word variations have been searched)
#3	(pediatric*):ti,ab,kw (Word variations have been searched)
#4	(paediatric*):ti,ab,kw (Word variations have been searched)
#5	(teen*):ti,ab,kw (Word variations have been searched)
#6	(youth*):ti,ab,kw (Word variations have been searched)
#7	MeSH descriptor: [Child] explode all trees
#8	MeSH descriptor: [Infant] explode all trees
#9	MeSH descriptor: [Adolescent] explode all trees
#10	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9
#11	(TBI):ti,ab,kw (Word variations have been searched)
#12	(brain injur*):ti,ab,kw (Word variations have been searched)
#13	(head NEAR/2 injur*):ti,ab,kw (Word variations have been searched)
#14	(brain NEAR/2 damage):ti,ab,kw (Word variations have been searched)
#15	(diffuse axonal injur*):ti,ab,kw (Word variations have been searched) (brain NEAR/2 damage):ti,ab,kw (Word variations have been searched)
#16	(DAI):ti,ab,kw (Word variations have been searched)
#17	(hematoma NEAR/3 (epidural OR extradural OR subdural OR intracerebral)):ti,ab,kw (Word variations have been searched)
#18	(haematoma NEAR/3 (epidural OR extradural OR subdural OR intracerebral)):ti,ab,kw (Word variations have been searched)
#19	(hemorrhage NEAR/3 (subarachnoid OR intraventricular OR intracerebral)):ti,ab,kw (Word variations have been searched)
#20	(haemorrhage NEAR/3 (subarachnoid OR intraventricular OR intracerebral)):ti,ab,kw (Word variations have been searched)
#21	(vascular dissection):ti,ab,kw (Word variations have been searched)
#22	(carotid artery cavernous sinus fistula):ti,ab,kw (Word variations have been searched)
#23	MeSH descriptor: [Brain Injuries] explode all trees
#24	MeSH descriptor: [Craniocerebral Trauma] explode all trees

#25	MeSH descriptor: [Cerebrovascular Trauma] explode all trees
#26	MeSH descriptor: [Intracranial Hemorrhage, Traumatic] explode all trees
#27	MeSH descriptor: [Hematoma] explode all trees
#28	MeSH descriptor: [Carotid Artery Diseases] explode all trees
#29	#11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28
#30	(parent*):ti,ab,kw (Word variations have been searched)
#31	(mother*):ti,ab,kw (Word variations have been searched)
#32	(mum):ti,ab,kw (Word variations have been searched)
#33	(mom):ti,ab,kw (Word variations have been searched)
#34	(father*):ti,ab,kw (Word variations have been searched)
#35	(dad):ti,ab,kw (Word variations have been searched)
#36	(carer*):ti,ab,kw (Word variations have been searched)
#37	(caregiver*):ti,ab,kw (Word variations have been searched)
#38	(guardian*):ti,ab,kw (Word variations have been searched)
#39	(famil*):ti,ab,kw (Word variations have been searched)
#40	MeSH descriptor: [Caregivers] explode all trees
#41	MeSH descriptor: [Nuclear Family] explode all trees
#42	#30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41
#43	#10 AND #29 AND #42
#44	(physiotherap*):ti,ab,kw (Word variations have been searched)
#45	(physical therap*):ti,ab,kw (Word variations have been searched)
#46	(PT):ti,ab,kw (Word variations have been searched)
#47	(occupational therap*):ti,ab,kw (Word variations have been searched)
#48	(OT):ti,ab,kw (Word variations have been searched)
#49	(rehabilitation):ti,ab,kw (Word variations have been searched)
#50	(neuro* NEAR/2 rehab*):ti,ab,kw (Word variations have been searched)
#51	(exercise*):ti,ab,kw (Word variations have been searched)
#52	(video game*):ti,ab,kw (Word variations have been searched)
#53	(virtual realit*):ti,ab,kw (Word variations have been searched)
#54	(biofeedback):ti,ab,kw (Word variations have been searched)
#55	(aerobic):ti,ab,kw (Word variations have been searched)
#56	(fitness):ti,ab,kw (Word variations have been searched)
#57	(strength*):ti,ab,kw (Word variations have been searched)
#58	(intervention):ti,ab,kw (Word variations have been searched)
#59	(group NEAR/2 therap*):ti,ab,kw (Word variations have been searched)
#60	(class NEAR/2 exercise*):ti,ab,kw (Word variations have been searched)
#61	(strateg* NEAR/3 (adherence OR perform* OR rehab* OR deliver* OR behaviour OR behavior OR enact* OR

	promot*)):ti,ab,kw (Word variations have been searched)
#62	MeSH descriptor: [Exercise Therapy] explode all trees
#63	MeSH descriptor: [Neurological Rehabilitation] explode all trees
#64	MeSH descriptor: [Activities of Daily Living] explode all trees
#65	MeSH descriptor: [Exercise] explode all trees
#66	MeSH descriptor: [Biofeedback, Psychology] explode all trees
#67	#44 OR #45 OR #46 OR #47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54 OR #55 OR #56 OR #57 OR #58 OR #59 OR #60 OR #61 OR #62 OR #63 OR #64 OR #65 OR #66
#68	(physical NEAR/2 function*):ti,ab,kw (Word variations have been searched)
#69	(adherence):ti,ab,kw (Word variations have been searched)
#70	(complian*):ti,ab,kw (Word variations have been searched)
#71	(behaviour*):ti,ab,kw (Word variations have been searched)
#72	(behavior*):ti,ab,kw (Word variations have been searched)
#73	(motor*):ti,ab,kw (Word variations have been searched)
#74	(movement*):ti,ab,kw (Word variations have been searched)
#75	(strength):ti,ab,kw (Word variations have been searched)
#76	(perform* NEAR/3 (exercise* OR rehab* OR activit* OR action* OR task* OR test* OR strateg*)):ti,ab,kw (Word variations have been searched)
#77	(competen*):ti,ab,kw (Word variations have been searched)
#78	(enact*):ti,ab,kw (Word variations have been searched)
#79	(recover*):ti,ab,kw (Word variations have been searched)
#80	(limb*):ti,ab,kw (Word variations have been searched)
#81	(arm*):ti,ab,kw (Word variations have been searched)
#82	(leg*):ti,ab,kw (Word variations have been searched)
#83	(trunk):ti,ab,kw (Word variations have been searched)
#84	(neck):ti,ab,kw (Word variations have been searched)
#85	(balanc*):ti,ab,kw (Word variations have been searched)
#86	(mobili*):ti,ab,kw (Word variations have been searched)
#87	(dexter*):ti,ab,kw (Word variations have been searched)
#88	(outcome measur*):ti,ab,kw (Word variations have been searched)
#89	(neuroplastic*):ti,ab,kw (Word variations have been searched)
#90	(neuro* plastic*):ti,ab,kw (Word variations have been searched)
#91	MeSH descriptor: [Health Behavior] explode all trees
#92	MeSH descriptor: [Physical Functional Performance] explode all trees
#93	MeSH descriptor: [Human Body] explode all trees
#94	MeSH descriptor: [Recovery of Function] explode all trees
#95	MeSH descriptor: [Regeneration] explode all trees
#96	MeSH descriptor: [Neuronal Plasticity] explode all trees
#97	#68 OR #69 OR #70 OR #71 OR #72 OR #73 OR #74 OR #75 OR #76 OR #77 OR #78 OR #79 OR #80 OR #81 OR #82 OR #83 OR #84 OR #85 OR #86 OR #87 OR #88 OR

	#89 OR #90 OR #91 OR #92 OR #93 OR #94 OR #95 OR #96
#98	#43 AND #67 AND #97

Appendix 3: Systematic review - References excluded after full text review

References excluded after full text review (n=83)

Study	**Reason for exclusion**	**Notes**
Al-Hakeem et al(Al-Hakeem et al., 2021)	Not parent led	Conference abstract only
Badr et al(Badr et al., 2006)	Not Traumatic Brain Injury	
Baque at al(Baque et al., 2016)	Not parent led	Conference abstract only
Beaulieu(Beaulieu, 2002b)	General summary	
Bedell et al(Bedell et al., 2005)	Focus not physical function	
Biezaitis and Drury(Biezaitis and Drury, 2005)	Focus not physical function	Conference abstract only
Blackman(Blackman, 2005)	Not parent led	
Braga(Braga, 2010a)	General summary	Conference abstract only
Braga(Braga, 2010b)	Duplicate	Conference abstract only
Carney et al(Carney et al., 2016)	Focus not physical function	Conference abstract only
Carney et al(Carney et al., 2014)	Focus not physical function	
Casselden and Pass(Casselden and Pass, 1990)	General summary	
Castelli(Castelli, 2003)	General summary	
Catroppa and Anderson(Catroppa and Anderson, 2009)	General summary	
Cavallo and Kay(Cavallo and Kay, 2005)	Focus not physical function	Book chapter
Chevignard et al(Chevignard et al., 2020)	Focus not physical function	
Clasby et al(Clasby et al., 2018)	Focus not physical function	
Cole et al(Cole et al., 2009b)	General summary	
Cole et al(Cole et al., 2009a)	Duplicate	
Curran(Curran, 2014)	Focus not physical function	
De Kloet et al(De Kloet et al., 2012)	Not parent led	Conference abstract only
Dumas et al(Dumas et al., 2003)	Not parent led	
Freeman et al(Freeman et al., 1990)	Not parent led	
Gan et al(Gan et al., 2010)	Focus not physical function	
Garcia et al(Garcia et al., 2010)	Not parent led	Conference abstract only
Gordon et al(Gordon et al., 2019)	Not Traumatic Brain Injury	Conference abstract only
Holt et al(Holt et al., 2012)	General summary	Conference abstract only
Hostler(Hostler, 1999)	Focus not physical function	
Huard et al(Huard et al., 2017)	General summary	Conference abstract only
Jimenez et al(Jimenez et al., 2021)	Focus not physical function	
Katz-Leurer et al(Katz-Leurer et al., 2009a)	Duplicate	
Khan et al(Khan et al., 2003)	Not parent led	
Kreutzer et al(Kreutzer et al., 1997)	Over 18 years old	
Lee et al(Lee et al., 2017)	Not parent led	
McLaughlin and Carey(McLaughlin and Carey, 1993)	Focus not physical function	
McLaughlin et al(McLaughlin et al., 2013)	Over 18 years old	
Moberg-Wolff et al(Moberg-Wolff et al., 2010)	General summary	
Moura(Moura, 2010)	Not Traumatic Brain Injury	Conference abstract only
Nees(Nees, 2002)	Not parent led	
Neuhaeuser(Neuhaeuser, 1974a)	General summary	Full text published in German. Support received for translation.
Nissen et al(Nissen et al., 2012)	Not parent led	Conference abstract only
Paes Huard(Paes Huard et al., 2018)	Not parent led	Conference abstract only
Pedrotty(Pedrotty, 2012)	Not parent led	Conference abstract only
Palacio-Navarro et al(Palacio-Navarro et al., 2019)	Focus not physical function	Full text published in Spanish. Support received for translation.
Pananivel and Burrough(Palanivel and Burrough, 2021)	General summary	

Prentiss(Prentiss, 1997)	Focus not physical function	Thesis
Prentiss(Prentiss, 1999)	Duplicate	Thesis
Prentiss(Prentiss, 1998)	Duplicate	Thesis
Ramritu and Croft(Ramritu and Croft, 1999)	Focus not physical function	
Reber et al(Reber et al., 2011)	Focus not physical function	
Rehn et al(Rehn et al., 2005)	Not parent led	Conference abstract only
Reidy et al(Reidy et al., 2013)	Not Traumatic Brain Injury	Conference abstract only
Rivara(Rivara, 1994)	Focus not physical function	
Rocchio(Rocchio, 1997)	Focus not physical function	
Roscigno(Roscigno, 2008)	Focus not physical function	
Russell et al(Russell et al., 1998)	Not parent led	Book chapter
Seel et al(Seel et al., 2013)	Not parent led	
Smith and Testani-Dufour(Smith and Testani-Dufour, 2002)	Not parent led	
Smucker(Smucker, 1996)	Focus not physical function	Thesis
Smucker(Smucker, 1997)	Duplicate	Thesis
Sohlberg et al(Sohlberg et al., 1998)	Focus not physical function	
Sohlberg et al(Sohlberg et al., 2001)	Not parent led	
Stortini et al(Stortini et al., 2010)	Not parent led	Conference abstract only
Sulzer and Karfeld-Sulzer(Sulzer and Karfeld-Sulzer, 2021)	Not parent led	
Szigeti et al(Szigeti et al., 2020)	Focus not physical function	Conference abstract only
Taub(Taub, 2012)	Not parent led	
Taub and Uswatte(Taub and Uswatte, 2013)	Not Traumatic Brain Injury	
Teplicky et al(Teplicky et al., 2005)	Focus not physical function	
Trayner(Trayner, 2020)	Focus not physical function	Conference abstract only
van Heugten et al(van Heugten et al., 2017)	Focus not physical function	
van Nieuwenhuizen and Stork(Van Nieuwenhuizen and Stork, 1980)	Not parent led	Full text published in Dutch. Support received for translation.
Varas-Arias and Rodriguez-Palero(Varas-Arias and Rodriguez-Palero, 2017)	General summary	Full text published in Spanish. Support received for translation.
Wales(Wales, 2005)	Focus not physical function	Conference abstract only
Wales et al(Wales et al., 2021)	Focus not physical function	
Weaver et al(Weaver et al., 2016)	Over 18 years old	
Williams(Williams, 2001)	Focus not physical function	Thesis
Witt et al(Witt et al., 2018)	Focus not physical function	
Wood(Wood, 1998)	General summary	
Woods(Woods, 2020)	Focus not physical function	Thesis
Wright et al(Wright et al., 2019)	Focus not physical function	
Yeleswarapu and Curran(Yeleswarapu and Curran, 2010)	Focus not physical function	
Yen and Wong(Yen and Wong, 2007)	General summary	
Ylvisaker et al(Ylvisaker et al., 2005)	General summary	

Reasons for exclusion:
‘Duplicate’ – duplicate identified during full text screening.
‘Focus not physical function’ – the focus of the study/intervention did not include physical or motor function.
‘General summary’ – the paper provides a general summary of rehabilitation, however, does not meet inclusion criteria.
‘Not parent led’ - no reference to parent led or supported rehabilitation.
‘Not Traumatic Brain Injury’ – the study did not include participants affected by traumatic brain injury.
‘Over 18 years old’ – the injured individual was over the age of 18 years.

***cont.* Appendix S3:** Theses from grey literature searches excluded after full text review (n=2)

Thesis	**Reason**
Hudepohl(84)	Focus not physical function
Warnken(85)	Focus not physical function

Reasons for exclusion:
‘Focus not physical function’ – the focus of the study/intervention did not include physical or motor function.

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Appendix 4: Systematic review - Changes in motor function using outcome measurement pre- and post-intervention

Author, year of publication, documented sources of funding	**Outcome measure**	**Group**	**Pre intervention**		**Post intervention**		**Outcome**
Braga et al. (2005)	**Motor function**:						
	SARAH scale for motor development, 2nd Ed.	Intervention	N = 44	2.5 (1.3)	N = 38	3.1 (0.8)	$p = 0.011$
No sources of funding were mentioned in the original report		Control	N = 43	2.4 (1.3)	N = 34	2.6 (1.1)	$p = 0.358$
							Between group difference $p = 0.018$
Cimolin et al. (2011)	**Upper limb function**:						
	Quality of Upper Extremities Skills Test (QUEST) total score	Intervention	N = 10	65.8 (7.9)	N = 10	71.1 (8.8)	Cohen’s d = 0.63, $p<0.05$
No sources of funding were mentioned in the original report	Besta scale						
	Grip			6.9 (3.3)		8.7 (2.8)	Cohen’s d = 0.54, $p<0.05$
	Bilateral manipulation			4.3 (3.8)		5.8 (4.1)	Cohen’s d = 0.43, $p<0.05$
	Motor function:						
	Gross Motor Function Measure (GMFM)			88.1 (9.9)		92.6 (8.7)	Cohen’s d = 0.48, $p<0.05$

	Kinematic measures completed to compare treatment intervention (n=10) to control (n=10): Please refer to the original publication for these results.						
Karman et al. (2003) No sources of funding were mentioned in the original report	**Upper limb function**:						
	Actual Amount of Use Test (AAUT)	Intervention	N = 7		N = 7		
	Amount of Use (AOU)			0.67(0.87)		1.23(0.92)	Cohen's d = 0.64
	Quality of Movement (QOM)			0.96(1.08)		1.96(1.63)	Cohen's d = 0.97
Katz-Leurer et al. (2008) No sources of funding were mentioned in the original report	**Walking performance**:			Mean (SD)		Mean difference (IQR)	
	10m walking test (metres/second)	Intervention	N = 9*	1.1 (0.2)	N = 9	0.31 (0.18 to 0.48)	p = 0.01
	Two-minute walk test (metres)			168.2 (33.7)		26.00 (2.50 to 40.50)	p = 0.02
	Energy expenditure index (beats/metre)			0.92 (0.21)		−0.25 (−0.62 to 0.01)	p = 0.20
	Balance:						
	Bruininks-Oseretsky Test of Motor Proficiency						
	One leg test on floor (seconds)			6.7 (3.5)		1.0 (0 to 4.5)	p = 0.24
	One leg test on balance beam (seconds)			7.5 (3.4)		1.0 (0 to 5)	p = 0.02

	Standing on one leg, eyes closed (seconds)			3.9 (3.6)		1.0 (0.25 to 2)	p = 0.03
	Walk forward on floor (no. of steps)			5.2 (1.0)		1.0 (0 to 1)	p = 0.15
	Walk forward on balance beam (no. of steps)			4.8 (1.4)		0.0 (0 to 1)	p = 0.25
	Walk heel–toe on floor (no. of steps)			4.7 (1.3)		1.0 (0.5 to 2)	p = 0.02
	Walk heel–toe on balance beam (no. of steps)			4.3 (1.5)		1.0 (0 to 2.5)	p = 0.15
	Steps over a stick (no. of steps)			0.5 (0.7)		1.0 (0 to 2)	p = 0.03
	Hand motor function:						
	Box and blocks test						
	With dominant hand (no. of blocks)			50.8 (13.3)		1.0 (-4.0 to 7.0)	p = 0.33
	With non-dominant hand (no. of blocks)			31.7 (19.3)		2.0 (-3.5 to 5.5)	p = 0.51
Katz-Leurer et al. (2009) No sources of funding were mentioned in the original report	**Balance**:					Change score	Difference between change scores
	The forward functional reach test (cm)	Intervention Control	N = 10 N = 10	18.7 (5.2) 19.3 (4.8)	N = 9 N = 10	3.0 (1.6) 1.9 (4.0)	p = 0.01
	Timed up and go test (metres/second)	Intervention Control		10.1 (3.0) 8.1 (1.6)		1.6 (2.1) 0.0 (0.7)	p <0.01
	Maximal isometric strength:						
	Hip abduction (kg)	Intervention		2.5 (2.5)		0.7 (1.9)	

		Control		3.7 (2.5)		0.8 (1.1)	p = 0.88
	Hip extension (kg)	Intervention		4.1 (3.7)		1.6 (2.2)	
		Control		5.7 (3.6)		0.7 (1.3)	p = 0.36
	Knee extensors (kg)	Intervention		4.9 (3.5)		0.2 (4.4)	
		Control		6.6 (3.7)		0.0 (0.7)	p = 0.63
	Knee flexors (kg)	Intervention		3.0 (3.2)		0.0 (3.0)	
		Control		4.2 (2.2)		0.1 (1.0)	p = 0.88
	Walking performance:						
	10m walk test (metres/second)	Intervention		0.92 (0.12)		0.04 (0.1)	
		Control		1.02 (0.19)		0.01 (0.1)	p = 0.84
	Two-minute walk test (metres)	Intervention		114.1 (23.9)		8.0 (13.5)	
		Control		118.9 (22.2)		0.2 (22.4)	p = 0.78
	Energy expenditure index (beats/metre)	Intervention		5.8 (2.1)		0.0 (0.1)	
		Control		5.1 (1.3)		0.0 (0.1)	p = 0.78
Sakzewski et al. (2016) Documented sources of funding as follows: Roslyn Boyd was supported by a Research Fellowship from the	**Activities of daily living**:						Comparison of outcomes between groups post-intervention
	Assessment of Motor and Process Skills (AMPS)						
	Process	Intervention	N = 29	0.72 (0.52)	N = 25	0.97 (0.43)	p = 0.589
		Control	N = 29	0.65 (0.51)	N = 26	0.99 (0.52)	
	Motor	Intervention		0.98 (0.57)		1.38 (0.42)	p = 0.192
		Control		1.2 (0.48)		1.43 (0.43)	
	Upper limb function:						
	Melbourne Assessment of Unilateral Upper Limb Function, median (IQR)	Intervention		92 (80.9, 95.3)		91 (74.5, 95.1)	p = 0.765
		Control		91 (85.8, 95.9)		90.6 (84.1, 95.9)	

NHMRC of Australia (1105038). Leanne Sakzewski was supported by a NHMRC ECR Fellowship (1090828). This project was supported by funding a Foundation for Children Grant and Smart Futures Co-Investment Program Grant	Jebsen–Taylor Test of Hand Function Impaired, median (IQR) Unimpaired, median (IQR) Assisting Hand Assessment (AHA), mean (SD) **Occupational performance**: Canadian Occupational Performance Measure (COPM) Performance Satisfaction	Intervention Control Intervention Control Intervention Control Intervention Control Intervention Control		65 (45.7, 103.5) 52 (43, 105.9) 41 (35.7, 43.6) 39 (33.7, 40.9) 69.2 (20.2) 72.5 (22.5) 3.5 (1.1) 4.0 (1.2) 3.3 (1.6) 3.7 (1.7)		57 (39.6, 92.5) 55.5 (40.5, 132.5) 34 (32, 40) 34.5 (32, 41.5) 68.9 (21.5) 76.9 (22.6) 5.4 (1.3) 5.7 (1.7) 5.3 (1.8) 6.1 (1.7)	p = 0.308 p = 0.918 p = 0.536 p = 0.752 p = 0.518

*Analysis completed only for the nine participants that completed pre- and post-intervention assessments.

