Evaluating Brain-in-Hand for Adults with an Acquired Brain Injury

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Abstract

Over one million people live with the long-term consequences of acquired brain injury (ABI). Individuals with ABI may find it difficult to self-manage the effects of injury and it is important to provide them with the skills to live independently. Many smart technologies exist to aid rehabilitation, but there is limited technology available to support self-management. Brain-in-Hand (BiH) is a smartphone application that was specifically engineered to support the management of persistent emotional and behavioural problems, which are commonly seen following ABI. However, it has not been systematically evaluated in this population. The aim of this thesis was to understand the perspectives and experiences of people with ABI and healthcare professionals after using BiH.

A systematic review was conducted to highlight the level of evidence available for smart technologies in the ABI population, and determine the effectiveness of technologies compared to usual care/other technologies on independence and functional outcomes. The review included six randomised controlled trials that utilised a range of technology interventions (e.g., smartphone, iPad, Neuropage). All included a measure of goal attainment/function, however none measured independence or fatigue. Only one measured quality of life and participation. The review highlighted a lack of studies focusing on some of the hidden consequences of ABI such as lack of independence, fatigue, anxiety and poor participation.

An engagement study was conducted with stakeholders (n=50) (including people with ABI, carers and professionals), to explore their views and opinions of BiH, and identify some of the barriers and facilitators to its use. A mixed methods approach was used (focus groups, questionnaires, and presentations) to obtain feedback. Stakeholders identified areas that BiH could potentially target such a memory and managing routine. They also highlighted some of the barriers to use

such as smartphone competency, lack of interest in technology, and not seeing a personal use for BiH. These findings informed the design of the subsequent case studies.

An n-of-1 mixed method case study design was used. All ABI participants were provided with BiH for 12 months. Data were collected using questionnaires (at baseline, 6 and 12 months post-intervention) and semi-structured interviews (at six months post-intervention) with ABI participants and healthcare professionals. Questionnaire data were used to determine whether BiH had any effect on functional outcomes, mood, fatigue, participation, quality of life and cognition of ABI participants. The interviews aimed to explore the barriers and facilitators associated with the use of BiH. These were thematically analysed using a framework informed by the Behaviour Change Wheel (BCW) and International Classification of Functioning, Disability and Health (ICF). A feasibility health economics evaluation was also conducted.

The quantitative findings showed that BiH had no effect on mood, functional independence, participation, quality of life, fatigue, or quality of life. However, there was a significant increase in goal attainment over the first six months. There was also a slight improvement in cognitive function. An overarching theme of context (personal/environmental factors) was identified as a key factor influencing the use and effectiveness of BiH. The four subthemes were: 1) insight and self-awareness following injury and its impact on BiH use; 2) patient and therapist support/training to use BiH; 3) motivation to use BiH and achieve goals; 4) technology specific barriers/facilitators. Having a sufficient level of insight, appropriate support (set up, training, monitoring etc.), and motivation appeared to facilitate BiH use. The health economics evaluation identified potential cost drivers as therapist appointments and the cost of BiH. It was feasible to collect this data from the ABI population.

Contextual factors need to be considered when implementing BiH, or similar technology interventions in the ABI population. Personal and environmental factors

play a key role in the use and effectiveness of BiH. It is important to identify important barriers and facilitators early in the implementation process, to guide the development of BiH for ABI, and its wider applicability to other long-term neurological conditions. Additional research is required to determine its effectiveness in the ABI population. BiH has the potential to be a valuable tool in community rehabilitation by facilitating independent living for people with ABI and providing a way to self-monitor and manage their fatigue/anxiety.

Keywords: acquired brain injury, smart technology, self-management, independence

Dedication

For my loving parents - Valerie and Dean.

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'It always seems impossible until it's done'

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Declaration

I certify that this is my own work, except where indicated by referencing. No part of this thesis has been submitted elsewhere for any other degree or qualification.



Jade Louise Kettlewell **Date: 20.02.19**

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Abbreviations

ABI	Acquired Brain Injury
ADL	Activities of Daily Living
A&E	Accident and Emergency
BCW	Behaviour Change Wheel
BiH	Brain-in-Hand
BSRM	British Society for Rehabilitation Research
CI	Confidence Interval
CIQ	Community Integration Questionnaire
COM-B	Capability, Opportunity, Motivation – Behaviour Components
EBP	Evidence Based Practice
EQ5D	EuroQol 5 Dimensions
FAS	Fatigue Assessment Scale
GAS	Goal Attainment Scaling
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
HCP	Healthcare Professional
HES	Hospital Episode Statistics
HTA	Health Technology Assessment
ICF	International Classification of Functioning Disability and Health
MRC	Medical Research Council
MSNQ	Multiple Sclerosis Neuropsychological Questionnaire
NAS	National Autistic Society
NEADL	Nottingham Extended Activities of Daily Living
NHS	National Health Service
NSF	National Service Framework

PDA	Personal Digital Assistant
PPI	Patient and Public Involvement
PSS	Personal Social Services
PSSRU	Personal Social Services Research Unit
PST	Personal Smart Technology
RCT	Randomised Controlled Trial
SD	Standard Deviation
TBI	Traumatic Brain Injury
UK	United Kingdom
UKABIF	United Kingdom Acquired Brain Injury Foundation
WHO	World Health Organisation

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Chapter 1 Introduction

1.1. Chapter Overview

This chapter introduces the thesis and discusses the causes and outcomes of acquired brain injury, rehabilitation pathways for people after injury, and classification of functioning, disability and health. It will explore the invisible sequelae of brain injury and stroke, such as fatigue and anxiety, which often receive less support and are difficult to manage. Healthcare models will be discussed, in particular the importance of the biopsychosocial model in rehabilitation, and the use of frameworks in defining health states and impairments following injury. It will introduce implementation research and the importance of early exploratory studies to inform the development of interventions. This chapter presents the current smart technologies available for acquired brain injury and identifies the gap in research. It will also introduce the intervention, Brain-in-Hand, which is a web-based programme and smartphone app, and the focus of this doctoral research.