SD = Standard deviation; IQR = Interquartile range; kg = Kilograms.

Appendix 5: Systematic review - Identified strategies with coded behaviour change techniques, intervention functions, mechanism of action and targets

Author, year	Identified strategy	Intervention content		Mechanism of action	
		Behaviour change techniques	**Intervention functions**	**Theory and techniques tool**	**Capability, opportunity, motivation-behaviour**
Braga et al. (2005)	Intervention group: Goals based on assessment findings	1.3 Goal setting (outcome)$^{++}$	Enablement	Goals, Motivation	Ref M
		1.4 Action planning^{+}	Enablement	Behavioural cueing	Ref M
	Visits to the home by clinicians provided information essential to adapting the rehabilitation programme to the everyday social and other routines of the family	8.3 Habit formation+	Training	Behavioural cueing	Auto M
	Simple activities that can be performed at home	1.1 Goal setting (behaviour)$^{++}$	Enablement	Intention, Goals	Ref M
		8.1 Behavioural practice/rehearsal^{+}	Training	Skill, Beliefs about capabilities	Phys C Psy C Ref M
	More than 200 illustrations of activities that could be selected and organized into an individualized manual for each child and family	4.1 Instruction on how to perform the behaviour^{++}	Training	Skill, Beliefs about capabilities	Phys C Psy C Ref M
		6.1 Demonstration of the behaviour^{++}	Training Modelling	Beliefs about capabilities, Social learning/imitation	Phys C Psy C Soc O Ref M

		8.1 Behavioural practice/rehearsal^{++}	Training	Skill, Beliefs about capabilities	Phys C Psy C Ref M
	Manual contents were frequently updated, based on the child's progress and feedback from the child and family	1.7 Review outcome goal(s)$^{+}$	Enablement	Goals	Ref M
		8.7 Graded tasks^{+} (Actor is the parent based on description)	Training Enablement	Skill, Beliefs about capabilities	Phys C Psy C Ref M
	Graphic illustrations were used rather than written instructions because many of the parents were illiterate and because illustrations of procedures are known to be easier for all adults to follow in learning unfamiliar procedures	4.1 Instruction on how to perform the behaviour^{++} (Actor is the parent based on description)	Training	Skill, Beliefs about capabilities	Phys C Psy C Ref M
		6.1 Demonstration of the behaviour^{++} (Actor is the parent based on description)	Training Modelling	Beliefs about capabilities, Social learning/imitation	Phys C Psy C Soc O Ref M
		8.1 Behavioural practice/rehearsal^{++} (Actor is the parent based on description)	Training	Skill, Beliefs about capabilities	Phys C Psy C Ref M

	Parents watched as professionals perform the intervention and developmental stimulation activities. They [the parents] systematically assumed increasing responsibility for the activity as they gained competence	4.1 Instruction on how to perform the behaviour^{++} (Actor is the parent based on description)	Training	Skill, Beliefs about capabilities	Phys C Psy C Ref M
		6.1 Demonstration of the behaviour^{++} (Actor is the parent based on description)	Training Modelling	Beliefs about capabilities, Social learning/imitation	Phys C Psy C Soc O Ref M
		8.1 Behavioural practice/rehearsal^{++} (Actor is the parent based on description)	Training	Skill, Beliefs about capabilities	Phys C Psy C Ref M
		9.1 Credible source^{++} (Actor is the parent based on description)	Persuasion	Attitude towards the behaviour, General attitudes/beliefs	Ref M
	Ongoing mentoring from the professional team	3.1 Social support (unspecified) $^{++}$ (Actor is the parent based on description)	Enablement	Social influences	Soc O

		9.1 Credible source^{++} (Actor is the parent based on description)	Persuasion	Attitude towards the behaviour, General attitudes/beliefs	Ref M
	The case managers offered support to the families, addressed their doubts and concerns	3.3 Social support (emotional)$^{+}$ (Actor is the parent based on description)	Enablement	None identified	Soc O
		9.1 Credible source^{++} (Actor is the parent based on description)	Persuasion	Attitude towards the behaviour, General attitudes/beliefs	Ref M
	During the initial 2 weeks, the parents attended daily information sessions and support group meetings. The information sessions offered basic information about traumatic brain injury, its pathophysiology and associated disabilities…Videos and other instructional materials were developed to facilitate understanding of the issues and engender questions and discussion	5.1 Information about health consequences^{+} (Actor is the parent based on description)	Education Persuasion	Knowledge, Beliefs about consequences, Intention, Attitude towards the behaviour, Perceived susceptibility/vulnerability	Psy C Ref M

	The support group meetings were also held daily for 2 weeks and were co-ordinated by a team psychologist within a group therapy approach. The parents were encouraged to discuss their feelings and misgivings about the changes in their families and their thoughts about the child. They were also invited to exchange ideas about the manner in which they were coping with the situation	3.1 Social support (unspecified)$^{+}$ (Actor is the parent based on description)	Enablement	Social influences	Soc O
		1.2 Problem solving^{+} (Actor is the parent based on description)	Enablement	Beliefs about capabilities, Behavioural regulation	Psy C Ref M
	They [parent and child] returned to the Paediatric Rehabilitation Clinic for bi-weekly visits, during which the child, parents and professionals collaboratively evaluated progress, adjusted the programme, set new goals and addressed problems	1.1 Goal setting (behaviour)$^{++}$	Enablement	Intention, Goals	Ref M
		1.2 Problem solving^{++}	Enablement	Beliefs about capabilities, Behavioural regulation	Psy C Ref M
		1.3 Goal setting (outcome)$^{++}$	Enablement	Goals, Motivation	Ref M
		1.5 Review behaviour goal(s)$^{++}$	Enablement	Goals	Ref M
		1.7 Review outcome goal(s)$^{+}$	Enablement	Goals	Ref M
		2.7 Feedback on outcome(s) of behaviour^{+}	Education Persuasion Incentivisation Coercion Training	Feedback processes	Ref M
	Control group: Parents were given information about the intervention programme,	5.1 Information about health consequences^{+}	Education Persuasion	Knowledge, Beliefs about consequences, Intention, Attitude towards the	Psy C Ref M

	but were not trained to implement any aspect of the programme…During the 2-week assessment period, parents of children in this group also attended information and support group sessions	(Actor is the parent based on description)		behaviour, Perceived susceptibility/vulnerability	
		3.1 Social support (unspecified) + (Actor is the parent based on description)	Enablement	Social influences	Soc O
		1.2 Problem solving+ (Actor is the parent based on description)	Enablement	Beliefs about capabilities, Behavioural regulation	Psy C Ref M
Cimolin et al. (2011)	Intervention group: In the second part of the session (1.5 hours), parents were instructed to interact with their own children by proposing unilateral tasks for them in play and daily living activities. Parents were trained to carry out similar 3-hour sessions at home on the remaining 4 days (this included the use of a mitt as part of CIMT)	1.1 Goal setting (behaviour) ++ (Actor is the parent based on description)	Enablement	Intention, Goals	Ref M
		1.4 Action planning++ (Actor is the parent based on description)	Enablement	Behavioural cueing	Ref M

		4.1 Instruction on how to perform the behaviour[++] (Actor is the parent based on description)	Training	Skill, Beliefs about capabilities	Phys C Psy C Ref M
		6.1 Demonstration of the behaviour[++] (Actor is the parent based on description)	Training Modelling	Beliefs about capabilities, Social learning/imitation	Phys C Psy C Soc O Ref M
		8.1 Behavioural practice/rehearsal[++] (Actor is the parent based on description)	Training	Skill, Beliefs about capabilities	Phys C Psy C Ref M
		12.5 Adding objects to the environment[++]	Environmental restructuring, Enablement	Environmental context and resources, Behavioural cueing	Phys O Auto M
	Control group: No intervention carried out	No BCTs coded			
Karman et al. (2003)	All rehabilitation professionals and all of the others administering CIMT [constraint induced	1.1 Goal setting (behaviour)[+]	Enablement	Intention, Goals	Ref M

	movement therapy] training [including parents] were instructed in appropriate task selection, use of feedback to enhance performance (i.e., shaping), and the importance of compliance in delivery of all scheduled treatment hours. Training included individual instruction and videotaped examples	(Actor is the parent based on description)			
		2.2 Feedback on behaviour++ (Actor is the parent based on description)	Education Persuasion Incentivisation Coercion Training	Motivation, Feedback processes	Ref M
		4.1 Instruction on how to perform the behaviour++ (Actor is the parent based on description)	Training	Skill, Beliefs about capabilities	Phys C Psy C Ref M
		5.1 Information about health consequences++ (Actor is the parent based on description)	Education Persuasion	Knowledge, Beliefs about consequences, Intention, Attitude towards the behaviour, Perceived susceptibility/vulnerability	Psy C Ref M
		6.1 Demonstration of the behaviour++ (Actor is the parent based on description)	Training Modelling	Beliefs about capabilities, Social learning/imitation	Phys C Psy C Soc O Ref M

		8.1 Behavioural practice/rehearsal^{++} (Actor is the parent based on description)	Training	Skill, Beliefs about capabilities	Phys C Psy C Ref M
		8.7 Graded tasks^{+} (Actor is the parent based on description)	Training Enablement	Skill, Beliefs about capabilities	Phys C Psy C Ref M
		9.1 Credible source^{++} (Actor is the parent based on description)	Persuasion	Attitude towards the behaviour, General attitudes/beliefs	Ref M
		12.5 Adding objects to the environment^{++}	Environmental restructuring, Enablement	Environmental context and resources, Behavioural cueing	Phys O
		14.4 Reward approximation^{++} (Actor is the child based on description)	Incentivisation	None identified	Auto M
	Staff and family members were instructed to remove the mitt for up to 5 minutes when a child	1.1 Goal setting (behaviour)$^{++}$	Enablement	Intention, Goals	Ref M

	complained of discomfort, or to offer small rewards (usually stickers or tokens) to avoid removal of the mitt	(Actor is the parent based on description)			
		1.4 Action planning^{++} (Actor is the parent based on description)	Enablement	Behavioural cueing	Ref M
		10.2 Material reward (behaviour)$^{++}$ (Actor is the parent based on description)	Incentivisation	Reinforcement	Auto M
	The authors observed training everyday for deviations from protocol and practice improvement. Shapers were required to submit record forms documenting the activities employed, time per activity, and numeric measures of shaping toward improved performance (e.g., greater number, speed, accuracy) for each hour of intervention	2.1 Monitoring behaviour by others without feedback^{+} (Actor is the parent based on description)	Incentivisation Coercion	None identified	Ref M
		2.3 Self-monitoring of behaviour^{+} (Actor is the parent based on description)	Education Incentivisation Coercion Training Enablement	Behavioural regulation, Feedback processes	Ref M

		2.4 Self-monitoring of outcome(s) of behaviour⁺ (Actor is the parent based on description)	Education Incentivisation Coercion Training Enablement	None identified	Ref M
Katz Leurer et al. (2008)	The second visit was for a pre-training evaluation, where children and parents were exposed to the training protocol. The participants were given a practice period under the supervision of the therapist in the clinic	1.1 Goal setting (behaviour)⁺⁺ (Actor is the child based on description)	Enablement	Intention, Goals	Ref M
		1.4 Action planning⁺⁺ (Actor is the child based on description)	Enablement	Behavioural cueing	Ref M
		4.1 Instruction on how to perform the behaviour⁺ (Actor is the child based on description)	Training	Skill, Beliefs about capabilities	Phys C Psy C Ref M
		6.1 Demonstration of the behaviour⁺	Training Modelling	Beliefs about capabilities, Social learning/imitation	Phys C Psy C Soc O

		(Actor is the child based on description)			Ref M
		8.1 Behavioural practice/rehearsal^{++} (Actor is the child based on description)	Training	Skill, Beliefs about capabilities	Phys C Psy C Ref M
	Every participant was provided with a booklet that included graphic displays of the exercises	4.1 Instruction on how to perform the behaviour^{++} (Actor is the child based on description)	Training	Skill, Beliefs about capabilities	Phys C Psy C Ref M
		6.1 Demonstration of the behaviour^{++} (Actor is the child based on description)	Training Modelling	Beliefs about capabilities, Social learning/imitation	Phys C Psy C Soc O Ref M
	Participants were requested to perform the exercises over the 4-week intervention period under the supervision of one of their parents. They were instructed to exercise every possible day (three sets of sit-stand-sit exercises and three sets of step-up exercises with each	1.1 Goal setting (behaviour)$^{++}$ (Actor is the child based on description)	Enablement	Intention, Goals	Ref M
		1.4 Action planning^{++}	Enablement	Behavioural cueing	Ref M

	leg daily, at least three times a week). The number of repetitions during the first 2 weeks was set at 60% of the individual maximal performance estimated during the pre-training measurement session, and up to 80% during the third and fourth weeks. The child was instructed to rest for 1 minute between sets	(Actor is the child based on description)			
		3.2 Social support (practical) ++ (Actor is the child based on description)	Enablement	Environmental context and resources, Social influences	Phys O Soc O
		8.7 Graded tasks++ (Actor is the child based on description)	Training Enablement	Skill, Beliefs about capabilities	Phys C Psy C Ref M
	Every child was provided with a diary in which he/she was requested to keep a record of the number of sets and repetitions completed daily	2.3 Self-monitoring of behaviour++ (Actor is the child based on description)	Education Incentivisation Coercion Training Enablement	Behavioural regulation, Feedback processes	Ref M
Katz-Leurer et al. (2009)	Intervention group: The experimental group participants were also instructed to continue with their regular daily activities, and in addition they were asked to do a series of exercises at home five days a week for six weeks. They were asked to return	1.1 Goal setting (behaviour) ++ (Actor is the child based on description)	Enablement	Intention, Goals	Ref M
		1.4 Action planning++	Enablement	Behavioural cueing	Ref M

	to the clinic for second measurements after the six weeks, and again, for the third time, after a further six weeks	(Actor is the child based on description)			
	This simple set of exercises was chosen based on the knowledge that using fewer exercises improves compliance for people participating in strength-training programmes	8.7 Graded tasks^{++} (Actor is the child based on description)	Training Enablement	Skill, Beliefs about capabilities	Phys C Psy C Ref M
	The therapist set a day each week that she called the child and parent to hear and to answer any questions and to solve any problems that arise during the programme	1.2 Problem solving^{++}	Enablement	Beliefs about capabilities, Behavioural regulation	Psy C Ref M
		3.1 Social support (unspecified) $^{++}$	Enablement	Social influences	Soc O
	Each child was provided with a diary in which he was requested to keep a record of the number of sets and repetitions completed daily	2.3 Self-monitoring of behaviour^{++} (Actor is the child based on description)	Education Incentivisation Coercion Training Enablement	Behavioural regulation, Feedback processes	Ref M
	We asked the child to perform the following five exercises at home, five times a week for six weeks: sit-to-stand and step-up with each leg in forward and sideward directions, three sessions of 1 minute each for every exercise, daily. The number of repetitions during the first two	1.1 Goal setting (behaviour) $^{++}$ (Actor is the child based on description)	Enablement	Intention, Goals	Ref M
		1.4 Action planning^{++}	Enablement	Behavioural cueing	Ref M

	weeks was set at 50% of the child's maximal performance estimated during the first measurement session, and up to 75% from the third week	(Actor is the child based on description)			
		4.1 Instruction on how to perform the behaviour^{++} (Actor is the child based on description)	Training	Skill, Beliefs about capabilities	Phys C Psy C Ref M
		8.7 Graded tasks^{++} (Actor is the child based on description)	Training Enablement	Skill, Beliefs about capabilities	Phys C Psy C Ref M
	The children were requested to carry out the exercise under parental supervision	2.1 Monitoring behaviour by others without feedback^{+} (Actor is the child based on description)	Incentivisation Coercion	None identified	Ref M
		3.2 Social support (practical)$^{++}$ (Actor is the child based on description)	Enablement	Environmental context and resources, Social influences	Phys O Soc O

	Control group: Received usual care	No BCTs coded			
Sakzewski et al. (2016); Boyd et al. (2015)	All participants will receive a Microsoft Kinect®, laptops and pre-paid internet dongles for families who are unable to access a computer and/or internet at home for the 20 weeks intervention period. If families experience any technical issues, a study telemedicine engineer will be available to troubleshoot any technical difficulties. Step blocks, wobble discs and weights are also provided to families as an additional challenge for tasks as they progress through the program	1.2 Problem solving^{+} (For technical issues)	Enablement	Beliefs about capabilities, Behavioural regulation	Psy C Ref M
		12.5 Adding objects to the environment^{++}	Environmental restructuring, Enablement	Environmental context and resources, Behavioural cueing	Phys O
	A therapist will deliver a lecture to explain the background and purpose of Mitii™, how the program works…and motivational strategies to encourage engagement in the program An overview of the background and purpose of Mitii™, specific training in how the programme worked, and practice of the training module devised by the therapists	4.1 Instruction on how to perform the behaviour^{+} (Actor is the child based on description)	Training	Skill, Beliefs about capabilities	Phys C Psy C Ref M
		5.1 Information about health consequences^{+}	Education Persuasion	Knowledge, Beliefs about consequences, Intention, Attitude towards the behaviour, Perceived susceptibility/vulnerability	Psy C Ref M

		(Actor is the child based on description)			
		6.1 Demonstration of the behaviour+ (Actor is the child based on description)	Training Modelling	Beliefs about capabilities, Social learning/imitation	Phys C Psy C Soc O Ref M
		8.1 Behavioural practice/rehearsal++ (Actor is the child based on description)	Training	Skill, Beliefs about capabilities	Phys C Psy C Ref M
	The program will be requested to be completed 30 minutes per day, six days a week for 20 weeks. This will provide a minimum potential treatment dose of 60 hours. The participant should be appropriately supervised by a parent/guardian (according to their age) to ensure activities are being completed safely and correctly	1.1 Goal setting (behaviour) ++ (Actor is the child based on description)	Enablement	Intention, Goals	Ref M
		1.4 Action planning++ (Actor is the child based on description)	Enablement	Behavioural cueing	Ref M
		2.1 Monitoring behaviour by others without feedback++	Incentivisation Coercion	None identified	Ref M Auto M

		(Actor is the child based on description)			
		3.2 Social support (practical) $^{++}$ (Actor is the child based on description)	Enablement	Environmental context and resources, Social influences	Phys O Soc O
	The three virtual trainers will together evaluate each participant's performance on a weekly basis and adjust module content variables to maintain the program at an appropriate level of difficulty or intensity to promote a training effect. Therapists access each participant's program remotely via the Mitii™ user interface "Cockpit" and can monitor how frequently the participant has logged into Mitii™, how long they have spent engaged in the program, games that have been skipped and progress in each module. The complexity of the modules can be adjusted by increasing or decreasing the level of difficulty of visual perceptual (images graded on a colour code	1.7 Review outcome goal(s) $^{++}$ (Actor is the child based on description)	Enablement	Goals	Ref M
		2.1 Monitoring behaviour by others without feedback^{++} (Actor is the child based on description)	Incentivisation Coercion	None identified	Ref M Auto M
		8.7 Graded tasks^{+} (Actor is the child based on description)	Training Enablement	Skill, Beliefs about capabilities	Phys C Psy C Ref M

	system of blue-green-red-black), cognitive (e.g. increasing the length of a memory sequence) and motor activities (e.g. reducing the base of support for balance)				
	Regular contact aimed to provide ongoing support and feedback, solve any technical issues, and discuss modification to the module to either increase or decrease complexity as required. The primary virtual trainer accessed the child's programme remotely on a weekly basis and adjusted the complexity of the module based on performance and feedback from the child and family. Weekly contact between the therapist and child, and the use of a Mitii™ rewards chart were used to foster continued engagement and motivation with the programme.	1.2 Problem solving++ (For technical issues)	Enablement	Beliefs about capabilities, Behavioural regulation	Psy C Ref M
		1.7 Review outcome goal(s) + (Actor is the child based on description)	Enablement	Goals	Ref M
		2.1 Monitoring behaviour by others without feedback++ (Actor is the child based on description)	Incentivisation Coercion	None identified	Ref M Auto M
		2.2 Feedback on behaviour++ (Actor is the child based on description)	Education Persuasion Incentivisation Coercion Training	Motivation, Feedback processes	Ref M

		3.1 Social support (unspecified) $^{++}$ (Actor is the child based on description)	Enablement	Social influences	Soc O
		5.1 Information about health consequences^{++} (Actor is the child based on description)	Education Persuasion	Knowledge, Beliefs about consequences, Intention, Attitude towards the behaviour, Perceived susceptibility/vulnerability	Psy C Ref M
		8.7 Graded tasks^{+} (Actor is the child based on description)	Training Enablement	Skill, Beliefs about capabilities	Phys C Psy C Ref M
	Motivational strategies will be discussed during the initial Mitii™ training session with families and will include weekly performance feedback, positive re-enforcement by parents/guardians and incorporating Mitii™ into the regular family routine. Each participant will also have the option of using a rewards chart	2.2 Feedback on behaviour^{++} (Actor is the child based on description)	Education Persuasion Incentivisation Coercion Training	Motivation, Feedback processes	Ref M
		8.3 Habit formation^{+} (Actor is the child and parent based on description)	Training	Behavioural cueing	Auto M

		10.2 Material reward (behaviour)++ (Actor is the child based on description)	Incentivisation	Reinforcement	Auto M
	Program options such as physiotherapists demonstrating aerobic activities that are used during activity modules and including real-world images in figure ground, spatial relations, match two images and memory modules, are more likely to appeal to teenagers will be incorporated in their programs	4.1 Instruction on how to perform the behaviour++ (Actor is the child based on description)	Training	Skill, Beliefs about capabilities	Phys C Psy C Ref M
		6.1 Demonstration of the behaviour++ (Actor is the child based on description)	Training Modelling	Beliefs about capabilities, Social learning/imitation	Phys C Psy C Soc O Ref M
	One of the three virtual trainers will be assigned as the main contact for the participant and their family and remain in weekly contact	3.1 Social support (unspecified) ++	Enablement	Social influences	Soc O
	Once participants have completed the 20 weeks intervention they will receive a small reward provided by study personnel and parents will be asked to complete an exit questionnaire	10.2 Material reward (behaviour)++	Incentivisation	Reinforcement	Auto M

		(Actor is the child based on description)			
	Control – usual care	No BCTs coded			

COM-B – Capability Opportunity Motivation Behaviour model comprising of: Phys C – Physical Capability, Psy C – Psychological Capability, Phys O – Physical Opportunity, Soc O – Social Opportunity, Ref M – Reflective Motivation, Auto M – Automatic Motivation; CIMT – Constraint-Induced Movement Therapy. Regarding behaviour change techniques, ‘$^{++}$’ was assigned when a behaviour change technique was deemed present beyond all reasonable doubt and ‘$^{+}$’ was assigned when the behaviour change technique was deemed to be present in all probability.

Appendix 6: Systematic review - Revised Cochrane risk-of-bias tool for randomized trials (RoB-2)[1]

The RoB-2 tool offers a framework to consider the risk of bias of findings from any form of randomised trial and is divided into five domains: bias arising from the randomisation process; bias due to deviations from intended interventions; bias due to missing outcome data; bias in measurement of the outcome; and bias in selection of the reported result. Overall risk of bias ranges from low to high with 'some concerns' providing an intermediate rating.

Study	The randomisation process	Deviations from the intended interventions	Missing outcome data	Measurement of outcome	Selection of the reported result	Overall risk of bias assessment
Braga et al., 2005[2]	Some concerns	High	High	Low	Some concerns	High
Katz-Leurer et al., 2009[3]	Low	Some concerns	Low	High	Some concerns	High
Sakzewski et al., 2016[4]	Low	Low	High	High	High	High
Low risk of bias indicates 'the study is judged to be at low risk of bias for all domains for this result'; **Some concerns** indicates 'the study is judged to raise some concerns in at least one domain for this result, but not to be at high risk of bias for any domain'; **High risk of bias** indicates 'the study is judged to be at high risk of bias in at least one domain for this result OR the study is judged to have some concerns for multiple domains in a way that substantially lowers confidence in the result'.						

1. Higgins JPT, Savović J, Page MJ, Sterne JAC. Revised Cochrane risk-of-bias tool for randomized trials (RoB 2). 2019.
2. Braga LW, Da Paz AC, Ylvisaker M. Direct clinician-delivered versus indirect family-supported rehabilitation of children with traumatic brain injury: a randomized controlled trial. Brain Inj. 2005;19(10):819-31.
3. Katz-Leurer M, Rotem H, Keren O, Meyer S. The effects of a 'home-based' task-oriented exercise programme on motor and balance performance in children with spastic cerebral palsy and severe traumatic brain injury. Clinical Rehabilitation. 2009;23:714–24.
4. Sakzewski L, Lewis MJ, McKinlay L, Ziviani J, Boyd RN. Impact of multi-modal web-based rehabilitation on occupational performance and upper limb outcomes: pilot randomized trial in children with acquired brain injuries. Dev Med Child Neurol. 2016;58(12):1257-64.

Appendix 7: Systematic review - Risk of Bias In Non-Randomised Studies – of Interventions (ROBINS-I)[1]

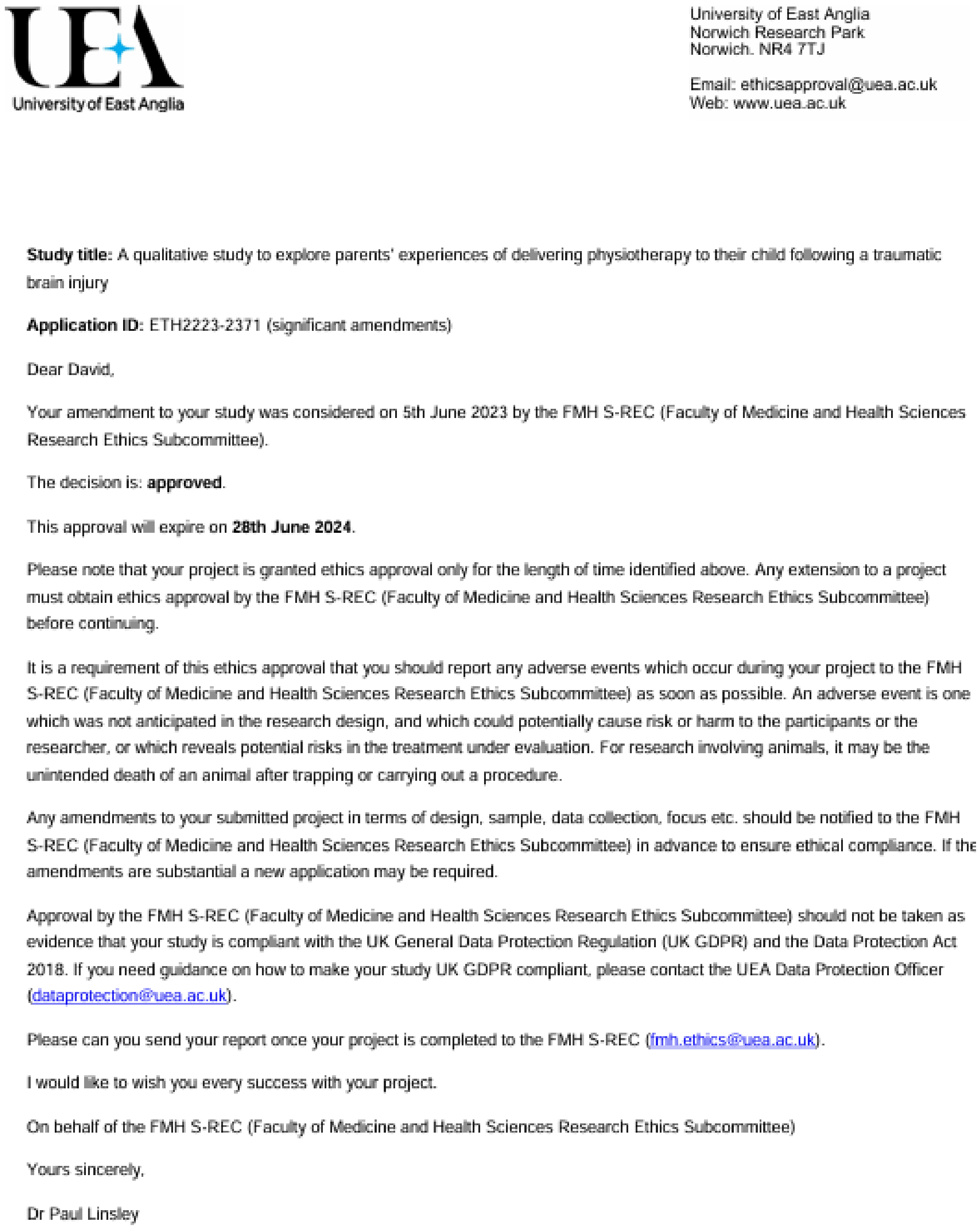
The ROBINS-I tool supports consideration of risk of bias from non-randomised studies of the effects of interventions which compare the effects of two or more interventions. The tool is divided into seven domains through which risk of bias may be introduced at three stages of a study: bias due to confounding and bias in selection of participants into the study (pre-intervention); bias in classification of interventions (at intervention); bias due to deviations from intended interventions, bias due to missing data, bias in measurement of outcome and bias in selection of the reported result (post-intervention). Overall risk of bias ratings ranges from low to critical with 'lack of information' offering an alternative rating where there is no clear indication for risk of bias.

Study	**Pre-intervention**		**At intervention**	**After intervention**				**Overall risk of bias assessment**
	Confounding	**Selection of participants**	**Classification of interventions**	**Deviation from intended interventions**	**Missing data**	**Measurement of outcomes**	**Selection of the reported result**	
Cimolin et al., 2011[2]	Serious	No information	Low	Low	Low	Serious	Low	Serious
Katz-Leurer et al., 2008[3]	No information	Critical	Low	Critical	Serious	Serious	Low	Critical

No information indicates there is no information 'on which to base a judgement about risk of bias for this domain';
Low risk of bias indicates 'the study is comparable to a well-performed randomized trial with regard to this domain';
Moderate risk of bias indicates 'the study is sound for a non-randomized study with regard to this domain but cannot be considered comparable to a well-performed randomized trial';
Serious risk of bias indicates 'the study has some important problems';
Critical risk of bias indicates 'the study is too problematic to provide any useful evidence on the effects of intervention'

1. Sterne JAC, Hernán MA, Reeves BC, Savović J, Berkman ND, Viswanathan M, et al. The Risk Of Bias In Non-randomized Studies – of Interventions (ROBINS-I) assessment tool.. BMJ. 2016;355:i4919.
2. Cimolin V, Beretta E, Piccinini L, Turconi AC, Locatelli F, Galli M, et al. Constraint-induced movement therapy for children with hemiplegia after traumatic brain injury: a quantitative study. J Head Trauma Rehabil. 2011;27(3):177-87.
3. Katz-Leurer M, Eisenstein E, Liebermann DG. Feasibility of motor capability training at home in children with acquired brain injury. Physiotherapy. 2008;94(1):71-7.

Appendix 8: Parent interviews - Ethical approval



University of East Anglia
Norwich Research Park
Norwich. NR4 7TJ

Email: ethicsapproval@uea.ac.uk
Web: www.uea.ac.uk

Study title: A qualitative study to explore parents' experiences of delivering physiotherapy to their child following a traumatic brain injury

Application ID: ETH2223-2371 (significant amendments)

Dear David,

Your amendment to your study was considered on 5th June 2023 by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee).

The decision is: **approved**.

This approval will expire on **28th June 2024**.

Please note that your project is granted ethics approval only for the length of time identified above. Any extension to a project must obtain ethics approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) before continuing.

It is a requirement of this ethics approval that you should report any adverse events which occur during your project to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) as soon as possible. An adverse event is one which was not anticipated in the research design, and which could potentially cause risk or harm to the participants or the researcher, or which reveals potential risks in the treatment under evaluation. For research involving animals, it may be the unintended death of an animal after trapping or carrying out a procedure.

Any amendments to your submitted project in terms of design, sample, data collection, focus etc. should be notified to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) in advance to ensure ethical compliance. If the amendments are substantial a new application may be required.

Approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) should not be taken as evidence that your study is compliant with the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. If you need guidance on how to make your study UK GDPR compliant, please contact the UEA Data Protection Officer (dataprotection@uea.ac.uk).

Please can you send your report once your project is completed to the FMH S-REC (fmh.ethics@uea.ac.uk).

I would like to wish you every success with your project.

On behalf of the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee)

Yours sincerely,

Dr Paul Linsley

Appendix 9: Parent interviews - Letter from Mr Gerard Anderson

Mr Gerard Anderson
Child Brain Injury Trust
Field View
Baynards Green Farm Trading Estate
Baynards Green
Nr Bicester
Oxfordshire
OX27 7SR

04/02/2022

Dear David,

Re: Doctoral research project support

Following on from your request to engage with the Child Brain Injury Trust in relation to your doctoral research project, I would like to confirm that I am happy for the Child Brain Injury Trust to support you in your endeavours.

To give some background, the Child Brain Injury Trust works alongside a network of Major Trauma Centres and specialist hospitals across the UK, supporting clinical and non-clinical trauma and Neuro-rehab teams who care for children and young adults affected by childhood acquired brain injury.

The Child Brain Injury Trust has been supporting hospitals and families affected by childhood acquired brain injury for over 30 years, providing non-clinical and non-medical advice, information and support.

As a service, our focus is on early intervention and the continuation of care through to adult services, which is why our journey with families begins when the injury or illness first occurs. We then work with the family and the professionals around them and act as a scaffold until they reach a point where support is no longer needed, or they reach the age of 25yrs (whichever comes first).

Working with key figures across the field of acquired brain injury, focusing on the prevention and reduction of long-term difficulties is key, and as such, we pride ourselves in working alongside, and with research teams and universities across the UK.

All research requests to the Child Brain Injury Trust go through a stringent assessment process where a research submission form is completed and then reviewed by the Child Brain Injury Trust to assess the impact and benefit that the research will have to the families being supported. If appropriate safeguards are not in place to support participants or it is felt that the research may have a negative impact or not benefit the long-term recovery of families affected by childhood acquired brain injury, then it is not authorised.

It is also the case where we do not wish to overburden families, and as such, if there is a current research project in place similar to the one proposed, then a research project may also be declined.

Child Brain Injury
Trust
'hope for tomorrow - today'

Following our communication where you have outlined your research, your procedures and steps you will be taking to gather ethical approval and safeguard participants, I would like to summarise those as following:

- You made contact with the Professional Research Group at the Child Brain Injury Trust in September 2021 to introduce your research project.
- You then submitted a formal research submission form to the Professional Research Group of the Child Brain Injury Trust which comprehensively outlined your research project and the proposed involvement of the Child Brain Injury Trust.
- After consideration of the research proposal, the Child Brain Injury Trust has made a formal assessment and approved your request in supporting your doctoral research project.
- The support provided by the Childs Brain Injury Trust will include but is not limited to: posting research flyers on our Facebook and Twitter pages, sending email invitations to eligible parents that meet the inclusion criteria for your research. This may include up to 20 participants from across each region of the UK and devolved nation.
- As part of the support following participation in your research, and as participants are actively supported by the Child Brain Injury Trust, I am authorising the Child Brain Injury Trust counselling service to be available should any families wish to access additional counselling support if affected by research participation. It should be noted however, that there is currently a waiting list of 3+ weeks for accessing counselling and terms and conditions apply (which should be noted).
- It has also been agreed that the Child Brain Injury Trust Professional Research Group team will review your research ethics application prior to submission to the relevant University ethics committee.

At no point will the Child Brain Injury Trust share any personal details of any participants with you, and at all times will adhere to strict General Data Protection (GDPR) regulations, policies and procedures in the transfer of data.

Where any participant has a query about the research, the Child Brain Injury Trust will direct participants to you using the contact details provided in the participant recruitment pack.

If you would like to chat further, please do not hesitate to contact me on 01869 341 075 (office), 07920 745 552 (mobile) or gerardanderson@cbituk.org.

Yours sincerely

Gerard Anderson
Head of Brain Injury Services

Child Brain Injury Trust,
Field View, Baynards Green Farm Trading Estate, Baynards Green, Nr Bicester, Oxfordshire, OX27 7SR
Phone: 01869 341075 Email: office@cbituk.org Web: www.childbraininjurytrust.org.uk
Registered Charity Number: 1113326 A Charity Registered in Scotland: SC 039703
Registered Company Number: 5738517 VAT Registration 125 7951

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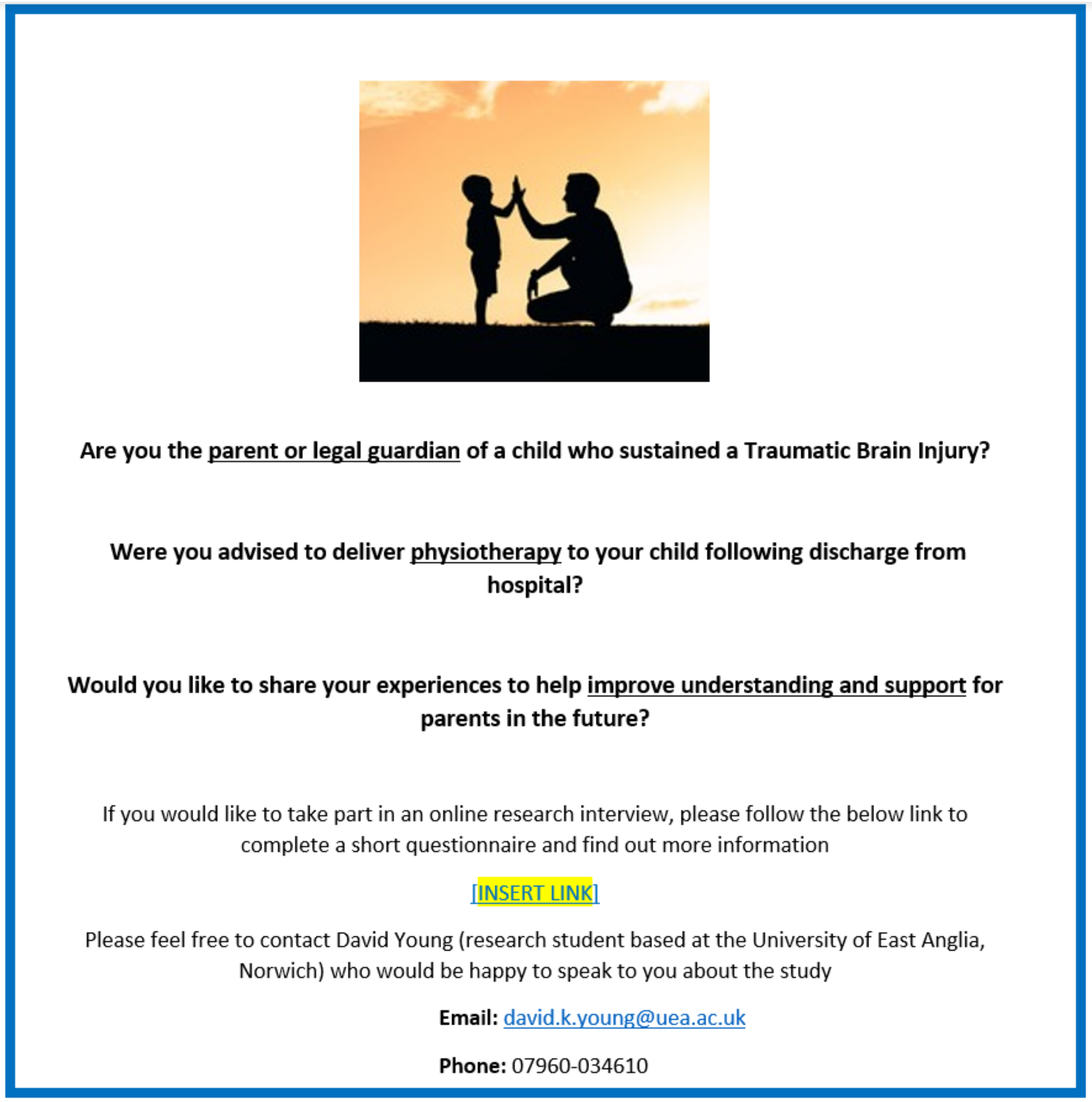
May 2018

Appendix 10: Parent interviews – Online recruitment flyer



Are you the parent or legal guardian of a child who sustained a Traumatic Brain Injury?