1.2. Overview of Acquired Brain Injury

Acquired brain injury (ABI) is an umbrella term that describes conditions resulting from damage to the brain. ABI is a complex, multifaceted phenomenon that can manifest in many ways (Daisley, Tams, & Kischka, 2009; Department of Health, 2005; Elbaum & Benson, 2007; Hurn, Kneebone, & Cropley, 2006). It is a widely recognised debilitating condition with varying outcomes that can be difficult to predict following injury (Turner-Stokes, Disler, Nair, & Wade, 2005). Symptoms include cognitive, emotional and behavioural problems that limit independence and restrict social participation (Daisley et al., 2009; Walsh, Fortune, Gallagher, & Muldoon, 2014).

1.3. Causes of Acquired Brain Injury

An ABI is said to have happened when an individual suffers any type of brain injury after birth (Headway, 2018b). ABI can result from traumatic injury (e.g., road traffic accident), brain tumour, stroke, haemorrhage, viral infection such as meningitis, and lack of oxygen to the brain. ABI is usually categorised as traumatic or non-traumatic injury (Figure 1-1). The brain controls various aspects of functioning (e.g., emotional, behavioural, physical, cognitive) and can have significant consequences if damaged. Even a mild injury has the potential to cause a serious disability depending on the area and severity of damage, which could limit independence and complicate functional activities (National Institute of Neurological Disorders and Stroke, 2015; Ribbers, 2010).

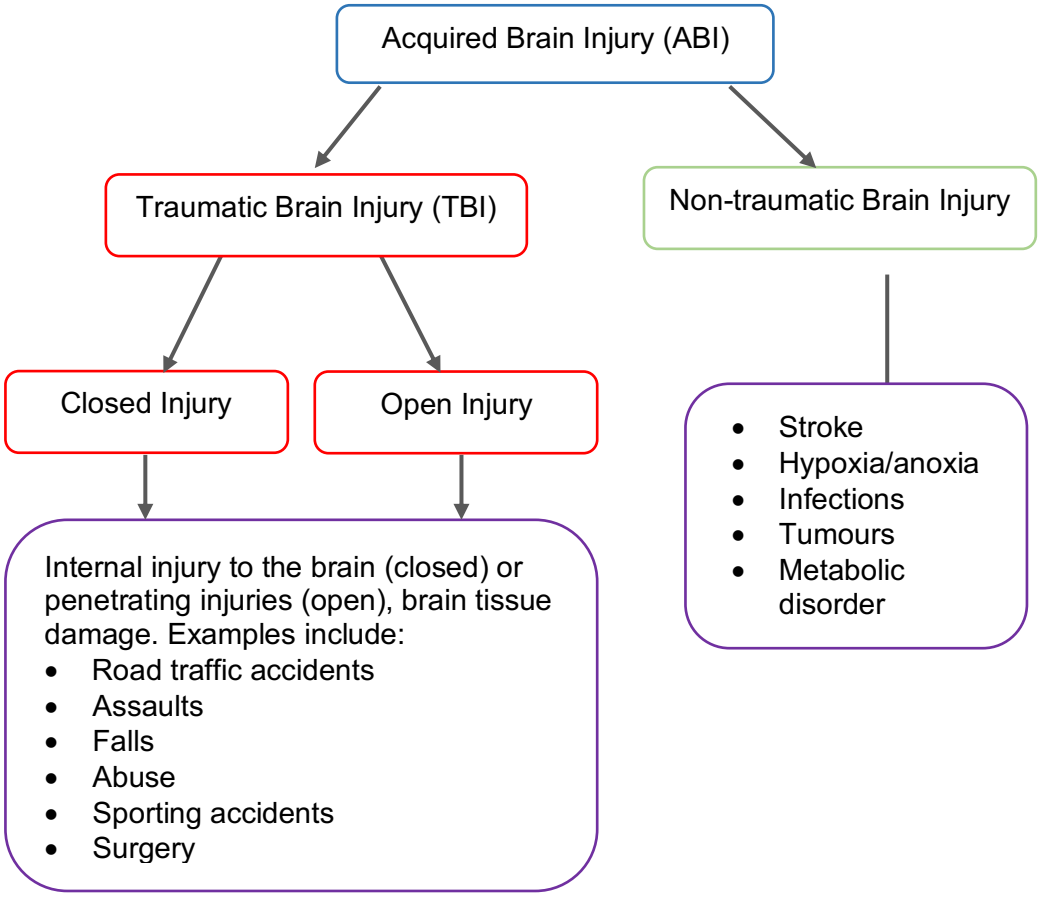


Figure 1-1 Classification and Causes of Acquired Brain Injuries
Adapted from (Brain Injury Association of Massachusetts, 2018)

A traumatic brain injury (TBI) is classed as an open or closed injury. Many people may suffer a head injury at some point during their life; however, the majority will not need hospital treatment and will only experience minor injury, such as concussion. Closed head injuries occur when the brain moves within the skull following impact, such as road traffic collisions or assault (Ivancevic, 2009). This movement can lead to brain tissue damage. An open head injury is caused by an object that penetrates the skull and enters the brain, resulting in tissue damage. Open head injuries are often caused by high-velocity objects such as bullets (Black, Gargollo, & Lipson, 2016). Skull fractures occurring because of road traffic accidents, falls, and sports injuries also can lead to open head injuries (Figure 1-1). Closed head injuries are more common than open injuries, and are often more difficult to treat (Faul, Xu, Wald, & Coronado, 2010). TBIs tend to result in localised damage that affects specific areas of the brain.

Non-traumatic brain injury is caused by internal forces, rather than the aforementioned external forces. There are many different causes of non-traumatic brain injury, including stroke, brain tumours, infections, substance abuse, hypoxia, ischemia, and encephalopathy (Figure 1-1). This type of injury is often less specific, affecting multiple areas of the brain. Non-traumatic brain injury may be as common as TBI, however it is not well recorded and sometimes unrecognised (Giustini, Pistarini, & Pisoni, 2013).

The most prevalent non-traumatic injury is stroke (Headway, 2015). A stroke occurs when blood supply to the brain is restricted, resulting in cell death. Strokes can be classified into two groups: ischaemic and haemorrhagic (Donnan, Fisher, Macleod, & Davis, 2008). Ischaemic stroke is caused by restricted blood supply to the brain, and haemorrhagic stroke is the result of a ruptured blood vessel in the brain or abnormal vascular structure. Approximately 87% of strokes are ischaemic (Donnan

et al., 2008). Brain tissue ceases to function if deprived of oxygen for more than 60 to 90 seconds. After approximately three hours, brain tissue will suffer irreversible injury, usually leading to infarction and brain damage (Deb, Sharma, & Hassan, 2010).

Brain tumours are another cause of non-traumatic injury and can be malignant or benign. Malignant tumours may originate from the brain (primary tumours) or may spread from other areas of the body. These tumours erode healthy brain tissue, leading to damage and injury within the enclosed skull. Benign tumours grow and cause pressure on the brain, leading to damage. As the brain has little room within the skull, any extra space used by tumours restricts blood flow to tissue, causing infarction. Sometimes, tumour removal can lead to unavoidable brain injury, damaging healthy tissue (Kinoshita, 2016).

Non-traumatic brain injury can also be the result of infections such as meningitis and encephalitis. Meningitis is caused by inflammation of the membranes (meninges) that surround the brain and spinal cord, because of viral or bacterial infection. This can lead to brain injury (Pfister & Scheld, 1997). Encephalitis is caused by an autoimmune condition, leading to brain tissue inflammation. The infection affects the immune system, causing it to malfunction and attack healthy brain tissue (Headway, 2018b). Lack of oxygen supply to the brain is another reason for brain tissue damage, commonly known as anoxia or hypoxia. Hypoxia refers to a limited supply of oxygen to an area of the brain, usually because of a severe asthma attack or choking. Anoxia refers to an absence of oxygen supply to an area of the brain. Brain tissue cannot survive without oxygen (Headway, 2013; Jacinto, Gieron-Korthals, & Ferreira, 2001).

ABI has multiple aetiologies, which explains the multifaceted nature of injury. ABI can lead to damage in any area of the brain, depending on its source and cause. This often makes brain injury difficult to treat and the outcomes challenging to predict (Baby & Shukla, 2017; Creutzfeldt, Longstreth, & Holloway, 2015; Daisley et al., 2009; Siddiqui et al., 2015). Rehabilitation outcomes can be defined as '*benefits and changes in the functioning of an individual over time that are attributable to a single measure or set of measures*' (Finch, 2002; World Health Organisation, 2011). Following ABI, clinical decisions about a person's care and rehabilitation are often guided by individual characteristics (such as size of injury, age, comorbidities, clinical scores) and clinician experience, however their prognosis often encompasses a range of uncertainties (Baby & Shukla, 2017; Deepika & Shukla, 2016). The heterogeneity of ABI makes it hard to reliably predict long-term outcomes such as cognitive impairment, lack of independence, and poor quality of life (section 1.5) (Baby & Shukla, 2017).

1.4. Epidemiology

The need for accurate up-to-date statistics to assist with service planning is well recognised (Lopes, Almeida, & Almada-Lobo, 2015; Mathioudakis, Rousalova, Gagnat, Saad, & Hardavella, 2016). Headway released a set of comprehensive figures to highlight the high incidence of ABI, which identifies it as a major public health concern. Headway compiled the first dataset of ABI-related hospital admissions in the UK. The figures presented were obtained using the England Hospital Episode Statistics system and equivalents in other parts of the UK. In 2016-17, there were 348,453 UK hospital admissions with an ABI – a total increase of 10% since 2005-6, with a 5% increase in male and 18% increase in female admissions (Headway, 2018a). Approximately every 90 seconds someone was admitted to a UK hospital with ABI in 2016-17 (Headway, 2015, 2018a) – a figure

anticipated to increase with population growth. The total rate of admissions in 2013-2014 was 531 per 100,000 of the population (Headway, 2018a), this demonstrates the large number of people sustaining an ABI each year.

ABI is the leading cause of death and disability in young adults (Walsh et al., 2014). Several million people were living with the long-term consequences of TBI in 2006, approximately seven million of these were in Europe and five million in the USA (Langlois, Rutland-Brown, & Wald, 2006; Tagliaferri, Compagnone, Korsic, Servadei, & Kraus, 2006). Exact up-to-date figures are unknown, but the UK Acquired Brain Injury Forum (UKABIF) estimate is that over one million people live with the long-term consequences of ABI (Headway, 2015; UKABIF, 2016b), highlighting the necessity for effective rehabilitation programmes and individualised care plans. There is no definitive way to quantify the amount of people living with the long-term disabling consequences of ABI, however Headway's figures provide the clearest depiction to date of the number of people requiring rehabilitation support, both long and short term (Headway, 2015). As admissions data does not reflect personal outcomes, or indicate the level of rehabilitation support required, it is difficult to determine the number of people in the UK with long-term impairments following ABI. As the population continues to rise and survival rates increase, it is important to recognise the growing pressure on health and social care resources. The majority of people admitted with ABI will survive and often have at least one problem as a result of injury (Daisley et al., 2009; Headway, 2015).