Were you advised to deliver physiotherapy to your child following discharge from hospital?

Would you like to share your experiences to help improve understanding and support for parents in the future?

If you would like to take part in an online research interview, please follow the below link to complete a short questionnaire and find out more information

[INSERT LINK]

Please feel free to contact David Young (research student based at the University of East Anglia, Norwich) who would be happy to speak to you about the study

Email: david.k.young@uea.ac.uk

Phone: 07960-034610

Appendix 11: Parent interviews – Participant Information Sheet

Participant Information Sheet
Version 5, 23/05/2022

Research student: David Young, University of East Anglia

University of East Anglia
Faculty of Medicine and Health Sciences
School of Health Sciences
University of East Anglia
Norwich Research Park
Norwich NR4 7TJ
United Kingdom

(1) What is this study about?

You are invited to take part in a research study about exploring parents' experiences of delivering physiotherapy exercises to their child following a traumatic brain injury. You can participate in this study if you are the parent of a child or young person that sustained a traumatic brain injury when they were under 18 years of age, and needed to spend at least three days in hospital. We are particularly interested to hear **your experiences of delivering physiotherapy exercises** to your child at home, once you left hospital. We will ask you questions about this in an online interview which will be held on Zoom, or over the telephone. The interview will last approximately one hour.

This study is being conducted to help understand parents' experiences, and what helps or makes it harder for parents to deliver physiotherapy exercises to their child at home. Findings will be used to inform the development of a new smartphone application (app) and website designed to support parents to deliver physiotherapy. Whilst the term *parents* is used throughout this leaflet, please be aware that *legal guardians* are also welcome to participate in this research.

This Participant Information Sheet tells you about the research study. Knowing what is involved will help you decide if you want to take part in the study or not. Please read this sheet carefully and ask David Young (research student) questions about anything that you don't understand or want to know more about. David can be contacted in the following ways;

Email: david.k.young@uea.ac.uk
Telephone: 07960034610.

Participation in this research study is voluntary. By giving consent to take part in this study you are telling us that you:

- ✓ Understand what you have read in this Participant Information Sheet, version 4, dated 11/04/2022.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described below.
- ✓ You have received a copy of this Participant Information Sheet to keep.

(2) Who is running the study?

The study is being carried out by paediatric physiotherapist and research student, Mr David Young, based at the University of East Anglia and Cambridge University Hospitals NHS Foundation Trust. David is completing this research as part of his PhD, funded by the National Institute for Health Research (NIHR301583); for more information see https://fundingawards.nihr.ac.uk/award/NIHR301583. David will conduct the interviews as a researcher and will not be able to comment on any physiotherapy exercises or elements of the medical care your child received. We recommend that you contact your own GP or relevant health professional if you require specific support or advice.

This study is taking place under the supervision of Professor Wendy Hardeman, University of East Anglia (w.hardeman@uea.ac.uk), Dr Kath Mares, University of East Anglia, and Dr Robbie Duschinsky, University of Cambridge. This study is also taking place with the collaboration of the Child Brain Injury Trust (registered charity no. 1113326).

(3) What will the study involve for me?

If you would like to be considered for an interview as part of this study, please click on the hyperlink and complete the short online questionnaire. The questionnaire will take no longer than 5 minutes to complete and relates to you, as well as your child's injury [insert hyperlink]. We will use your responses to make sure that you are suitable to take part in an interview. Please provide a valid email address that you are happy to be contacted on by the research student about the study. By providing your email address you are giving consent to your name and email address being securely stored in relation to this study (for more information please see section 8. 'What will happen to information provided by me and data collected during the study?').

If you are the parent of a child or young person that sustained a traumatic brain injury below the age of 18 years, following which they were in hospital for at least 3 days and you were recommended to deliver physiotherpay exercises following discharge you may be eligible. If you are eligible to take part in this research study, after at least one week of completing the questionnaire and providing an email address, the research student will contact you by email. He will answer any questions or concerns you may have about the research. He will also provide you with information about how to complete an online consent form (a form which says that you agree to taking part in the study) and make arrangements for the online or telephone interview.

The interview

The interview will take place online via Zoom, or over the telephone if you prefer. It is anticipated that the interview will take appriximately one hour. You will be asked a series of questions about your experiences of learning physiotherapy exercises and delivering them to your child at home, what you found was helpful and what made it challenging. We are also interested to know what you think should be included in an app to support parents to deliver physiotherapy. You will also have a debrief with the research student following the interview.

The online interview will be recorded on Zoom and also on an audio recorder (back-up) so that following the interview the researcher can accurately recall what you said; you are free to turn off your camera during the interview if you would like to. For telephone interviews only an audio recorder will be used. You will be able to pause the interview at any time and stop the interview if you would like to.

You will have the opportunity to review a written copy of your interview (known as a transcript) after the interview to make sure it is accurate; please tick the relevant box on the consent form if you would like to do this. You will also receive a summary of the findings of the study by email once the study has finished.

Support during the interview
You are welcome to invite a supportive adult to join you during the interview. Unlike you, the supportive adult will not be a participant in the study. If they say anything during the interview we may not report their views. Any childcare costs that you have as a result of participating in this study can be reimbursed.

Please tell the research student as soon as possible if you require a translator if English is not your first language; if a translator is required, they will join the interview on Zoom. If you need any additional support to be able to take part in the interview. Every effort will be made to accommodate you appropriately.

Anonymisation of your interview
Following the interview, a word for word version of what was said (a verbatim transcript) will be written. The transcript will be anonymised so that nobody will be able to link your interview back to you personally. Your name or details about you will not be used, instead the transcript will include a participant ID number which is unique to you.

(4) Do I have to be in the study? Can I withdraw from the study once I have started?

Participating in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your access to healthcare services or social care support.

If you decide to take part in the study, you can withdraw your consent without providing a reason and your interview recording and transcript can be deleted following the interview. However, once the data analysis process has been completed (when an interview is reviewed and analysed together with all the other interviews) you are able to withdraw from the study but your data can no longer be removed.

You can withdraw your consent by contacting the research student or primary supervisor via email at any time (contact details are provided above). You do not have a provide a reason for withdrawing.

(5) What are the consequences if I withdraw from the study?

Prior to the interview you can withdraw from the study and your name, contact details and research data will be permanently deleted from the study records. During the interview you are free to stop at any time. Any recordings to that point will be used in the analysis process unless you request for them to be erased. In that case the information you have provided will be deleted and will not be included in the study results. You may also decline to answer any specific questions during the interview.

If you decide to withdraw from the study after being interviewed, we will remove your information from our records and your data will not be included in any results, up to the point we have analysed the results.

(6) Are there any risks or costs associated with being in the study?

If you participate you will spend approximately one hour being interviewed: you can choose when the interview takes place so that it is at a time which suits you. Parents may find recalling and talking about their child's injury and delivering physiotherapy exercises emotional and challenging. You are welcome to bring a supportive adult with you to the interview (e.g., a partner or friend). You are also able to request for the interview to be paused at any time; the interview will only resume once you feel happy for it to. If you want to stop the interview, this will be done immediately. You can then reschedule the interview with the research student, or withdraw from the study.

At the end of the interview you will have a discussion with the research student to reflect on what was talked about during the interview (this is referred to as a debrief). You will also be supported by the research student to access additional support if this is required, as outlined below.

Seeking support following the interview

If you appreciate emotional support following the interview, please complete a self-referral form and send it to the Child Brain Injury Trust counselling service. More information can be found at https://childbraininjurytrust.org.uk/counselling-project/. You can also contact the Child Brain Injury Trust via telephone: 01869 341075.

If you would like support for your own health, your child's health or your child's rehabilitation following the interview, we recommend that you contact your own GP or a relevant health professional. In the event that there is a legal requirement to share your information, the research student will do this in accordance with the appropriate legal and University procedures.

(7) Are there any benefits associated with being in the study?

A key benefit of taking part in the study is that you will be helping to improve the current understanding of parents’ experiences of delivering physiotherapy exercises to their child following a traumatic brain injury. The study findings will be published and shared with health professionals which can influence practice and how services are run for families affected by traumatic brain injury. Importantly, you will also contribute to the development of a new app and website designed to support parents.

(8) What will happen to information provided by me and data collected during the study?

The information you provide, and research data collected during the study will be stored securely in password protected files within the University of East Anglia’s computer system. Your identity will be kept strictly confidential at all times and will not be shared with anyone else. Only the research student and primary supervisor will have access to information about out. A unique code using letters and numbers (participant ID) will be assigned to a written copy of your interview so that nobody is able to link the interview to you personally.

Study findings will be published, but you will not be identified in these publications. This means that short extracts of your interview may be used in written form to be published, used in presentations and included in the research student’s PhD thesis, which will be available in the public domain. Again, this will be anonymised using your participant ID so that nobody will be able to connect the short extracts with you personally.

Your personal data and information will only be used as outlined in this Participant Information Sheet, unless you consent otherwise. Data management will follow the Data Protection Act 2018 (DPA 2018) and UK General Data Protection Regulation (UK GDPR), and the University of East Anglia's Research Data Management Policy.

Storage of data after the study is finished

Your data will be stored securely in password protected files within the University of East Anglia's computer system. Your research data will be permanently deleted as soon as it is no longer required, and certainly by the end of the research student's doctoral research (when they finish their PhD) in August 2024.

An anonymised copy of your interview transcript will be kept and securely stored for at least 10 years in passwork protected files within the Cambridge University Hospitals server, in agreement with the Research and Development service. Only the research student will have access to the anonymised transcript and it will not be accessible by members of the public. Future researchers or professionals with a legitimate interest in the area may make requests to the research student for access to the transcript for research and educational purposes only. Any requests will be considered on an individual basis by the research student and Cambridge University Hospitals Research and Development service.

(9) What if I would like further information about the study?

When you have read this information sheet, David Young is happy to discuss it with you further and answer any questions you may have. David is contactable by email or telephone as detailed above.

(10) Will I be told the results of the study?

Yes, you will recieve a summary of the research study once it has been completed. This will take the form of a one page summary of the research study.

You also have the opportunity to be involved in co-development workshops where the design of the rehabilitation app will be discussed. Please indicate on the consent form if you would like to receive more information about this.

(11) What if I have a complaint or any concerns about the study?

If you have any concerns, please contact David Young via email or telephone (contact details can be found above). If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the Dean of the School of Health Sciences, Professor Sally Hardy. Professor Hardy can be contacted by email (s.hardy@uea.ac.uk) or telephone (01603-593940).

(12) How do I know that this study has been approved to take place?

To protect your safety, rights, wellbeing and dignity, all research in the University of East Anglia is reviewed by a Research Ethics Body. This research was approved by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee).

(13) What is the general data protection information I need to be informed about?

According to data protection legislation, we are required to inform you that the legal basis for processing your data as listed in Article 6(1) of the UK GDPR is because this allows us to process personal data when it is necessary to perform our public tasks as a University.

In addition to the specific information provided above about why your personal data is required and how it will be used, there is also some general information which needs to be provided for you:

- The data controller is the University of East Anglia.
- For further information, you can contact the University’s Data Protection Officer at dataprotection@uea.ac.uk
- You can also find out more about your data protection rights at the Information Commissioner's Office (ICO).
- If you are unhappy with how your personal data has been used, please contact the University’s Data Protection Officer at dataprotection@uea.ac.uk in the first instance.

(14) OK, I want to take part – what do I do next?

Please complete the online questionnaire and provide an email address that the research student can contact you on. If you are eligible to participate in the study, after at least one week the research student will contact you by email and ask you to complete the online consent from and arrange a date and time for the interview.

(15) Further information

This information was last updated on 23rd May 2022.

This Participant Information Sheet is for you to keep

Appendix 12: Parent interviews - Consent form

PARTICIPANT CONSENT FORM

I, ... [PRINT NAME], **am** willing to participate in this research study.

In giving my consent I state that:

- I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.
- I have read the Participant Information Sheet, which I may keep, for my records, and have been able to discuss my involvement in the study with the research student if I wished to do so.
- The research student has answered any questions that I had about the study and I am happy with the answers.
- I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of East Anglia (or Cambridge University Hospitals) now or in the future.
- I confirm that I am 18 years of age or older.
- I understand that I may stop the interview at any time if I do not wish to continue. Any recordings to that point will be used in the analysis process, unless I request for them to be erased, in which case the recording and any information I have provided (research data) will be deleted and not be analysed or included in the study results.
- I understand that I may decline to answer any specific questions I do not wish to answer during the interview.
- I understand that my interview may be transcribed by an individual outside of the research team.
- I understand that I am able to withdraw from this study following the interview and can request for my research data to be deleted, until the point that the results have been analysed.
- I understand that the results of this study will be published, but that any publications will not contain my name or any identifiable information about me.
- I understand that personal information about me that is collected over the course of this study will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.
- I understand that the data collected in this study will be stored securely in digital files at the University of East Anglia and be accessible only to the research student and primary supervisor.
- I understand that in future, an anonymised version of my interview transcripts will be shared with Cambridge University Hospitals for storage and may be made available for scholarly and educational purposes only, as outlined in the Participant Information Sheet.

I consent to:

Audio-recording of the interview
YES ☐ NO ☐

Video-recording of the interview (Zoom interview only)
YES ☐ NO ☐

Reviewing my transcript after the interview

YES ☐ NO ☐

Storing my personal details so that the research student can make contact with me about co-development workshops and future research opportunities
YES ☐ NO ☐

Storing and use of data as described
YES ☐ NO ☐

Sharing an anonymised copy of my interview transcript with Cambridge University Hospitals for storage
YES ☐ NO ☐

Participate in this study
YES ☐ NO ☐

As you are completing an online consent form, you are unable to provide your written signature. Instead, please provide your electronic signature by marking the box below.

☐
Electronic signature

………………………………………………………………
PRINT name

………………………………………………………………
Date

Appendix 13: Parent interviews – Interview topic guide

Interview topic guide

Version 1, 12/04/2022

Research student: David Young, University of East Anglia

Please note, this interview topic guide is indicative of the types of questions which will be asked in the semi-structured participant interviews. The questions asked during the interview will depend on the participant.

Introduction from David (research student)

- Introduce myself and reason for the interview.
- Thank the participant for agreeing to participate and offer them the opportunity to ask any remaining questions.
- Reiterate that the participant should only answer questions that they feel comfortable to answer during the interview, and that they are able to pause or stop the interview at any time.
- Check the participant is in a quiet and comfortable location where they are happy to be for the duration of the interview (approximately one hour).
- Offer support to blur or change background image.

Research student starts recording

- Confirm participant's name, participant ID, date of interview.
- Re-confirm consent verbally to participate and record the interview.

Start interview questions

- Establish history of child's injury and hospital admission.

Questions about the participant's experience of physiotherapy

- Questions about meeting the physiotherapist(s) in hospital.
- How did the physiotherapist(s) support the participant to learn and understand physiotherapy exercises?

Questions about influences on delivering physiotherapy at home

- Questions about the participants thoughts, experiences, emotions towards leaving hospital and delivering physiotherapy exercises at home.
- Was there anything that made it easier or more difficult to deliver the physiotherapy exercises that had been recommended?
- Did the participant's experience of delivering physiotherapy exercises change over time?

Questions about possible content of the intervention

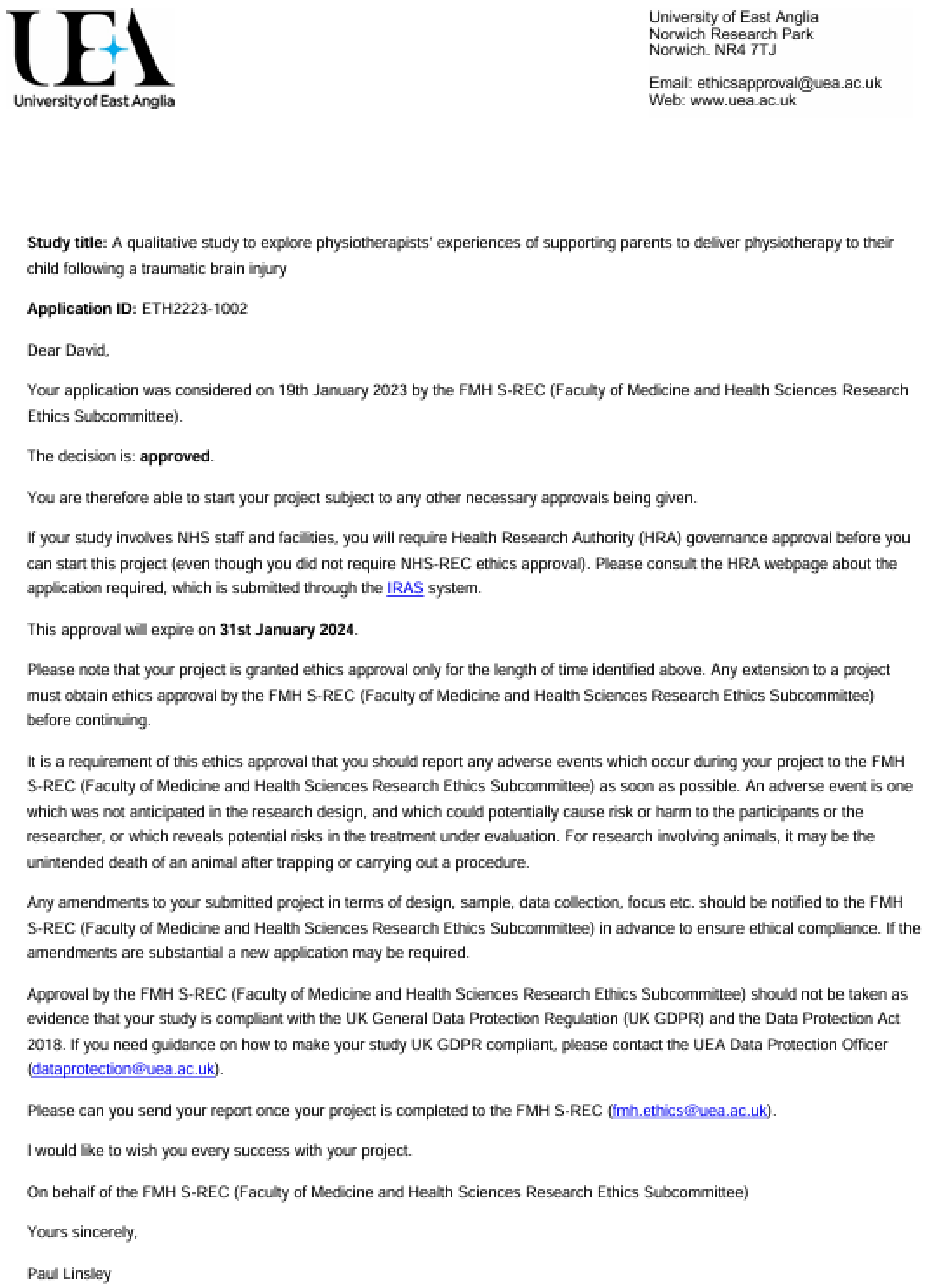
- What does the participant think is important to include in an app which supports parents to deliver physiotherapy exercises at home?