Stroke is the leading cause of severe disability in the UK (Adamson, Beswick, & Ebrahim, 2004; Department of Health, 2007). A stroke occurs approximately 152,000 times in a year, which is nearly half the total ABI hospital admissions (British Heart Foundation, 2012). In 2016, there were almost 14 million first-time strokes worldwide, which equates to one stroke every two seconds (Institute for

Metrics and Health evaluation, 2016). In the UK, there are over 100,000 strokes each year (Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP), 2016; Stroke Association, 2018). These statistics highlight the extensive impact of this ABI, with over 1.2 million stroke survivors in the UK alone. Around one million people with stroke will require care following hospital discharge (Patel et al., 2017; Stroke Association, 2018). Traumatic brain injury and stroke appear to be highly prevalent in the UK and do not receive the funding they desperately need, to improve long-term rehabilitation and preventative research (Barber et al., 2018; Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP), 2016)

1.5. Sequelae of Acquired Brain Injury

ABI can affect various parts of the brain and not all people will experience the same outcomes; each injury is unique. There are many sequelae that can manifest following injury, most of which appear at different stages. Certain symptoms predominate depending on the source and cause of brain injury. The majority of sequelae have an impact on daily life for a person with brain injury.

Four categories of symptoms may be evident following ABI: (1) physical; (2) cognitive; (3) communicative; and 4) behavioural and emotional (National Institute of Neurological Disorders and Stroke, 2015; Turner-Stokes, 2003). Physical effects are best recognised, as they are often visible, such as paralysis, seizures, visual/hearing loss, fatigue, and sensory deficits. Cognitive symptoms can be more difficult to identify, but become apparent as rehabilitation progresses. They include memory loss, difficultly making decisions, inattention, lack of insight, difficulty planning or initiating tasks and inability to express thoughts (McAllister, 2008; Rabinowitz & Levin, 2014; Turner-Stokes, 2003) . Behavioural and emotional symptoms are

frequently unrecognised and although common, can be overshadowed by the well-defined physical consequences of brain injury (Tyerman, 2016). These 'invisible' psychological sequelae are among the greatest unmet needs of the ABI population. They include anxiety, anger or irritability, depression, poor initiation, disinhibition and poor motivation (Ferro, Caeiro, & Figueira, 2016; Nicholl & LaFrance, 2009; Turner-Stokes, 2003). Table 1-1 provides a summary.

Behavioural and emotional sequelae may be under-prioritised by clinicians when more obvious and 'severe' outcomes need addressing (Maimaris & Worthington, 2012). This may impact on rehabilitation. It can affect social participation, independence, and self-confidence, which ultimately has an influence on individual quality of life. Although fatigue is well recognised, especially by brain injury specialists, the attention it deserves may be overshadowed by other impairments that are deemed more severe (e.g., physical disability, cognitive dysfunction). The majority of people with ABI will experience varying levels of fatigue following injury, with one in four people suffering from extreme fatigue post-stroke (Lerdal et al., 2011). It is a life-limiting symptom and people with ABI often forget to rest, usually with unrealistic daily goals. The consequences of injury influence the long-term outcomes for individuals following ABI.

The sequelae of ABI that are currently neglected by researchers and clinicians are the emotional and behavioural impairments experienced following injury. Fatigue is also one of the consequences of ABI that receives little attention and can be overshadowed by some of the well-known cognitive and physical impairments. This thesis will focus on the invisible sequelae of ABI and the unmet needs of this population, specifically anxiety, depression and fatigue, and the impact these problems have on poor functional independence, social participation and quality of life.

Table 1-1 Potential sequelae of ABI – impairments, limitations, restrictions and impact following injury. Adapted from (Turner-Stokes, 2003)

Impairments				Activities	Participation	Social Impact	Financial Impact
Physical/Sensory Impairments	**Behavioural/ Emotional**	**Cognitive Impairments**	**Communication**				
• Motor deficits: - Limb paralysis - Abnormal muscle tone - Ataxia - Coordination • Sensory: - Visual problems - Hearing loss - Loss of taste/smell • Fatigue • Pain • Seizures	• Anxiety • Depression • Mood change • Aggression • Decreased motivation • Lack of initiative • Disinhibition • Difficulty accepting injury • Psychosis	• Memory impairment • Attention deficits • Difficulties with problem solving planning and information processing • Reduced ability to self-monitor • Lack of insight • Impaired social judgement	• Language deficits – expression and comprehension • Dysarthria • Dyslexia • Dysgraphia	Limitations with: • Activities of daily living: - Mobility - Kitchen tasks (cooking, making food, shopping) - Domestic tasks (managing money, housework) - Leisure (using the phone, driving) • Self-care • Communicating	Restrictions with: • Maintaining social networks • Maintaining relationships (family, friends) • Being independent and maintaining autonomy • Employment or education • Social activities • Leisure activities	Potential impact: • Relationship breakdown • Reduced quality of life and wellbeing • Change in role (such as inability to care for children) • Loss of friends and reduced social life • Inability to drive leading to reduced social activities	Potential impact: • Loss of job • Reduced working hours • Partner/carer reducing working hours or leaving job • Loss of household earnings • Increased household costs (more time spent at home, cost of assistive equipment) • Reliance on state benefits

1.5.1. Outcomes of ABI

Functional outcomes (e.g., psychosocial, vocational and cognitive function) are believed to constitute quality of life (Mohamed & Abdul, 2018; Vickery, Gontkovsky, & Caroselli, 2005). Activities of daily living (ADL) are tasks integral to an individual's everyday functioning. Functional limitations in ADL are common following brain injury and are often related to physical, cognitive and behavioural impairments (Barman, Chatterjee, & Bhide, 2016; National Guideline Clearinghouse, 2012). Assessing the functional status and outcome of people with ABI is a key component of rehabilitation programmes. Examples of functional goals for people with ABI are managing their own garden, using the telephone, doing their own shopping, and travelling on public transport (Nouri & Lincoln, 1987). The main goal of rehabilitation is to facilitate a person's ability to improve outcomes (such as better cognitive function, self-management, greater participation in society and returning to work) and regain functional independence via goal-based learning (Young & Tolentino, 2011). As this thesis focuses on specific impairments following ABI (independence, anxiety, depression, insight, self-awareness/management, fatigue), they will be discussed in more detail.