Research student stops recording

- Debrief following the interview led by the research student.
- Thank the participant for their participation in the interview.

End of interview

Appendix 14: Physiotherapy focus groups - Ethical approval



University of East Anglia
Norwich Research Park
Norwich. NR4 7TJ

Email: ethicsapproval@uea.ac.uk
Web: www.uea.ac.uk

Study title: A qualitative study to explore physiotherapists' experiences of supporting parents to deliver physiotherapy to their child following a traumatic brain injury

Application ID: ETH2223-1002

Dear David,

Your application was considered on 19th January 2023 by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee).

The decision is: **approved**.

You are therefore able to start your project subject to any other necessary approvals being given.

If your study involves NHS staff and facilities, you will require Health Research Authority (HRA) governance approval before you can start this project (even though you did not require NHS-REC ethics approval). Please consult the HRA webpage about the application required, which is submitted through the IRAS system.

This approval will expire on **31st January 2024**.

Please note that your project is granted ethics approval only for the length of time identified above. Any extension to a project must obtain ethics approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) before continuing.

It is a requirement of this ethics approval that you should report any adverse events which occur during your project to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) as soon as possible. An adverse event is one which was not anticipated in the research design, and which could potentially cause risk or harm to the participants or the researcher, or which reveals potential risks in the treatment under evaluation. For research involving animals, it may be the unintended death of an animal after trapping or carrying out a procedure.

Any amendments to your submitted project in terms of design, sample, data collection, focus etc. should be notified to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) in advance to ensure ethical compliance. If the amendments are substantial a new application may be required.

Approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) should not be taken as evidence that your study is compliant with the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. If you need guidance on how to make your study UK GDPR compliant, please contact the UEA Data Protection Officer (dataprotection@uea.ac.uk).

Please can you send your report once your project is completed to the FMH S-REC (fmh.ethics@uea.ac.uk).

I would like to wish you every success with your project.

On behalf of the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee)

Yours sincerely,

Paul Linsley

Appendix 15: Physiotherapy focus groups – Letter from Dr Jane Simmonds

THE ASSOCIATION OF PAEDIATRIC CHARTERED PHYSIOTHERAPISTS

A Professional Network of the Chartered Society of Physiotherapy

David Young
Paediatric Physiotherapist
School of Health Sciences
University of East Anglia

APCP Research Officer

research@apcp.org.uk

4-10-2022

Dear David

The APCP is delighted to support the recruitment of paediatric physiotherapists for your research project supporting parents of children with Traumatic Brain Injury (TBI) to deliver rehabilitation to their child after returning home from hospital.

You will need to provide evidence of ethical approval prior to us circulating the recruitment advertisement.

Best wishes for your research.

Jane Simmonds

APCP Research Officer

For information on all APCP activities visit:

http://apcp.csp.org.uk

Appendix 16: Physiotherapy focus groups – Recruitment email

Research advertisement to be circulated by the Association of Paediatric Chartered Physiotherapists to members of the professional network

Version 1.0, 02/11/2022
Research student: David Young, University of East Anglia

Subject: Information about a research study – Exploring physiotherapists' experience of supporting parents to deliver physiotherapy

Attachment: Participant Information Sheet

Dear APCP members,

Are you a qualified physiotherapist with experience of delivering rehabilitation to children and young people (up to 18 years of age) following traumatic brain injury?

Do you have experience of supporting parents and carers to learn physiotherapy exercises to be continued at home following discharge from hospital?

If so, please consider taking part in an online discussion (focus group) with other physiotherapists. The focus group is specifically seeking to understand your experiences of working with children and families following traumatic brain injury and how you support parents to learn and deliver physiotherapy exercises at home.. By participating, you will be helping to inform the design of a rehabilitation smartphone app (digital intervention) to support parents to deliver rehabilitation at home. Your involvement from the very start of the design process is crucial for developing the best possible support.

If you would like to participate, please following the below link or scan the QR code and complete a short online questionnaire (which should take no longer than 5 minutes to complete). You will also be able to download the Participant Information Sheet for more details about the study. If you are eligible and selected to participate you will then be sent a link to the online consent form.

Feel free to contact David Young, paediatric physiotherapist and research student conducting this study as part of his NIHR funded PhD research (NIHR301583), with any questions.

You can contact David by email: david.k.young@uea.ac.uk

[Insert hyperlink]

[Insert QR Code]

Appendix 17: Physiotherapy focus groups – Participant Information Sheet

Participant Information Sheet

Version 1.0, 08/12/2022

Research student: David Young, University of East Anglia

Faculty of Medicine and Health Sciences
School of Health Sciences
University of East Anglia
Norwich Research Park
Norwich NR4 7TJ
United Kingdom
University of East Anglia

(1) What is this study about?

You are invited to take part in a research study which aims to explore physiotherapists' experiences of supporting parents to deliver physiotherapy exercises to their child following a traumatic brain injury. You can participate in this study if you are a qualififed physiotherapist with direct experience of supporting children and young people as well as their families following a traumatic brain injury. We are particularly interested to hear **your experiences of supporting parents to deliver physiotherapy exercises to their child at home** after leaving hospital. You will participate in an online group discussion (focus group) with other qualified physiotherapists, so you will be part of a group of professionals discussing your experiences. The focus group will last approximately one hour.

This study is being conducted to help understand physiotherapists' experiences, and explore what helps or makes it harder for you to educate and support parents to deliver physiotherapy exercises to their child at home. Findings will be used to inform the development of a new smartphone application (app) and website designed to support parents to deliver physiotherapy. Whilst the term *parents* is used throughout this leaflet, please be aware that this also includes *legal guardians* who may be involved in delivering physiotherapy in the home environment.

This Participant Information Sheet tells you about the research study. Knowing what is involved will help you decide if you want to take part in the study or not. Please read this sheet carefully and ask David Young (research student) questions about anything that you don't understand or want to know more about. David can be contacted in the following ways;

Email: david.k.young@uea.ac.uk
Telephone: 07960034610.

Participation in this research study is voluntary. By giving consent to take part in this study you are telling us:

- ✓ You understand what you have read in this Participant Information Sheet, version 1.0, dated 08/12/2022.
- ✓ You agree to take part in the research study as outlined below.
- ✓ You agree to the use of your personal information as described below.
- ✓ You have received a copy of this Participant Information Sheet to keep.

(2) Who is running the study?

The study is being carried out by paediatric physiotherapist and research student, David Young, based at the University of East Anglia and Cambridge University Hospitals NHS Foundation Trust. David is completing this research as part of his PhD, funded by the National Institute for

Health and Care Research (NIHR301583); for more information see https://fundingawards.nihr.ac.uk/award/NIHR301583. David will conduct the interviews as a researcher and will not be able to comment on physiotherapy treatment approaches or services designed to support children's rehabilitation. We recommend that you contact the Association of Paediatric Chartered Physiotherapists or seek support locally within your place of work if you like like to discuss more about the care for children and young people after traumatic brain injury following the focus group.

This study is taking place under the supervision of Professor Wendy Hardeman, University of East Anglia (w.hardeman@uea.ac.uk), Dr Kath Mares, University of East Anglia, and Dr Robbie Duschinsky, University of Cambridge. This study is also taking place with the collaboration of the Association of Paediatric Chartered Physiotherapists, a recognised Professional Network of the Chartered Society of Physiotherapy.

(3) What will the study involve for me?

If you would like to be considered for an online group discussion (focus group), please click on the hyperlink and complete the short online questionnaire. The questionnaire should take no longer than 5 minutes to complete and relates to you and your professional background [insert hyperlink]. We will use your responses to make sure that you are eligible to take part in a focus group. Please provide a valid email address that you are happy to be contacted on by the research student about the study. By providing your email address you are giving consent to your name and email address being securely stored in relation to this study (for more information please see section 8. ‘What will happen to information provided by me and data collected during the study?’). You will also have the option of providing a contact telephone number which will be securely stored in the same way.

After completing the online questionnaire, after at least three working days the research student will contact you by email (or telephone if they he is unable to reach you by email) if you are eligible to take part in this research study. He will answer any questions or concerns you may have about the research. He will also provide you with information about how to complete an online consent form (a form which says that you agree to taking part in the study) and confirm arrangements for the online focus group. If you are not eligible to participate in a focus group or you complete the questionnaire after recruitment is completed, the research student will contact you be email explaining why are unable to participate.

The focus group

The focus group will take place online via Zoom. It is anticipated that the focus group will take approximately one hour. Participants in the focus group will be asked a series of questions about their experiences of supporting parents to learn and deliver physiotherapy exercises to their child, what was helpful and what made it challenging. We are also interested to know what you think should be included in an app to support physiotherapists’ empowerment of parents to deliver physiotherapy. Participants will take part in a short debrief with the research student following the interview.

The online interview will be recorded on Zoom and also on an audio recorder as a back-up. This is so that following the interview the researcher can accurately recall what was discussed; participants are free to turn off their camera during the interview.

Once the study has finished, you will also receive a summary of the findings of the study by email.

Anonymisation

Following the interview, a word for word version of what was said (a verbatim transcript) will be written. The transcript will be anonymised so that nobody will be able to link your participation in the focus group back to you personally. Your name or any details about you will not be used, instead the transcript will include an anonymous participant ID number which is unique to you.

(4) Do I have to be in the study? Can I withdraw from the study once I have started?
Participating in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect you, your employment or your access to healthcare services or social care support in any way.

If you decide to take part in the study, you can withdraw your consent at any time without providing a reason. If you withdraw from the study before participating in a focus group, your personal details and data will be permanently removed from the research student's password protected files at the earliest opportunity. If you withdraw from the study during or following the focus group, data will be used in the analysis process and cannot be removed due to the nature of discussion within a focus group (i.e., participants respond to one another during the discussion, therefore it is not possible to remove what one individual has said from overall dialogue of the focus group). You may however request that your data is not directly quoted when reporting the results of the study; you can make this request by contacting either the research student or primary supervisor (please find contact details above). Once the data analysis process is completed, you have the right to withdraw from the study, however your data cannot be removed, as outline above.

You are free to withdraw your consent at any time by contacting the research student or primary supervisor via email (contact details are provided above). You do not have a provide a reason for withdrawing.

(5) What are the consequences if I withdraw from the study?
Prior to the focus group, you can withdraw from the study and your name, contact details and research data will be permanently deleted from the study records. During and following the focus group, you are free to withdraw at any time. If you decide to withdraw, your data will be used in the analysis process and cannot be removed due to the nature of discussion within a focus group (as detailed above in section 4).

You may decline to answer any specific questions during the focus group, or not contribute to the discussion if you choose not to.

(6) Are there any risks or costs associated with being in the study?
If you participate you will spend approximately one hour taking part in a focus group: the focus group will be held a suitable time so that those wishing to attend are able to do so (for example, in the evening which falls outside of typical working times).

Physiotherapists may find recalling details about emotionally challenging situations difficult. You are free to not contribute to the discussion where you wish not to. You are also free to leave the focus group at any time and you have the option to withdraw from the study altogether.

At the end of the interview you will have a group discussion with the research student to reflect on what was discussed during the focus group (this is referred to as a debrief).

Seeking support following the interview

If you would like to seek professional support following the interview, please contact the Association of Paediatric Chartered Physiotherapists by completing their online form (available from https://apcp.csp.org.uk/contact-apcp).

If you would like to speak to someone in relation to your own place or work, we recommend you contact your line manager in the first instance. In the event that there is a legal requirement to share your information, the research student will do this in accordance with the appropriate legal and University procedures.

(7) Are there any benefits associated with being in the study?

A key benefit of taking part in the study is that you will be helping to improve the current understanding of physiotherapists' experiences of supporting parents to learn and deliver physiotherapy exercises to their child following a traumatic brain injury. In addition, you will be aiding understanding of how support for parents can be improved. The study findings will be published and shared with other health professionals which can influence practice and how services are run. Importantly, you will also contribute to the development of a new app and website designed to support parents to deliver physiotherapy.

(8) What will happen to information provided by me and data collected during the study?

The information you provide, and research data collected during the study will be stored securely in password protected files within the University of East Anglia's OneDrive system. Your identity will be kept strictly confidential at all times and will not be shared with anyone else. Only the research student and primary supervisor will have access to information about out. A unique code using letters and numbers (participant ID) will be assigned to a written copy of the focus group discussion so that nobody is able to link your participation in the focus group to you personally.

Study findings will be published, but you will not be personally identified in these publications. This means that short extracts of your contributions to the focus group may be used in written form to be published, used in presentations and included in the research student's PhD thesis, which will be available in the public domain. Again, this will be anonymised using your participant ID so that nobody will be able to connect the short extracts with you personally.

Your personal data and information will only be used as outlined in this Participant Information Sheet, unless you consent otherwise. Data management will follow the Data Protection Act 2018 (DPA 2018) and UK General Data Protection Regulation (UK GDPR), and the University of East Anglia's Research Data Management Policy.

Storage of data after the study is finished

Your data will be stored securely in password protected files within the University of East Anglia's OneDrive system. Your research data will be permanently deleted as soon as it is no longer required, and certainly by the end of the research student's doctoral research (when they finish their PhD) in August 2024.

An anonymised copy of the focus group transcript will be kept and securely stored for at least 10 years in password protected files within the Cambridge University Hospitals server, in agreement with the Research Design Service. Only the research student will have access to the anonymised transcript and it will not be accessible by members of the public. Future researchers or professionals with a legitimate interest in the area may make requests to the research student for access to the transcript for research and educational purposes only. Any requests will be considered on an individual basis by the research student and Cambridge University Hospitals Research Design Service.

(9) What if I would like further information about the study?
When you have read this information sheet, David Young is happy to discuss it with you further and answer any questions you may have. David is contactable by email or telephone as detailed above.

(10) Will I be told the results of the study?
Yes, you will recieve a summary of the research study once it has been completed. This will take the form of a one page summary of the research study.

You also have the opportunity to be involved in co-development workshops where the design of the rehabilitation app will be discussed amongst parents, physiotherapists, app developers and other key stakeholders. Please indicate on the consent form if you would like to receive more information about this.

(11) What if I have a complaint or any concerns about the study?
If you have any concerns, please contact David Young via email or telephone (contact details can be found above). If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the Dean of the School of Health Sciences, Professor Kenda Crozier. Professor Crozier can be contacted by email (k.crozier@uea.ac.uk) or telephone (01603-593940 ext. 7094).

(12) How do I know that this study has been approved to take place?
To protect your safety, rights, wellbeing and dignity, all research in the University of East Anglia is reviewed by a Research Ethics Body. This research was approved by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee).

(13) What is the general data protection information I need to be informed about?
According to data protection legislation, we are required to inform you that the legal basis for processing your data as listed in Article 6(1) of the UK GDPR is because this allows us to process personal data when it is necessary to perform our public tasks as a University.

In addition to the specific information provided above about why your personal data is required and how it will be used, there is also some general information which needs to be provided for you:

- The data controller is the University of East Anglia.
- For further information, you can contact the University's Data Protection Officer at dataprotection@uea.ac.uk
- You can also find out more about your data protection rights at the Information Commissioner's Office (ICO).
- If you are unhappy with how your personal data has been used, please contact the University's Data Protection Officer at dataprotection@uea.ac.uk in the first instance.

(14) OK, I want to take part – what do I do next?
Please complete the online questionnaire and provide an email address that the research student can contact you on. If you are eligible to participate in the study, after at least three

working days the research student will contact you by email and ask you to complete the online consent from.

(15) Further information

This information was last updated on 8th December 2022.

This Participant Information Sheet is for you to keep

Appendix 18: Physiotherapy focus groups – Eligibility and socio-demographics questionnaire

Participant Eligibility and Socio-Demographics Questionnaire
Version 1.0, 08/12/2022

Research student: David Young, University of East Anglia

Thank you for your interest in our study.

Please complete the following questionnaire which should take you no longer than 5 minutes to complete. The research student will use your responses to ensure that you are able to participate in this study which will involve an online discussion (focus group) with other qualified physiotherapists.

Please follow the link below to the Participant Information Sheet if you do not already have a copy. Please download the Participant Information Sheet which provides more information about the study and keep a copy for your own records: [Insert Link]

If you have any questions about this study, please contact David Young (research student at the University of East Anglia) via email david.k.young@uea.ac.uk or telephone (07960-034610).

By completing the questionnaire and ticking the box below, you are providing your consent to the research student using your anonymised responses in this study, as well as the secure storage of your name and contact details on the University of East Anglia's server. Your details will be saved in a password protected file and will be used only in relation to this study and not shared with anyone else.

By ticking 'agree' below, you are providing your electronic signature and giving consent for your name, contact details and questionnaire responses to be securely stored on the University of East Anglia's server and for the research student (David Young) to contact you by email about this study.

☐ Agree

Please complete all mandatory questions which have a *

1. What is your name? *

   Name:

2. What is your current Agenda for Change banding (or equivalent) within your place of work? * (please select one)

   Band 5 / Band 6 / Band 7 / Band 8 / Other:

3. How long have you been a qualified physiotherapist?

Response in years

4. Do you have direct experience of caring for children and young people following a traumatic brain injury? *
   - ○ Yes
   - ○ No

If yes, please provide more information about your experience in the box below

☐

5. How many years of experience do you have of caring for children and young people following traumatic brain injury as a qualified physiotherapist?

   Response in years

6. How would you describe your current place of employment?
   - ○ NHS - Major Trauma Centre
   - ○ NHS - Trauma Unit
   - ○ NHS – Other acute setting
   - ○ NHS – Community service
   - ○ Specialist centre for rehabilitation
   - ○ Charity
   - ○ Private practice
   - ○ Other

Please provide any further relevant information about your place of work below

☐

7. Do you have any additional qualifications relevant to your profession? * (please select one)

   No / Higher degree (e.g., Masters or PhD) / Specialist training / Other:

8. How would you describe your employment status? * (please select one)

   Employed full time / Employed part time / Self-employed

9. If you are eligible to participate in this study, would you be happy to take part in an online group discussion (focus group) via Zoom? *
   - ○ Yes
   - ○ No

   If yes, do you have access to a smartphone, computer, laptop or tablet which has access to the internet? *
   - ○ Yes
   - ○ No

Thank you for completing the questionnaire.

If you are interested in participating in this study, please type a valid email address in the box below on which you are happy for the research student to contact you about this study*.

Email address:

Please also feel free to provide a telephone number for the research student to contact you on if he is unable to contact you by email

Telephone number:

Appendix 19: Physiotherapy focus groups – Focus group topic guide

Focus group topic guide

Version 2.0, 07/12/2022

Research student: David Young, University of East Anglia

Please note, this focus group topic guide is indicative of the types of questions which will be asked in the focus groups. The questions asked during the focus group will depend on the participants' responses.

Introduction from David (research student)

- Introduce myself and reason for the focus group.
- Thank the participants for agreeing to participate and offer them the opportunity to ask any remaining questions.
- Reiterate that the participants should only take part in discussions that they feel comfortable to.
- Check the participants are in a quiet and comfortable location (if feasible) where they are happy to be for the duration of the focus group (approximately one hour).
- Offer support to blur, change background image or turn off cameras.

Research student starts recording

- Confirm participants names, participant IDs, date of focus group.
- Re-confirm consent verbally to participate and record the focus group.

Start interview questions

- Experiences of working with children and young people following a traumatic brain injury.

Questions about the participant's experiences of supporting parents

- Questions about working with parents in hospital.
- How do physiotherapists approach educating and supporting parents?
- What is important to consider here?
- Are focuses different between the hospital and community settings?

Questions about influences on supporting parents

- Questions about the participants' thoughts and experiences of supporting parents.

- Is there anything that makes it easier or more difficult to support parents?
- How might this support be encouraged / challenges be overcome?
- Which strategies do physiotherapists currently use to support parents to adhere to home-based rehabilitation? Which appear to work well / not work well?
- Do these strategies change according to setting – hospital or home setting?

Questions about possible content of the intervention

- What does the participants think is important to include in an app which supports parents to deliver physiotherapy exercises at home?
- How might an app be integrated into practice? What is needed to support integration?

Research student stops recording

- Debrief following the interview led by the research student.
- Thank the participants for their participation in the interview.

End of interview

Appendix 20: Physiotherapy focus groups – Consent form

Participant consent form

Version 2.0, 08/12/2022

Research student: David Young, University of East Anglia

PARTICIPANT CONSENT FORM

I, ... [PRINT NAME], **am** willing to participate in this research study.

In giving my consent I state that:

- I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.
- I have read the Participant Information Sheet, which I may keep, for my records, and have been able to discuss my involvement in the study with the research student if I wished to do so.
- The research student has answered any questions that I had about the study and I am happy with the answers.
- I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of East Anglia (or Cambridge University Hospitals) now or in the future.
- I confirm that I am 18 years of age or older.
- I understand that the focus group will be recorded (video and audio) for the purpose of transcription, and that I may turn my camera off if I choose to.
- I understand that I may exit the online focus group at any time if I do not wish to continue.
- I understand that I do not have to contribute to the focus group discussion if I do not wish to.
- I understand that the focus group may be transcribed by an individual outside of the research team.
- I understand that I can withdraw from this study following the focus group, however my research data within the focus group cannot be erased. I may request that my data not be directly quoted when reporting the findings of the study by contacting the research student or primary supervisor.
- I understand that the results of this study will be published, but that any publications will not contain my name or any identifiable information about me.
- I understand that personal information about me that is collected over the course of this study will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.
- I understand that the data collected in this study will be stored securely in digital files at the University of East Anglia and be accessible only to the research student and primary supervisor.
- I understand that in future, an anonymised version of focus group transcripts will be shared with Cambridge University Hospitals for storage and may be made available for scholarly and educational purposes only, as outlined in the Participant Information Sheet.

I consent to:

Audio-recording of the focus group
YES ☐ NO ☐

Video-recording of the focus group
YES ☐ NO ☐

Storing and use of data as described
YES ☐ NO ☐

Sharing an anonymised copy of the focus group transcript with Cambridge University Hospitals for storage
YES ☐ NO ☐

Storing my personal details so that the research student can make contact with me about co-development workshops and future research opportunities
YES ☐ NO ☐

Participate in this study
YES ☐ NO ☐

As you are completing an online consent form, you are unable to provide your written signature. Instead, please provide your electronic signature by checking the box below.

☐
Electronic signature

....
PRINT name

....
Date

Appendix 21: User requirements - Workshop facilitator notes

Paediatric Physiotherapy design workshop

Facilitator Notes

—

Alexander Kenney
UBQO Limited

Material

- Laptop & power cable
- Miro Board
- Microsoft Teams (incl. Breakout rooms)

Agenda

11:00 - 11:10

Arrivals

11:10 - 11:20

Technical Setup

- Ensure Miro board is accessible to all
- Ensure break out rooms are setup

11:20 - 11:30

Scene Setting

- Clinical Team: Introduce the project
- Alex: Set the scene and explain why we do these sessions

11:30 - 12:00

Product Vision

Our first activity is orientated towards identifying what success looks like for this project.

Unfortunately 72% of all new products fail. Primarily because of a poor fit between the product and the customers needs. To ensure we are in that 28% of successful products, we need to start thinking about what success looks like AND understand the needs of the customer.

So, let's start by uncovering what we think success looks like. The answers to this will help us to formulate the long term vision for the product.

Activity	In 5 years. Positive headlines.
Explanation	**Imagine it is 5 years in the future and the project has been a roaring success** You are the editor of a newspaper or medical journal. and **you are now writing a headline about this success.** I want you to come up with as many headlines for the product as you can. Write each one on a post it note. At the end of the task we will all come up, put up our post-it notes and read them out to the group.
Example	"App enables hundreds of families to take control of their care"
Time	You have 4 minutes. 4 minutes to discuss.
Format	2 breakout rooms (Clinicians: BLUE; Patients: YELLOW)
Materials	Boat image; Miro board

Activity	In 5 years. Negative headlines.
Explanation	**Now we are 5 years in the future and the product has been an unmitigated disaster.** You are the same editor of a newspaper or medical journal and you are now writing a headline about the disaster. I want you to come up with as many headlines for the product as you can. Write each one on a post it note. At the end of the task we will all come up, put up our post-it notes and read them out to the group.
Example	"App causes families to use incorrect physio guidance".
Time	You have 4 minutes. 4 minutes to discuss.
Format	2 breakout rooms
Materials	Boat image; Miro board

Get each team to go through their canvas briefly. 10 minutes

12:00 - 12:20

Customer Personas

We're now going to shift our focus to understanding our customers. From our research, we have defined distinct personas that we would like to look at in greater depth.

- Patient
- Clinician

Because most products fail due to a poor fit with the needs of their customers, we need to try to understand their needs in much greater depth to increase our chances of success.

To do this, we first need to build a persona for a clinician and a patient.

Activity	Customer Personas
Explanation	**We have created a template for 2 personas. A patient and a clinician.** In your breakout rooms, we would like you to build the persona based on the initial descriptions we have provided.
Example	
Time	You have 5 minutes. 5 minutes to discuss.
Format	2 breakout rooms
Materials	Personas; Miro board

12:20 - 12:25

Understanding Our Customers

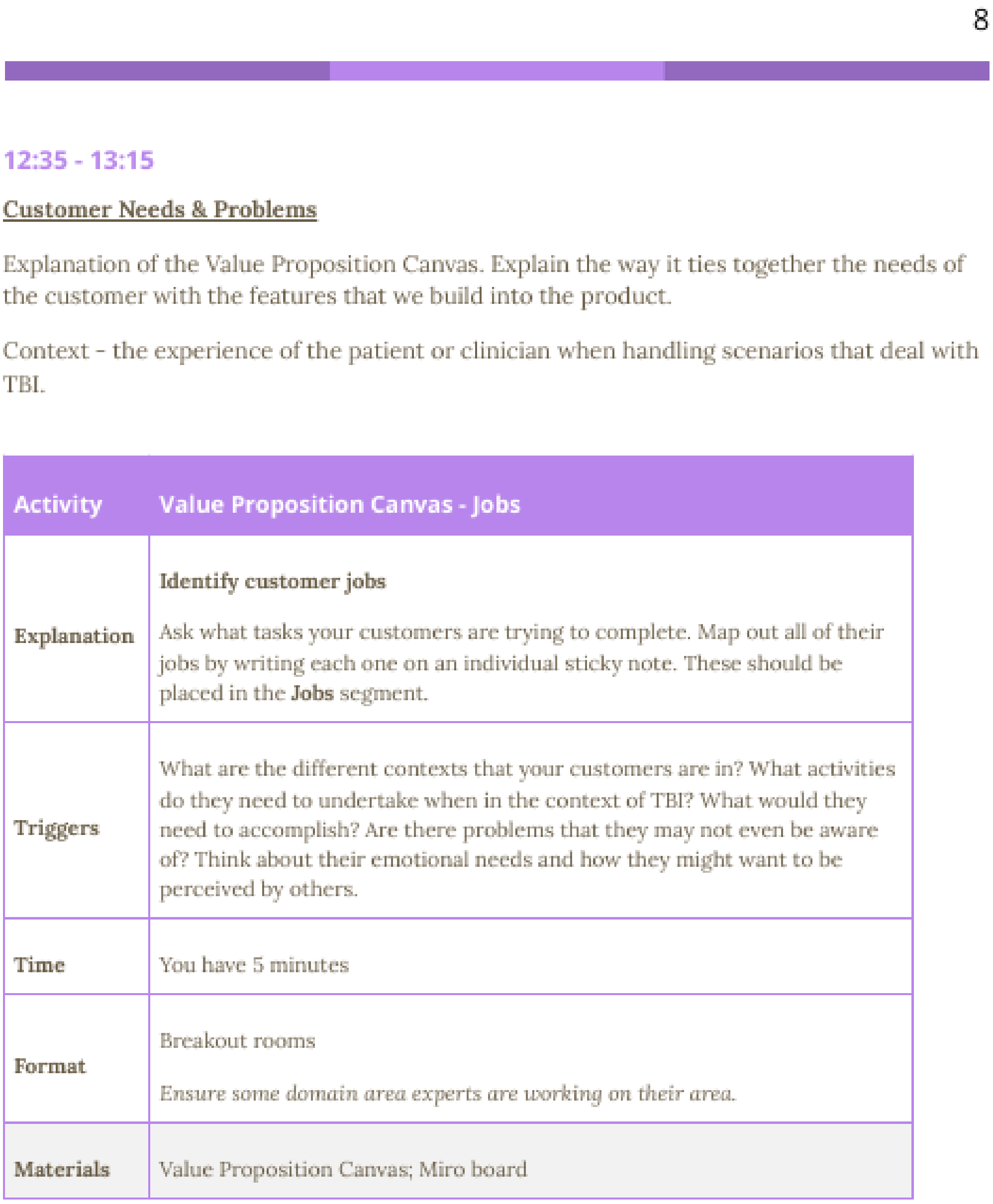
The remaining sessions will look at how these personas interact and navigate the healthcare environment to achieve their aims. Focussing specifically on physiotherapy and the management of traumatic brain injury.

Because most products fail due to a poor fit with the needs of their customers, we need to try to understand their needs in much greater depth to increase our chances of success.

So let's have a break and when we come back in 10 minutes we can start to work through them.

12:25 - 12:35

Break



12:35 - 13:15

Customer Needs & Problems

Explanation of the Value Proposition Canvas. Explain the way it ties together the needs of the customer with the features that we build into the product.

Context - the experience of the patient or clinician when handling scenarios that deal with TBI.

Activity	Value Proposition Canvas - Jobs
Explanation	**Identify customer jobs** Ask what tasks your customers are trying to complete. Map out all of their jobs by writing each one on an individual sticky note. These should be placed in the **Jobs** segment.
Triggers	What are the different contexts that your customers are in? What activities do they need to undertake when in the context of TBI? What would they need to accomplish? Are there problems that they may not even be aware of? Think about their emotional needs and how they might want to be perceived by others.
Time	You have 5 minutes
Format	Breakout rooms *Ensure some domain area experts are working on their area.*
Materials	Value Proposition Canvas; Miro board

Activity	Value Proposition Canvas - Pains
Explanation	**Identify customer pains** What pains do your customers have? Anything that annoys them before, during or after trying to get a job done. Pains also describe risks and potential bad outcomes. Write down as many as you can come up with, including obstacles and risks. These should be placed in the **Pains** segment
Triggers	Do things take too much time or require substantial effort? What are their frustrations or things that give them a headache? How does the current situation under perform? What are the main difficulties and challenges? What risks do they fear? Are there technical risks? Are there barriers to using a new product?
Time	You have 5 minutes

Activity	Value Proposition Canvas - Gains
Explanation	**Identify customer gains** What outcomes and benefits do your customers want to achieve? Write down as many gains as you can come up with. These should be placed in the **Gains** segment
Triggers	What savings in terms of time, money and effort would they value? What quality levels do they look for? What would make your customers jobs / lives easier? What makes your customer look good? Gains can also include positive emotions.
Time	You have 5 minutes

Get each team to go through their canvas briefly. 10 minutes

13:15 - 13:25

Break

13:25 - 13:50

Value Proposition

Activity	Value Proposition Canvas - Pain Relievers
Explanation	**Outline pain relievers** Outline how a potential product or service could help customers alleviate pains by eliminating undesired outcomes, obstacles, or risks. They outline how you intend to eliminate or reduce some of the things that annoy your customers as they complete their jobs. Write down as many as you can come up with. These should be placed in the **Pain Relievers** segment.
Triggers	Use the customer pains as triggers for these relievers. How could the product produce savings of time or money? Could it make the customer feel better? Could it produce better quality outcomes for the customer? Could it reduce fear or the potential for things to go wrong? Could it eliminate worries or help them sleep better at night? Could it eradicate mistakes?
Time	You have 5 minutes
Format	Breakout rooms
Materials	Value Proposition Canvas; Miro board

Activity	Value Proposition Canvas - Gain Creators
Explanation	**Outline gain creators** Explain how your products and services could create expected or desired outcomes and benefits for customers. They outline how you intend to produce outcomes and benefits that customers expect, desire or would be surprised by. Write down as many as you can come up with. These should be placed in the **Gain Creators** segment.
Triggers	How could the product create savings for the customer? Produce outcomes that exceeded their expectations? Make your customers work or life easier? Create positive social consequence? Could the product make adoption easier through lower cost or better performance?
Time	You have 5 minutes

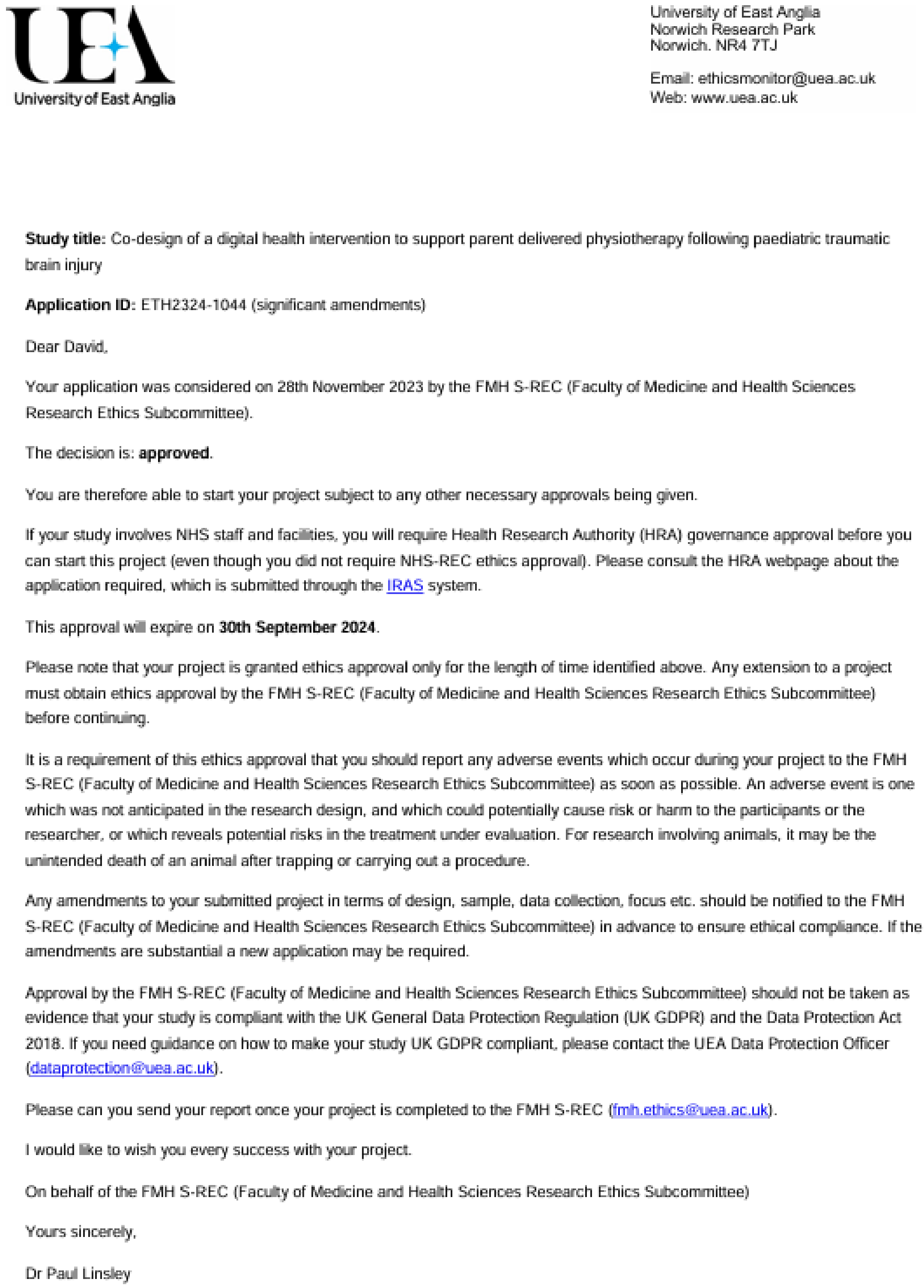
Get each team to go through their canvas briefly. 10 minutes

13:50 - 14:00

Discussion, thank you and that's it!

- Brief discussion on what has been covered
- Thank you
- Will keep people updated on progress

Appendix 22: User requirements – Ethical approval



University of East Anglia
Norwich Research Park
Norwich. NR4 7TJ

Email: ethicsmonitor@uea.ac.uk
Web: www.uea.ac.uk

Study title: Co-design of a digital health intervention to support parent delivered physiotherapy following paediatric traumatic brain injury

Application ID: ETH2324-1044 (significant amendments)

Dear David,

Your application was considered on 28th November 2023 by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee).

The decision is: **approved**.

You are therefore able to start your project subject to any other necessary approvals being given.

If your study involves NHS staff and facilities, you will require Health Research Authority (HRA) governance approval before you can start this project (even though you did not require NHS-REC ethics approval). Please consult the HRA webpage about the application required, which is submitted through the IRAS system.

This approval will expire on **30th September 2024**.

Please note that your project is granted ethics approval only for the length of time identified above. Any extension to a project must obtain ethics approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) before continuing.

It is a requirement of this ethics approval that you should report any adverse events which occur during your project to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) as soon as possible. An adverse event is one which was not anticipated in the research design, and which could potentially cause risk or harm to the participants or the researcher, or which reveals potential risks in the treatment under evaluation. For research involving animals, it may be the unintended death of an animal after trapping or carrying out a procedure.

Any amendments to your submitted project in terms of design, sample, data collection, focus etc. should be notified to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) in advance to ensure ethical compliance. If the amendments are substantial a new application may be required.

Approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) should not be taken as evidence that your study is compliant with the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. If you need guidance on how to make your study UK GDPR compliant, please contact the UEA Data Protection Officer (dataprotection@uea.ac.uk).

Please can you send your report once your project is completed to the FMH S-REC (fmh.ethics@uea.ac.uk).

I would like to wish you every success with your project.

On behalf of the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee)

Yours sincerely,

Dr Paul Linsley

Appendix 23: User requirements - Eligibility questionnaire

Participant eligibility questionnaire, v1.0, 11/07/2023

Co-design of a digital health intervention to support parent delivered physiotherapy following paediatric traumatic brain injury

Research student: David Young, University of East Anglia

Thank you for your interest in our study.

Please complete the following questionnaire which should take you no longer than 5 minutes to complete. The research student will use your responses to ensure that you are able to participate in this study and take part in an interview.

Please follow the link below to the Participant Information Sheet if you do not already have a copy. Please download the Participant Information Sheet which provides more information about the study and keep a copy for your own records: [Insert Link]

If you have any questions about this study, please contact David Young (research student at the University of East Anglia) via email david.k.young@uea.ac.uk or telephone (07960-034610).

By completing the questionnaire and ticking the box below, you are providing your consent to the research student using your anonymised responses in this study, as well as the secure storage of your name and email address on the University of East Anglia's server. Your details will be saved in a password protected file and will be used only in relation to this study and not shared with anyone else.

By ticking 'agree' below, you are providing your electronic signature and giving consent for your name, email address and questionnaire responses to be securely stored on the University of East Anglia's server and for the research student (David Young) to contact you by email about this study

☐ Agree

Please complete all mandatory questions which have a *

10. What is your name? *

Name:

11. How old are you? *

Age in years:

12. Are you completing this form related to your role as a:
    - ○ Parent or legal guardian
    - ○ Representative of a registered charity based in the United Kingdom or Northern Ireland

If you answered 'Parent or legal guardian', please move to question 7.

If you answered ‘Representative of a registered charity based in the United Kingdom or Northern Ireland’, please complete questions 4-6.

13. Which registered charity do you represent? *

    Charity name:

14. How many years’ experience do you have of supporting children, young people and their families following traumatic brain injury? *

    Number of years:

15. If you are eligible to participate in this study, would you be happy to join online workshops hosted on Microsoft Teams? *
    - ○ Yes
    - ○ No

    If yes, do you have access to a smartphone, computer, laptop or tablet which has access to the internet? *
    - ○ Yes
    - ○ No

Thank you. Please type a valid email address in the box below on which you are happy for the research student to contact you about this study *.

You are also welcome to add a contact telephone number as a second means of communication.