1.5.1.1. Independence and self-management.

Independence can be defined as the state of being independent, having freedom from the control of others, or not being dependent on anything for function (Dictionary, 1989). In ABI this can mean the ability to carry out everyday activities without support from others, not being dependent on another person and not relying on others for help. Many report the inability to lead an independent life following ABI. This can be compounded by family members and people around them (Tyerman, 2016), who make it difficult for the person to improve self-management and self-efficacy by not allowing them to complete tasks alone. This is usually through

concern or worry that they are not ready to be independent (Klonoff, 2014). As a result, rehabilitation can be hindered as the lack of independence can lead to low confidence and self-esteem, impacting on long term outcomes (Fleminger, 2010). Autonomy can be defined as having the freedom to choose or determine one's actions (Dictionary, 1989). An autonomous person may remain dependent (i.e., unable to perform ADL without help) for various reasons that can relate to social isolation, psychological and behavioural impairments, which are commonly seen following ABI (Davies, Laker, & Ellis, 1997). Individuals may also lack the insight needed to self-manage outcomes of their injury, thus remain dependent (Flashman & McAllister, 2002; Prigatano et al., 1998). Self-management is important for independent living, as people with ABI need to be able to recognise their limitations and make informed decisions, without the support of others (Hughes, 2004). Some of the hidden sequelae of ABI such as anxiety, which will be explored in the next section, need to be managed if individuals wish to live independently.

1.5.1.2. Management of behavioural, emotional, and cognitive impairments.

ABI can cause a complex array of emotional, behavioural, and psychosocial changes, which ultimately have an effect on rehabilitation progress, relationships, ADL and participation in society. Individuals with ABI can experience depression, anxiety, loneliness, low self-esteem, and behavioural changes, such as irritability and anger (Williams & Evans, 2003). These invisible sequelae often have a great impact on an individual's quality of life, and historically, have received little attention from policymakers and service planners, highlighting unmet needs for the ABI population (Dombovy & Olek, 1997; Heinemann, Sokol, Garvin, & Bode, 2002; Jacobs, 1988; Rimel, Giordani, Barth, & Jane, 1982; Silver, Kramer, Greenwald, & Weissman, 2001; World Health Organisation, 2011). This means emotional disturbances are frequently undertreated (Cook et al., 2011; Driskell, Starosta, & Brenner, 2016).

Depression and anxiety are the most common psychological problems experienced post-TBI (Schwarzbold et al., 2008). Depression is common after stroke and anxiety affects around 25% stroke survivors (Chun Ho-Yan, Whiteley William, Dennis Martin, Mead Gillian, & Carson Alan, 2018). Anxiety is thought to have a greater impact on social functioning than cognitive impairment following injury. A systematic review revealed a number of interventions to improve occupational performance for psychological and behavioural impairments following ABI, these include: 1) education interventions such as group-based and individual sessions to address emotional/behavioural impairments; 2) peer mentoring; 3) goal-directed interventions; 4) physical activity such as aquatic exercise and aerobic exercise; 5) skills training interventions directed at behavioural, social and functional skills; 6) cognitive-behavioural therapy (group, individual and virtual) (Wheeler, Acord-Vira, & Davis, 2016).

Impairments of insight and self-awareness are common consequences of TBI and pose a challenge for long-term rehabilitation (Bach & David, 2006; Sherer et al., 1998). The prevalence of self-awareness deficits following ABI ranges from 20-48% (Smeets et al., 2014). Increased awareness of impairments and insight is associated with improved employment outcomes and rehabilitation progress (Leung & Liu, 2011; Ownsworth & Clare, 2006). However, one study showed that greater self-awareness was associated with increased stress and anxiety at discharge for people with TBI, which suggests the need for emotional support in the transition period from inpatient to community setting (Geytenbeek, Fleming, Doig, & Ownsworth, 2017). People who lack insight tend to set unrealistic goals, leading to a lack of motivation (Smeets et al., 2014) and poor psychosocial outcomes (e.g., unemployment, social isolation) (Geytenbeek et al., 2017; Malec & Moessner, 2000; Morton & Wehman, 1996; Ownsworth, McFarland, & Mc Young, 2000).