Email address:	Contact telephone number:

16. How would you describe your marital or civil partnership status? * (please select one)

    Single / Married / In a civil partnership / Separated / Divorced / Living with a partner / Prefer not to say / Other:

17. Do you have caring responsibilities for adults or children? *
    - ○ Yes
    - ○ No

    If yes, do you have caring responsibilities for * (please select one)
    - ○ Only adults
    - ○ Only children
    - ○ A mixture of adults and children
    - ○ Other

Please provide more information about your caring responsibilities in the box below

18. What is your highest level of education? * (please select one)

    GSCEs or equivalent / A Levels or equivalent / Apprenticeship / Degree or equivalent / Higher degree (e.g., Masters or PhD) / Other:

19. How would you describe your employment status? * (please select one)

    Employed full time / Employed part time / Self-employed / Unemployed / Zero hours contract / Not working due to caring responsibilities / Not working due to ill health or disability / Studying / Other:

20. How would you describe your ethnicity? * (please select one)

    White / Black Caribbean / Black African / Black other / Chinese / Pakistani / Bangladeshi / Indian / Other Asian / Mixed or multiple ethnic groups / Prefer not to say / Other

21. Are you the parent/legal guardian of a child or young person that sustained a traumatic brain injury when they were below the age of 18? *
    ○ Yes
    ○ No
    If yes, how old were they when they sustained the traumatic brain injury? *
    Age in years:

22. Did your child need to be admitted to hospital following their traumatic brain injury? *
    ○ Yes
    ○ No

23. Was your child in hospital for 3 days or more? *
    ○ Yes
    ○ No
    If yes, how long was your child in hospital for? *

24. Was your child ever admitted to paediatric intensive care? *
    ○ Yes
    ○ No

25. Have you and your child now returned home from hospital? *
    ○ Yes
    ○ No

26. Did a physiotherapist recommend that you deliver physiotherapy exercises to your child at home? *
    ○ Yes
    ○ No

27. If you are eligible to participate in this study, would you be happy to join online workshops hosted on Microsoft Teams? *
    ○ Yes
    ○ No

If yes, do you have access to a smartphone, computer, laptop or tablet which has access to the internet? *

○ Yes
○ No

Thank you for completing the questionnaire.

If you are interested in participating in this study, please type a valid email address in the box below on which you are happy for the research student to contact you about this study *.

You are also welcome to add a contact telephone number as a second means of communication.

Email address:

Contact telephone number:

Appendix 24: User requirements - Consent form

Participant consent form, v2.0, 14/09/2023

Co-design of a digital health intervention to support parent delivered physiotherapy following paediatric traumatic brain injury

Research student: David Young, University of East Anglia

PARTICIPANT CONSENT FORM

I, ... [PRINT NAME], **am willing** to participate in this research study.

In giving my consent I state that:

- I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.
- I have read the Participant Information Sheet, which I may keep, for my records, and have been able to discuss my involvement in the study with the research student if I wished to do so.
- The research student has answered any questions that I had about the study and I am happy with the answers.
- I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of East Anglia (or Cambridge University Hospitals) now or in the future.
- I confirm that I am 18 years of age or older.
- I understand that elements of workshops will be recorded (video and audio) for the purpose of transcription and analysis, and that I may turn my camera off if I choose to.
- I understand that I may exit the online workshops at any time if I do not wish to continue.
- I understand that I do not have to contribute to workshop discussions if I do not wish to.
- I understand that workshops discussions may be transcribed by an individual outside of the research team.
- I understand that I can withdraw from this study following the workshops, however my research data to that point cannot be erased. I may request that my data not be directly quoted when reporting the findings of the study by contacting the research student or primary supervisor.
- I understand that I will have the opportunity to access the prototype physiotherapy app during the study using a 'dummy' (artificial) account – I won't have to use my own name or personal information.
- I understand that feedback I give in the app will be collected by the developers (UBQO Ltd.) and will be permanently deleted once transferred to a dedicated folder within the research student's University of East Anglia OneDrive system.
- I understand that the results of this study will be published, but that any publications will not contain my name or any identifiable information about me.
- I understand that personal information about me that is collected over the course of this study will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.
- I understand that the data collected in this study will be stored securely in digital files at the University of East Anglia and be accessible only to the research student and research team.

- I understand that in future, anonymised versions of workshop discussions and notes will be shared with Cambridge University Hospitals for storage and may be made available for scholarly and educational purposes only, as outlined in the Participant Information Sheet.

I consent to:

Audio- and video-recording of elements of the workshops
YES ☐ NO ☐

The developers (UBQO Ltd.) collecting data from workshops and user-testing and using it to inform the development of the prototype physiotherapy app
YES ☐ NO ☐

Storing and use of data as described
YES ☐ NO ☐

Sharing anonymised versions of workshop discussions and notes with Cambridge University Hospitals for storage
YES ☐ NO ☐

Participate in this study
YES ☐ NO ☐

As you are completing an online consent form, you are unable to provide your written signature. Instead, please provide your electronic signature by checking the box below.

☐
Electronic signature

…………………………………………………………
PRINT name

…………………………………………………………
Date

Appendix 25: User requirements - Participant persona template

Persona template, v1.0, 12/07/2023

Co-design of a digital health intervention to support parent delivered physiotherapy following paediatric traumatic brain injury

Research student: David Young, University of East Anglia

My name is:

____

I am _____ years old **Today's date: __________**

My gender is: __________

My role: Parent Physiotherapist Other

Brief description of my role: ____

Other important caregivers/team members:

Context within which I am based as a parent, physiotherapist or other:

Important tasks that I undertake related to physiotherapy are…

Typical assistive technologies that I interact with/use:

Wheelchair
Mobility aids
Splints
Other:

Standing frame (or similar)
Equipment to support balance
Equipment for other care needs (e.g., suction)
If other, please provide more detail below:

Highlights of my role…

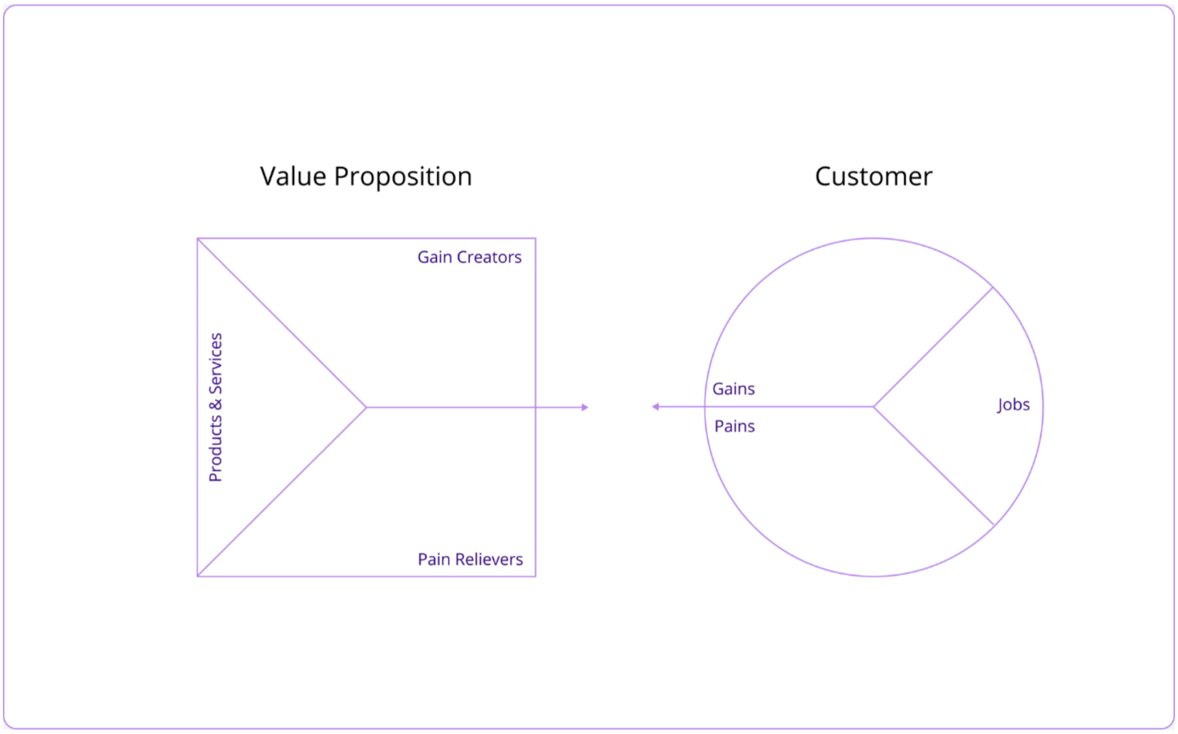
Challenges/frustrations of my role…

What could help me to overcome these challenges/frustrations:

Other important details about me:

-
-
-

Appendix 26: User requirements - Value Proposition Canvas template



Appendix 27: User requirements - Research summaries of the parent interview study and the physiotherapy focus group study

Parent interviews summary

Background

A traumatic brain injury (TBI) happens when outside force causes damage to the brain. Many children and young people are admitted to hospital following a TBI and go on to require rehabilitation from physiotherapists. The aim of physiotherapy is to help the child to regain physical skills such as standing and walking, whilst learning new or different ways of doing day-to-day activities.

Once home from hospital many children will need ongoing physiotherapy. It is widely accepted that parents play a very important role in supporting their child at home following a TBI. This includes supporting improvements in their physical skills and movement by delivering physiotherapy at home (known as a physiotherapy programme).

Having said that, there has been no research looking into parents' experience of meeting physiotherapists in hospital, learning physiotherapy exercises and delivering them at home. This is an important area to investigate if the best support is to be developed and given to parents.

Five parents took part in online interviews between August 2021 and February 2022. Interviews were based on a similar set of questions asked by a research student. Interviews were written into word-for-word accounts and analysed to identify patterns of meaning between them. These patterns are referred to as themes.

Themes

Overall, four themes were developed across the interviews, these are:

Theme 1 - Parents' purpose and motivation

Parents said that their priorities change when their child is in hospital and that they need to be there to support their child. This gives parents a focus and a sense of purpose when their child is in hospital.

Theme 2 - Information needs to be very clear

Parents can experience information overload when their child is in hospital, therefore information needs to be very clear. This includes clear information about why doing physiotherapy with their child is important and understand how and when to deliver the exercises. Clear communication and resources support this.

Theme 3 - Gaining confidence and skills through the learning process

Lots of information is new for parents and learning takes time. Parents gain both the necessary skills and confidence with the right support. Seeing their child make improvements gives parents confidence and helps to motivate them to continue.

Theme 4 - Learning how to integrate physiotherapy into everyday life

When it comes to delivering the physiotherapy exercises at home, parents need to navigate the challenges of everyday life. Learning how to adapt ways of doing physiotherapy and problem solve can be important here.

Implications

The importance of this research is that for the first time, parents have been able to specifically express their experiences of learning and delivering physiotherapy exercises to their child following a TBI. Understanding parents' experiences and factors that support or make delivering physiotherapy harder, provide a basis for better supporting parents. This is important both in the hospital setting but also when leaving hospital and returning home.

These findings will be used to help to develop a rehabilitation app designed to support parents to deliver physiotherapy to their child at home.

Plain English Summary – physio focus groups

Background

A traumatic brain injury (TBI) happens when outside force causes damage to the brain. Many children and young people are admitted to hospital following a TBI and go on to require rehabilitation from physiotherapists. The aim of physiotherapy is to help the child to regain physical skills such as standing and walking, whilst learning new or different ways of doing day-to-day activities.

Physiotherapists work with children and young people as well as their parents and families. This may begin as early as the intensive care unit in a hospital, through to rehabilitation in a ward setting and then in the community once the child returns home. Physiotherapists are experts in supporting the child or young person's movement and recovery. It is also important for them to support parents to be able to also practice exercises and support their child's recovery following TBI. This may happen in the hospital, a rehabilitation setting and in the community. Although this is important, no research to date has explored physiotherapists' experience of supporting parents to learn and deliver physiotherapy exercises.

To explore physiotherapists' experiences, two focus groups were completed online between May to June 2023. Eleven physiotherapists in total took part across the two focus groups and varied in levels of experience and the settings in which they worked. The focus groups were based on a similar set of questions asked by a research student. Word-for-word accounts of the discussions were analysed to identify patterns of meaning between them. These patterns are referred to as themes.

Themes

Overall, four themes were identified across the focus groups, these were:

Theme 1: Actively involving parents as part of the team

Parents play an enormous role in their child's care following a head injury. Physiotherapists actively involve them in caring for their child. This begins in the hospital and continues throughout rehabilitation at home and in the community.

Theme 2: Supporting parental adjustment to life following their child's brain injury

Parents experience enormous challenges and need to adapt and learn new skills following their child's head injury. A physiotherapist's role goes beyond hands-on therapy and helping parents to learn physiotherapy exercises. They support parents to adjust to life following their child's head injury.

Theme 3: Aligning physiotherapy with the interests of the child and parents

It is extremely important for physiotherapists to get to know the child and parents, then make sure that advice and recommendations fit with their interests. This can help parents and children to become involved in physiotherapy.

Theme 4: Working within contextual constraints

Physiotherapists need to be very flexible in the way that they work. They must be able to adapt to different challenges such as where they work – for example, limited space for rehabilitation – where families live compared to the hospital and the pathways of care that children with head injury and their families experience.

Implications

The importance of this research is that for the first time, physiotherapists have expressed their experiences of supporting parents following their child's TBI. Physiotherapists need to be flexible and adaptable in their approaches and the changing needs of parents over time. There is potential for developing more ways that help physiotherapists to work effectively with parents.

These findings will be used to assist in the development of a rehabilitation app which will be used by physiotherapists to support parents to deliver physiotherapy to their child at home.

Appendix 28: User requirements – Meeting summary notes

The following notes have been taken from meetings with the tech developers and PPI representatives following the co-design workshop to ascertain what should be included within the intervention and how the intervention will function. I have summarised the notes from the discussions spanning a three month period (January to March 2024) and have ordered them chronologically.

12.1.24

A meeting between myself and the PPI representative

This meeting involved discussing the workshop data related to hearing from children and parents in their 'own words'. From the physio focus group, there was reference to the F-words of child development which was also mentioned during the workshop.

We discussed how the F-words could be useful in helping to structure goal setting and spoke about the final F-word being 'Future' which could be expanded to include 'Future hopes'. We were in agreement that future hopes related to what the child and parents want to work towards which provides the context for goal setting discussions.

The PPI representative with lived experience of caring for a child with pTBI expressed that the difficulty with goal setting as a set rehabilitation activity is that goals can sometimes feel very distant and not entirely relevant to what the family is experiencing or wanting to work towards. Therefore, goal setting can at times feel like a negative process and the term 'goal' (or synonyms such as 'target' or 'achievement') can be quite loaded words. Instead, the F-words and particularly 'Future hopes' can be a more inclusive and inviting way to support parents and children to express themselves.

It is therefore not goal setting itself which can be challenging, but rather the approach used to get there. Use of the F-words together with collaborative goal setting discussions can be helpful.

16.1.24

A meeting between myself and the technology developers

The discussion focussed on the behaviour change technique 'Problem solving'. According to the BCTTv1, **'Problem solving' is about empowering parents to analyse factors, which help**

overcome barriers or increase facilitators to delivering rehabilitation exercises. Is there a way that the intervention can help to identify / support parents to identify barriers or difficulties and support a way for parents to re-frame and think about the ways to navigate this. This could either relate to retrospective review of problems that have arisen, or proactive completion in preparation for a new context or situation deemed potentially problematic.

It was discussed during the workshop about having a notes page / diary that parents could use to documents thoughts, ideas, questions etc. The notes page could be a helpful resource which could support problem solving through reflection and the analysis of factors which influence physio exercise delivery. It could also be a useful space to support self-monitoring of behaviours.

24.1.24

A meeting between myself and the technology developers

Today we spoke in more detail about the workshop findings and the core components and features of the intervention. We spoke about the F-words providing the basis for goal setting discussions, the physio making related exercise recommendations, parents being able to input what they have done and track the delivery of exercises.

We also spoke about the general resources page and the addition of some helpful information and links for parents to access.

Today I shared my proposition about developing a logic model with the developers and we spoke through how we anticipate the core components of the intervention to function. We discussed the workshop findings and agreed upon the following list of core components for inclusion within the prototype intervention, some of which consist of one or more components:

- Standardised information and education for all users
  - This is to consist of two features:
    - What is physiotherapy and how does it help?
    - ‘The role of family and friends’
- Getting to know the child and parents in their ‘own words’
  - This component is to focus on:
    - Gaining background information using the F-words of childhood development
- Exercise recommendations from the physiotherapist

        - This component is to focus on:
            - Exercise recommendations with written instructions plus picture or video examples to be checked off once completed. The option to add a rating of confidence and/or note to support problem solving will also be important
            - Providing summary feedback and reports
- Features to support access to social support
    - This is to consist of two features:
        - Contact details for physiotherapists
        - A general resources page
- Notes page to aid self-monitoring and support problem solving
    - This is designed to be a blank and flexible space for parents to document questions, thoughts, ideas or reflections. Also a place to upload comments or pictures/videos to celebrate success or achievements their child has made
- Glossary of terms to aid understanding of new medical terms
    - This will include a list of common medical terms to aid understanding

29.1.24

A meeting between myself and the technology developers

The meeting today with the developers was moving a little further along the design process from not only the workshop findings but to consider how the intervention will function.

We spoke about how parents will access the intervention and what they will be required to do to use it. In this sense we had a metaphorical 'walk through' of how the intervention might work and clarified some of the key features within the intervention. I reiterated what was previously discussed about the key features including the F-words of child development to support goal setting discussions and inform physio exercise recommendations. We also spoke in further detail about some of the core features of the intervention. This included the standardised educational and information materials that all users can access, the resources page and physio contact details to support accessing social support, the notes page / diary feature for parents to use, also the glossary of terms.

7.2.24

A meeting between myself, the technology developers and a physiotherapy colleague

In today's meeting we built on the previous discussions about the content and function of the intervention to consider how the current process of parent delivered physiotherapy works.

We spoke through the pathway of care from PICU, to the inpatient wards, to rehabilitation, to discharge. We also spoke through how physiotherapists primarily offer paper-based leaflets of exercises for parents to follow.

The discussion moved on to consider how the digital intervention could be implemented within the exiting pathway of care and how it functions beyond a simple tool for prescribing exercises. For example, the use of the F-words of child development is a feature which is not currently routinely integrated into acute care following pTBI. Also, the fact that confidence ratings and the notes page offer additional means of gathering and storing important information.

There was a consensus within the group that Physio Together could be a good addition to the current pathway of care provided it is well designed and adds value above and beyond what is currently available and used within clinical practice.

8.2.24

A meeting between myself and the PPI representative

Now that the intervention Physio Together is starting to take shape and the core features have been determined, I took the opportunity to demonstrate the working prototype to the PPI representative. I showed them how a parent would access the intervention and demonstrated some of the core components and features that we have agreed upon.

The feedback that I received was very positive and the PPI representative liked how the design very much reflected the findings from the co-design workshop. Feedback and suggestions came in the form of ensuring that clear font and colour schemes are used to support the accessibility for people with dyslexia and other specific learning difficulties, also reducing 'visual noise' to enhance accessibility. There were some additional suggestions about other organisations that can be included within the resources page.

22.2.24

A meeting between myself and the technology developers

Today I met with the technology developers to review the features for Physio Together. We had a long discussion about modifying the text in relation to exercises. One developer felt strongly that structure is important to ensure there is consistency and meaning from the data which is captured. I was representing the view that some modification is really important so that the physio can adapt what is in the description of an exercise to make it more personalised, relevant and meaningful to the patient.

The second developer did a great job of helping us understand the tension here and say that big data sets are important and meaningful, however we are looking at relatively small numbers here where that level of adaptation will be important (e.g., adapting pages one and two of a five page flow). The developer also noted that people in clinical practice will find a 'way round' the block so the data that you think you are capturing, you actually aren't because it isn't being used in the way it was designed to be used.

We also had a broader dialogue around the fact that, for me, being able to say that the parent interacted with the device and delivered 'a balance exercise' leading to on average 'this level of change in confidence', is more important than saying 'balance exercise 1' was delivered and led to this outcome, or 'balance exercise 2' led to this outcome. There are too many factors and variables involved here which make it more complicated and difficult to draw these more linear conclusions.

On reflection, I think a level of structure with some possibility to tweak and adapt certain elements is important and will lead to a useful tool for physios working clinically, as well as a means of capturing and analysing data in a meaningful way.