Interventions are needed for people in the early stages of ABI recovery to enhance self-awareness (Fleming & Ownsworth, 2006), but also to facilitate compensatory strategies that will contribute to improvement in long-term outcomes, such as work, ADL, independence and social participation (Kervick & Kaemingk, 2005). Various interventions have been reported to improve self-awareness following ABI (Fleming & Ownsworth, 2006; Schmidt, Lannin, Fleming, & Ownsworth, 2011). The use of direct feedback from therapists regarding task performance is a fundamental component of various awareness interventions, with timeliness, specificity and consistency of feedback playing a key role in its success (Fleming & Ownsworth, 2006). Literature describes group support programmes as an effective method of improving self-awareness and social skills (Barco, Crosson, Bolesta, Werts, & Stout, 1991; Boake, 1991; Delmonico, Hanley-Peterson, & Englander, 1998; Lundqvist, Linnros, Orlenius, & Samuelsson, 2010). One study implemented a 16-week group self-awareness programme (16 x 90 minute interactive workshops) for people with ABI and found that individuals with impaired executive function improved their self-management skills as a result of the intervention, however those who displayed a defensive coping mechanism (i.e., in denial about impairments) did not benefit from the programme (Ownsworth & McFarland, 2004; Ownsworth et al., 2000). Individuals who minimised their impairments were found to underreport psychosocial difficulties as a way of coping with their injury (Ownsworth & McFarland, 2004). This highlights the need to recognise and consider the impact of other deficits on self-awareness and insight when delivering interventions. A review suggested that motivational interviewing (a validated therapeutic approach aimed at changing behaviours) may facilitate the journey of recognition and acknowledgement of impairments for people following ABI (Medley & Powell, 2010). Another study evaluated the effect of six individualised treatment sessions (over three weeks) focusing on ADL on the self-awareness of people with ABI (Goverover, Johnston,

Toglia, & DeLuca, 2007). Participants were asked to predict their performance before completing a task and immediately after. Findings showed that the intervention had a positive effect on self-awareness, suggesting that this ongoing method of training would be useful in rehabilitation, however the sample size was small (n=20) and further research is still needed (Goverover et al., 2007).

Cognitive impairment is also common following ABI and one of the more researched consequences of injury (Nys et al., 2005; Oksala et al., 2009; Rabinowitz & Levin, 2014). Around 65% of people that have moderate to severe TBIs will experience problems with cognitive functioning (Whiteneck, Gerhart, & Cusick, 2004). One study found that 71% (108/152) people who made an excellent clinical recovery at three months post-stroke, still had a level of cognitive impairment - mainly issues with memory and executive function (Jokinen et al., 2015). Cognitive impairment is a risk factor for poor rehabilitation outcomes, as adaptation to new strategies may be compromised (Whyte, Skidmore, Aizenstein, Ricker, & Butters, 2011). Thus, rehabilitation needs to be tailored to accommodate cognitive problems (Whyte et al., 2011), as individuals may not remember how to complete ADL. Various interventions have been evaluated and shown to be successful at improving aspects of cognitive function in the ABI population and they include: goal management training (Rabinowitz & Levin, 2014), aerobic exercise training (Chin, Keyser, Dsurney, & Chan, 2015), reminding technologies and assistive devices (to be discussed in section 1.11), and virtual reality (Shin & Kim, 2015). Vigorous aerobic exercise was found to improve overall cognition, executive function and processing speed in the TBI population (Chin et al., 2015), which also resulted in increased cardiorespiratory fitness. However, subjects were highly educated and scored highly on cognitive assessments at baseline, suggesting the need for a larger trial. A review suggested that virtual reality (including virtual environment tasks, driving simulator and simulated supermarket) is an effective cognitive therapy for people with ABI,

specifically targeting memory and attention (Shin & Kim, 2015). The benefit of these interventions is the ability to tailor programmes to different injuries and cognitive ability.

1.5.1.3. Management of fatigue.

Fatigue is one of the most frequent and persistent symptoms experienced following brain injury and stroke (Cumming et al., 2018; Stubberud et al., 2017), however further research is needed to fully understand its aetiology and the best ways to manage this consequence of ABI (Penner & Paul, 2017). It is also one of the most problematic symptoms for people with other long-term neurological conditions, including multiple sclerosis, post-polio syndrome and Parkinson's disease (Ghahari, Leigh Packer, & Passmore, 2010). Fatigue has an impact on quality of life (Benedict et al., 2005). It can be explained by the 'coping hypothesis', which suggests that fatigue is a result of the brain working harder to compensate for cognitive impairments, such as slower information processing and inattention (Belmont, Agar, & Azouvi, 2009; Belmont, Agar, Hugeron, Gallais, & Azouvi; Ziino & Ponsford, 2006). However, it is not linked to brain injury severity, therefore hard to predict (Michael, 2002). Fatigue may become apparent in the early stages of recovery following discharge, when people start to regain independence following ABI. It sometimes goes unnoticed in a hospital environment, overshadowed by other symptoms. Not all people will experience the same levels of fatigue and it can manifest in different ways. It is thought that sustained attention, daytime sleepiness, depression, and anxiety are important factors associated with post-ABI fatigue (Ashman et al., 2004; Bushnik et al., 2015; Gould, Ponsford, & Spitz, 2014; Ponsford & Sinclair, 2014; Ponsford et al., 2012). One study found that fatigue exacerbates cognitive impairment and contributes to anxiety, depression, and daytime sleepiness following TBI (Bushnik et al., 2015). A systematic review found no evidence of a significant association between post-stroke fatigue and global cognitive function, however

attention, memory and information processing may be linked to fatigue after stroke (Lagogianni, Thomas, & Lincoln, 2018). Although larger, more accurate studies are needed to confirm the relationship between these factors and fatigue, it can be suggested that post-ABI fatigue may be alleviated by addressing the aforementioned factors (Bushnik et al., 2015).

There is no definitive way to measure fatigue as it is a subjective symptom (Jonasson, Levin, Renfors, Strandberg, & Johansson, 2018). However, studies suggest that impaired cognitive performance during extended test sessions could be an indicator of mental fatigue following ABI (Johansson & Ronnback, 2015; Jonasson et al., 2018). If fatigue is poorly managed, it may create a setback in recovery and progress (Borgaro, Baker, Wethe, Prigatano, & Kwasnica, 2005; de Groot, Phillips, & Eskes, 2003; Glader, Stegmayr, & Asplund, 2002; Michael, 2002). In the long-term, this may have an impact on quality of life, self-confidence, independence and can hinder rehabilitation (Ponsford, Kelly, & Couchman, 2014).

Few long-term studies have been carried out to evaluate the effects of fatigue following ABI (Chalder et al., 1993; Ziino & Ponsford, 2005). There is limited evidence for fatigue management and individuals often feel unprepared for this (Wheatcroft, 2014). Post-ABI fatigue is complex and influenced by physical, psychological, biological, and behavioural factors (Cantor et al., 2008; Cantor, Gordon, & Gumber, 2013; Ponchel, Bombois, Bordet, & Hénon, 2015; Stubberud et al., 2017; Wu et al., 2015), making the management of this symptom particularly challenging. Strategies for managing fatigue include pacing activities, setting reminders to rest, or planning and prioritising tasks. Methods of managing post-ABI fatigue should assist the recovering person to regulate their lifestyle by considering cognitive and physical limitations, such as reducing daily demands and working hours, planning frequent rests, and reducing the need to multitask (Ponsford et al.,

2012). Individuals that have greater self-awareness are more likely to manage fatigue better (Fasotti, Kovacs, Eling, & Brouwer, 2000).

Currently, the National Institute for Health and Care Excellence (NICE) guidelines do not address fatigue management following stroke and limited information is available regarding the management of fatigue after TBI (NICE, 2014c). These guidelines aim to provide national guidance and advice to improve health and social care; therefore, it is important that fatigue is recognised as a major symptom following ABI. Various methods have been used to manage fatigue in other neurological conditions, including pharmacological and non-pharmacological interventions. Cognitive behavioural therapy (CBT), yoga and increased exercise are among some of the non-pharmacological interventions recommended, but there is limited evidence supporting their effectiveness (Ghahari et al., 2010). One of the standardised interventions for people with multiple sclerosis (a long-term neurological condition) is a six-week self-management programme encouraging energy conservation (Ghahari et al., 2010; Mulligan et al., 2016). Other researchers have developed online self-management tools for fatigue. It is clear that fatigue requires greater attention following ABI. More long-term studies to evaluate the effectiveness of fatigue management interventions (as with other neurological conditions) need to be conducted to influence the NICE guidelines.

1.6. Economic Impact

ABI can have a large economic impact on the healthcare system when considering the costs of treatment and care within the NHS, but also the loss of earnings both people with ABI and carers will experience.

It is difficult to estimate the costs to the state of ABI due to inconsistency in figures; however, one individual with a TBI being admitted to an ordinary ward for two days will cost of around £300 per day (UKABIF, 2016a). The UK Acquired Brain Injury Foundation (UKABIF) estimates a cost of £78 million per year as a result of TBI (UKABIF, 2011, 2016b). Some people need care in a high dependency unit, which costs the NHS about £2000 per day and many will need to stay in a rehabilitation ward for several months, costing around £400 per day (Stroke Association, 2018; UKABIF, 2011). The annual cost of stroke to the UK society is approximately £26 billion, with the informal care sector (i.e., relatives/friends caring for stroke survivors) contributing £15.8 billion to the cost (Stroke Association, 2018).

ABI not only affects the state, but the individual who loses earnings and needs to rely on other means of income. Finally, people may require a legal settlement following their injury, which can be large depending on the cause and nature of ABI. UKABIF estimates that an average legal settlement for a young man with a severe TBI, who requires life-long care and compensation for loss of earnings amounts to about £5 million (UKABIF, 2011). Overall, the total cost of TBI in the UK is thought to be at least £1 billion per year (UKABIF, 2016b). With such a large number of hospital admissions each year and the cost of social care increasing, it is important that we develop timely rehabilitation tools to decrease societal pressure and reduce healthcare reliance.

Often those that have an ABI are of working age and will be unable to return to work for some time, or in the worst case not be able to work at all. Brain injury and stroke have an impact on a person's ability to return to work (Edwards, Kapoor, Linkewich, & Swartz, 2018; Radford et al., 2018; Radford & Walker, 2008; van Velzen, van Bennekom, van Dormolen, Sluiter, & Frings-Dresen, 2011). One study found that only 41% of people returned to work two years after having a TBI (van Velzen et al.,

2011). Another study found that 65% of those in work before their stroke had to leave their job and 14% had to change their hours because of their stroke (Kersten, Low, Ashburn, George, & McLellan, 2002). Stroke survivors see returning to work as a significant indication of recovery (Alaszewski, Alaszewski, Potter, & Penhale, 2007; Medin, Barajas, & Ekberg, 2006). However, one study found that 52% of stroke survivors reported a reduction in or loss of work activities, and 18% experienced a loss in income (McKevitt et al., 2011). Another study reported that 60% of people were financially affected by their stroke, and 75% people under retirement age were affected by financial changes on a daily basis as a result of their stroke (Walsh, Galvin, Loughnane, Macey, & Horgan, 2015). Those managing to return to work following ABI may have to reduce their hours or change roles. More people may need to rely on state benefits or experience a reduction in salary. This can put huge financial burden on families, adding to the other pressures and emotional effects following ABI. The societal cost of TBI is estimated at 2.8 billion euros (Rickels, von Wild, & Wenzlaff, 2010), which equates to around £2.5 billion, in terms of lost work and personal benefits claimed. Following TBI, individuals are 66% more likely to receive welfare and disability payments compared to the non-TBI population (Silver et al., 2001). It is estimated that within the first 12 months post-stroke, the average societal cost of stroke per person is £45,409 (Patel et al., 2017). Approximately one in six people experience loss of income after stroke (Stroke Association, 2018). In 2015, the cost of lost productivity as a result of stroke was £1.305 billion, which is predicted to increase to £2.012 billion by 2025 (Patel et al., 2017). One study reported income losses of £740 million due to disability resulting from stroke (Saka, McGuire, & Wolfe, 2009). It is predicted that in 2025, the cost of stroke in the UK for people over 45 years will increase to £43 billion from £26 billion in 2015 (Patel et al., 2017).