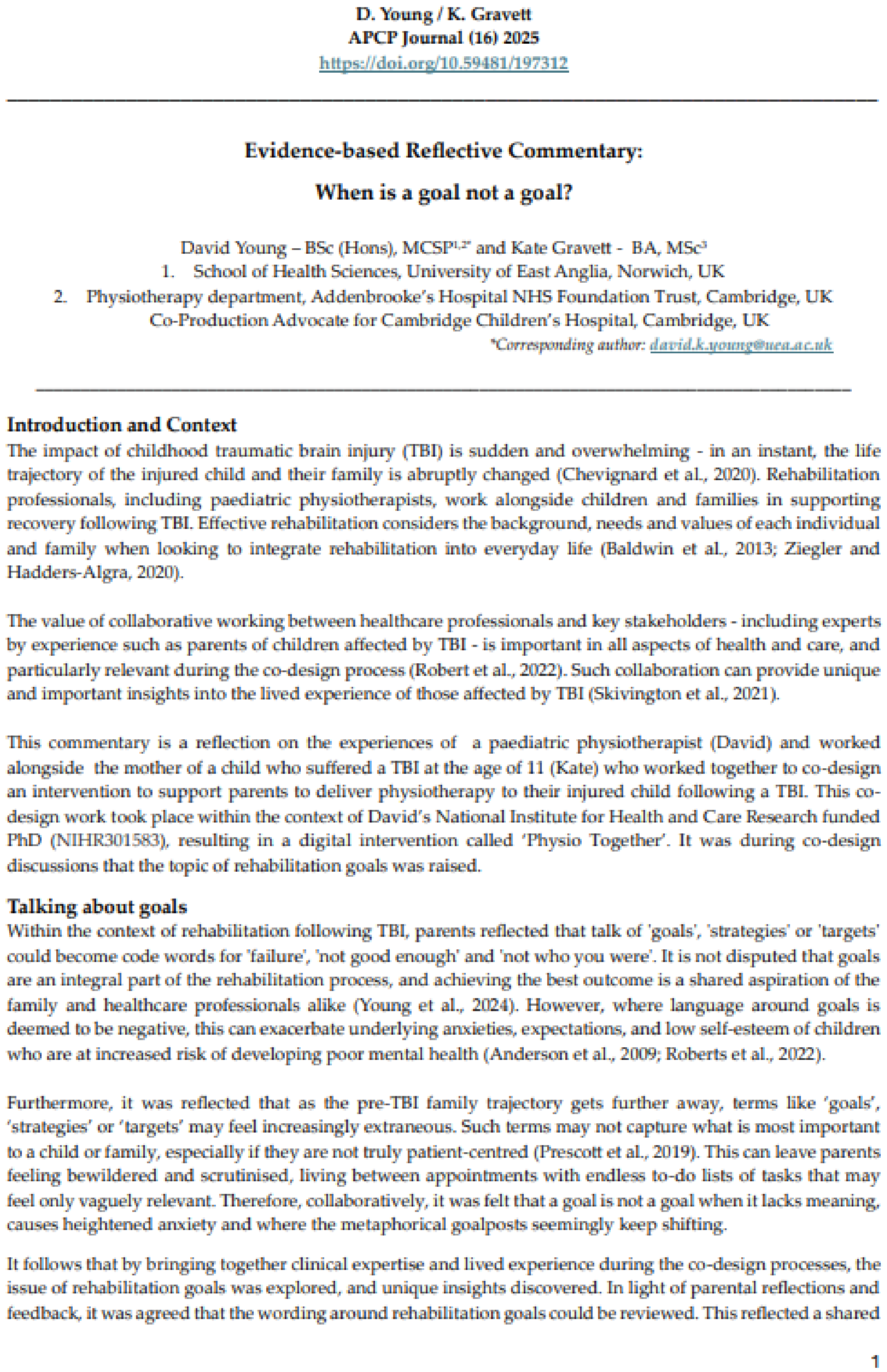
6.3.24

A meeting between myself and the technology developers

Rounding off this stage of initial development of the prototype intervention Physio Together, I met with the technology developers. We discussed that the next stages of development and refinement of the intervention should involve elements of user-testing and feedback. We spoke about use of frameworks such as the Technology Acceptance Model to consider users' perspectives on the perceived usefulness and perceived ease of use of the intervention. These factors directly influence how users consider the acceptability and therefore the adoption of the intervention which can help to inform how it should be refined moving forwards.

Appendix 29: A copy of the evidence-based reflective commentary entitled 'When is a goal not a goal?'

Full reference: Young, D. & Gravett, K. 2025. Evidence-based Reflective Commentary: When is a goal not a goal? *The Association of Paediatric Chartered Physiotherapists Journal,* 16**,** 3-6



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Evidence-based Reflective Commentary:

When is a goal not a goal?

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Introduction and Context

The impact of childhood traumatic brain injury (TBI) is sudden and overwhelming - in an instant, the life trajectory of the injured child and their family is abruptly changed (Chevignard et al., 2020). Rehabilitation professionals, including paediatric physiotherapists, work alongside children and families in supporting recovery following TBI. Effective rehabilitation considers the background, needs and values of each individual and family when looking to integrate rehabilitation into everyday life (Baldwin et al., 2013; Ziegler and Hadders-Algra, 2020).

The value of collaborative working between healthcare professionals and key stakeholders - including experts by experience such as parents of children affected by TBI - is important in all aspects of health and care, and particularly relevant during the co-design process (Robert et al., 2022). Such collaboration can provide unique and important insights into the lived experience of those affected by TBI (Skivington et al., 2021).

This commentary is a reflection on the experiences of a paediatric physiotherapist (David) and worked alongside the mother of a child who suffered a TBI at the age of 11 (Kate) who worked together to co-design an intervention to support parents to deliver physiotherapy to their injured child following a TBI. This co-design work took place within the context of David's National Institute for Health and Care Research funded PhD (NIHR301583), resulting in a digital intervention called 'Physio Together'. It was during co-design discussions that the topic of rehabilitation goals was raised.

Talking about goals

Within the context of rehabilitation following TBI, parents reflected that talk of 'goals', 'strategies' or 'targets' could become code words for 'failure', 'not good enough' and 'not who you were'. It is not disputed that goals are an integral part of the rehabilitation process, and achieving the best outcome is a shared aspiration of the family and healthcare professionals alike (Young et al., 2024). However, where language around goals is deemed to be negative, this can exacerbate underlying anxieties, expectations, and low self-esteem of children who are at increased risk of developing poor mental health (Anderson et al., 2009; Roberts et al., 2022).

Furthermore, it was reflected that as the pre-TBI family trajectory gets further away, terms like 'goals', 'strategies' or 'targets' may feel increasingly extraneous. Such terms may not capture what is most important to a child or family, especially if they are not truly patient-centred (Prescott et al., 2019). This can leave parents feeling bewildered and scrutinised, living between appointments with endless to-do lists of tasks that may feel only vaguely relevant. Therefore, collaboratively, it was felt that a goal is not a goal when it lacks meaning, causes heightened anxiety and where the metaphorical goalposts seemingly keep shifting.

It follows that by bringing together clinical expertise and lived experience during the co-design processes, the issue of rehabilitation goals was explored, and unique insights discovered. In light of parental reflections and feedback, it was agreed that the wording around rehabilitation goals could be reviewed. This reflected a shared conviction that rehabilitation should move away from prescribed lists of exercises to taking part in interesting and meaningful activities (Novak, 2011). This included the idea of 'rehab in disguise', described by Kate as being a way of sustaining positive engagement in personalised and meaningful rehabilitation integrated into family life.

Shifting the language towards participation

The language of the World Health Organization's International Classification of Function, Disability and Health (ICF), can be helpful in moving rehabilitation towards a more participation-based focus (WHO, 2001). Additionally, the F-words of childhood development is a child and family-friendly framework that embeds the words Functioning, Family, Fitness, Fun, Friends, and Future into the ICF and enables a holistic understanding of the child and family context prior to the onset of TBI whilst also guiding rehabilitation and shared decision making (Rosenbaum and Gorter, 2011).

Collaboratively, we propose that the final F-word 'Future' could be expanded to include 'Future hopes'. This provides a shared focus for 'what we are collectively working towards' and offers an alternative way of framing the concept of goals beginning in the acute hospital setting and continuing throughout rehabilitation. Our collaboration revealed that the timing of discussions about 'Future hopes' with families should be a fluid and dynamic process. If done sensitively, considering 'Future hopes' in this way could meaningfully connect rehabilitation with existing interests and passions of the child and family. It could also provide flexibility in capturing and incorporating new interests and endeavours as they change over time.

'Future hopes' – an example

An example of this was shared by Kate, who described how her child participated in a set of beginner Kung Fu classes with other children with TBI, plus siblings if they wished (CBIT, 2016). The classes were part of a collaboration between the Child Brain Injury Trust (CBIT) and Cambridge Centre for Paediatric Neuropsychological Rehabilitation (CCPNR), Notable motor benefits accrued by her child were evident to Kate in the areas of gross motor function, coordination, proprioceptive and vestibular function, and balance. Additionally, other skills critical to cognitive processing, interpersonal communication and social functioning were also fostered. Kung Fu was originally presented as an opportunity to 'learn something new' by doing a familiar activity that peers took part in, however quickly evolved into a 'Future hope' as it became a new-found passion for Kate's child who over time built on the initial skills to become a part-time Kung Fu teacher.

In this example, learning Kung Fu has provided a platform for self-expression whilst fostering new connections with siblings and friends following the TBI (Lyon et al., 2021). Kate reflected that gaining new interests, skills and confidence has been a reciprocal process for both her child and the wider family enabling them to review and reframe meaningful 'Future hopes'.

Conclusion

As each family is unique in its composition and experiences, it is vital in our opinion, to include a trauma-informed and individualised approach to rehabilitation according to the ecology of each family (Hobfoll et al 2007; Baldwin et al., 2013). Outcomes for children and families are reciprocal and bi-directional (Wade et al., 2019; Jenkin et al., 2022), therefore specialists working in this field are fundamental in guiding them from the outset to continue a successful and evolving neurorehabilitation programme. Having a clear means of establishing and relating rehabilitation to what is meaningful to children and families may play an important part in this process.

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Keywords: Physiotherapy; neurorehabilitation; goal setting; F-words of neuro development; family-centred care.

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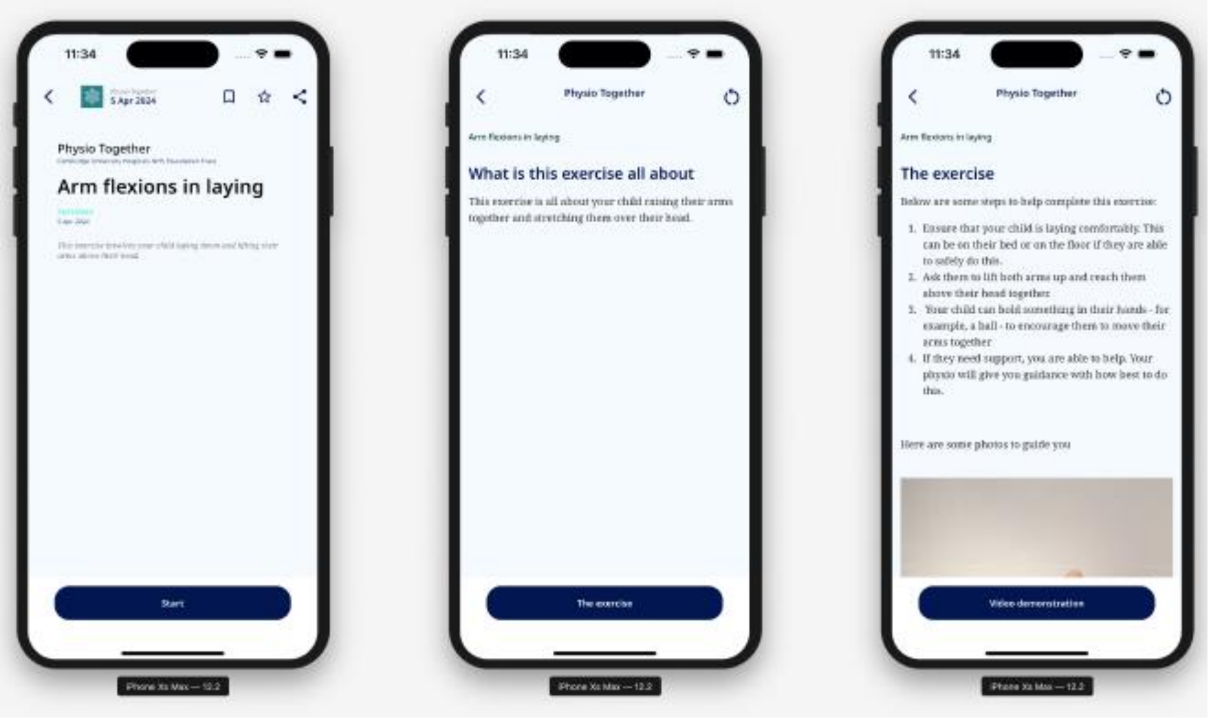
Appendix 30: Larger versions of the illustrative exercise recommendations



Arm flexions in laying

What is this exercise all about

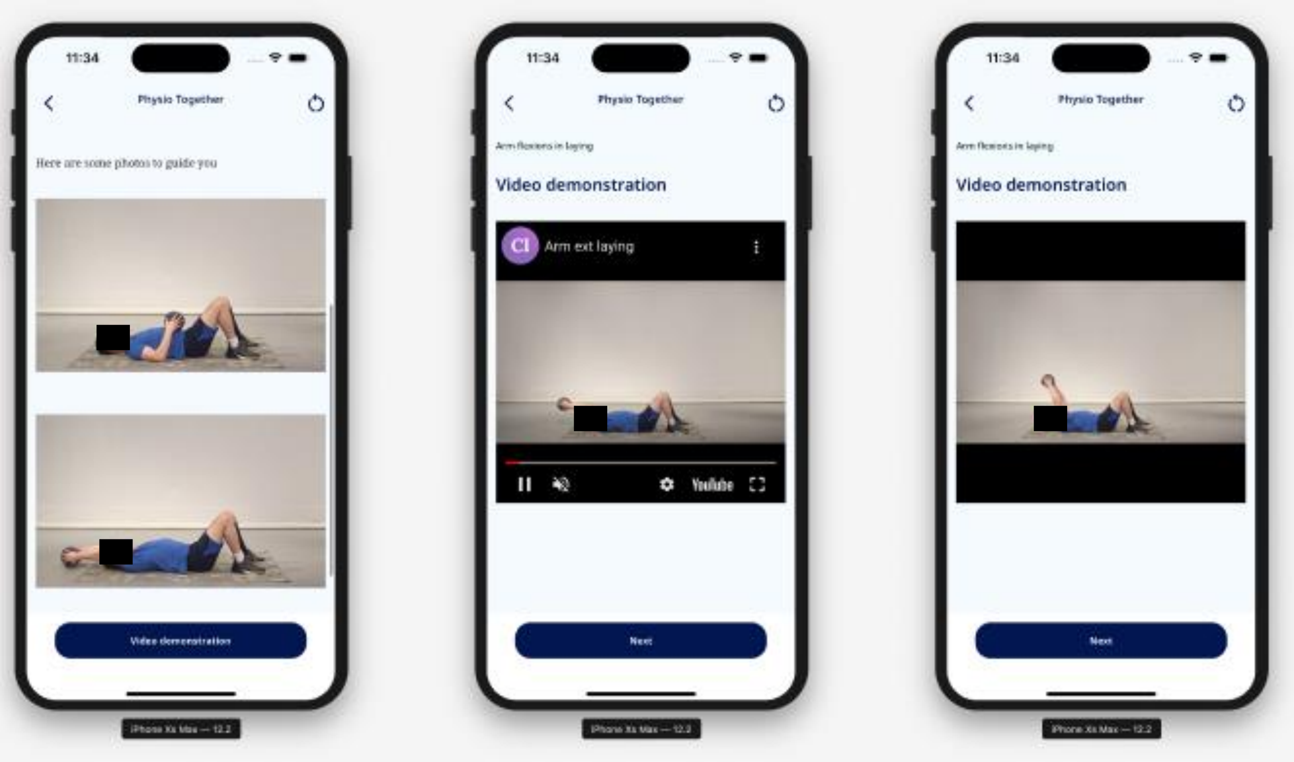
This exercise is all about your child raising their arms together and stretching them over their head.

The exercise

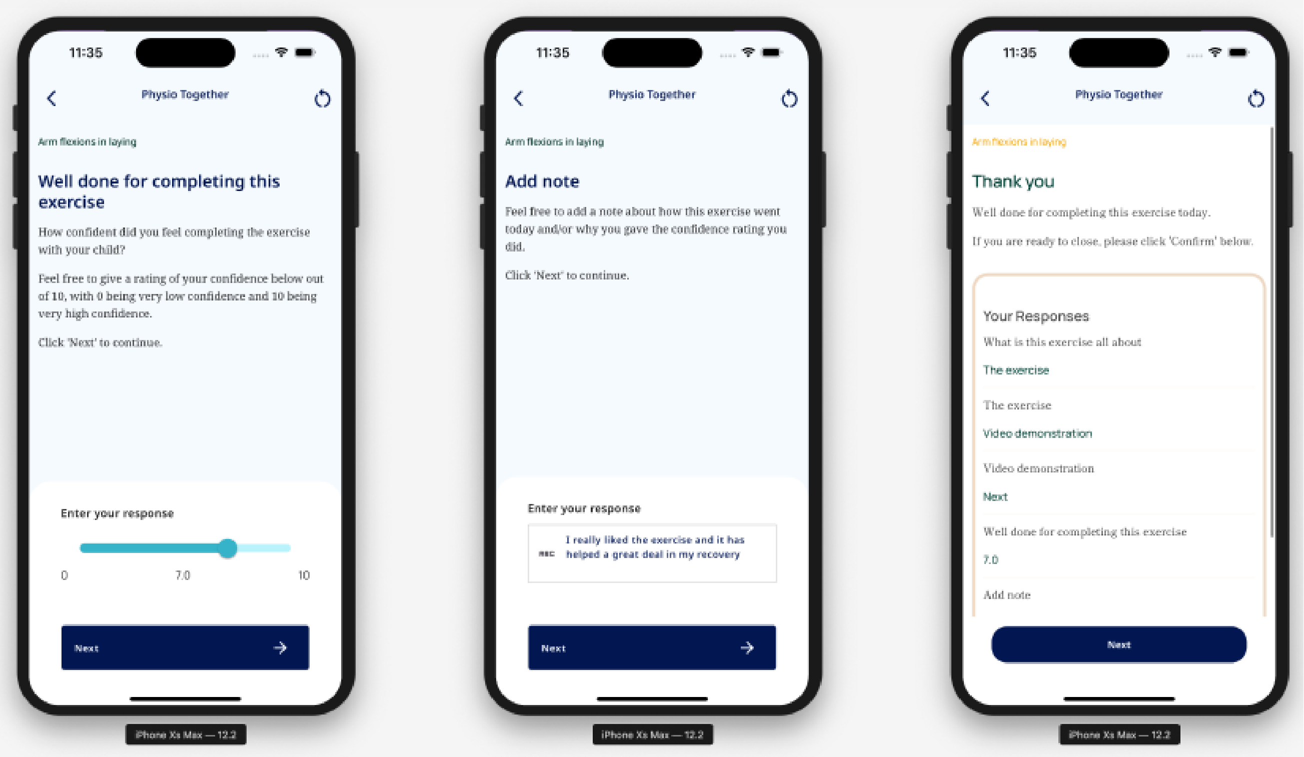
Below are some steps to help complete this exercise:

1. Ensure that your child is laying comfortably. This can be on their bed or on the floor if they are able to safely do this.
2. Ask them to lift both arms up and reach them above their head together.
3. Your child can hold something in their hands - for example, a ball - to encourage them to move their arms together
4. If they need support, you are able to help. Your physio will give you guidance with how best to do this.

Here are some photos to guide you



Here are some photos to guide you



Well done for completing this exercise

How confident did you feel completing the exercise with your child?

Feel free to give a rating of your confidence below out of 10, with 0 being very low confidence and 10 being very high confidence.

Click 'Next' to continue.

Add note

Feel free to add a note about how this exercise went today and/or why you gave the confidence rating you did.

Click 'Next' to continue.

I really liked the exercise and it has helped a great deal in my recovery

Thank you

Well done for completing this exercise today.

If you are ready to close, please click 'Confirm' below.

Your Responses

What is this exercise all about

The exercise

The exercise

Video demonstration

Video demonstration

Next

Well done for completing this exercise

7.0

Add note

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