1.7. Social Impact

The social impact of ABI can be great, especially for carers and family members. It can put large strain on relationships (Berryhill, Peterson, Jones, & Tanoue, 2012; Jones et al., 2011). Some people exhibit awkwardness and inappropriate behaviour due to the inability to read social cues (Daisley et al., 2009; Tyerman, 2016). This may lead to isolation, as people with ABI avoid situations where difficult communication and social awkwardness can arise (Tyerman, 2016). Social isolation may impact on mental health as people become depressed and anxious (Fleminger & Ponsford, 2005).

ABI often has an impact on relationships, ranging from personal to working connections (Jones et al., 2011). Brain injury can make social interaction difficult, with some experiencing inappropriate communication. People with ABI can feel frustrated with their situation and find it difficult to express their emotions (Coetzer, 2008). This can lead to anger and irritability towards family and friends, detrimentally affecting relationships (Peters, Stambrook, Moore, & Esses, 1990). Significant others do not always relate behaviour to the person's brain injury, which may cause relationship difficulties. This is applicable to many situations, potentially leading to divorce, loss of friends and jobs (Wood & Yurdakul, 1997). Some of the main factors influencing caregiver distress and poor family functioning are: time since injury and severity, behavioural and psychological problems, lack of insight into one's injury and poor social support of caregiver (Ergh, Rapport, Coleman, & Hanks, 2002). Following brain injury, people often find it difficult to cope and need adequate support from rehabilitation services (Turner-Stokes, 2003).

ABI survivors may lose their independence and have to rely on others for everyday tasks (Mazaux et al., 1997), which has a negative effect, as they feel their life and

decisions are no longer within their control (Coetzer, 2008; Dalton et al., 2014). Injury can be a difficult change to accept, affecting relationships and self-confidence. If a partner, relative, or friend takes on the caring role, it may put a strain on their relationship (Verhaeghe, Defloor, & Grypdonck, 2005). The ABI survivor may feel as if they have lost their autonomy (Mazaux et al., 1997; Qadeer et al., 2017; Riley, 2016). Carers may be vulnerable to stress and anxiety, especially if they had to leave their existing job (Kneafsey & Gawthorpe, 2004). A major source of stress for carers is the on-going changes in personality, emotional control and behaviours post-injury (Turner-Stokes, 2003). This tends to present in the later stages of recovery and can put great burden on family life (Kreutzer et al., 2009; Verhaeghe et al., 2005)

1.8. Rehabilitation

Rehabilitation is broadly defined by the World Health Organisation (WHO) as *"a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments"* (World Health Organisation, 2011). Rehabilitation aims to maximise functioning of the individual, however long-term outcomes following ABI are often difficult to predict.

The brain is known to have neuroplasticity, meaning that many areas remain changeable throughout a person's lifetime (Gage, 2004). Behaviour, environmental stimuli, thoughts, and emotions can induce neuroplastic change (Pascual-Leone et al., 2011), which has implications for brain injury recovery, healthy development, learning and memory. This provides hope for ABI survivors and is important for rehabilitation, to encourage the use of alternative strategies for daily tasks (Kleim & Jones, 2008), which develop new neural pathways to compensate for damaged connections (Hosp & Luft, 2011; Warraich & Kleim, 2010). Studies found that rehabilitation strategies which promote motor learning-related neuroplasticity (i.e. relearning motor functions) have the potential to improve functional outcomes, especially following stroke (Cotman & Berchtold, 2002; Cotman, Berchtold, & Christie, 2007; Mang, Campbell, Ross, & Boyd, 2013; Warraich & Kleim, 2010). Neuroplasticity supports the scientific basis for ABI rehabilitation and the implementation of goal-directed therapeutic interventions (Dimyan & Cohen, 2011; Nahum, Lee, & Merzenich, 2013).

Rehabilitation for people with ABI can be defined more specifically as, "*an educational, problem solving process that focuses on activity limitations and aims to optimize patient social participation and well-being, and so reduce stress on*

carer/family" (Wade, 2005a). Throughout rehabilitation, individuals with ABI are expected to take an active role in their treatment and work towards goals (Turner-Stokes & Ward, 2009). Rehabilitation intensity varies depending on the individual and the severity of injury, but all have an end goal of regaining function and enabling participation in chosen activities. Studies have shown that early intervention and greater intensity of rehabilitation in ABI is most successful in terms of improving outcomes (Musicco, Emberti, Nappi, & Caltagirone, 2003; Zhu, Poon, Chan, & Chan, 2007). However, a systematic review concluded that there was limited evidence to suggest that early intensive rehabilitation can lead to improved outcomes (Turner-Stokes et al., 2005). Individuals with ABI may demonstrate various types of impairments that may not be consistent with diagnosis, such as fatigue, behavioural and emotional impairments (Elbaum & Benson, 2007). This poses an issue for long-term rehabilitation, as individual needs change over time meaning that services provided need to be altered accordingly. This ultimately results in greater social and economic burden.

1.8.1. Rehabilitation cycle

The rehabilitation cycle/process is summarised in Figure 1-2. It typically involves the identification of a person's needs following ABI and the problems they are experiencing. These problems are then attributed to relevant factors within the environment or personal factors. Rehabilitation is an ongoing, active process. Goal setting and monitoring goal attainment is a core part of rehabilitation (Wade, 2009) (Rosewilliam, Roskell, & Pandyan, 2011) and is recognised by the National Service Framework (NSF) for long-term conditions as a marker of good practice (Department of Health, 2005). Rehabilitation programmes should be tailored to the individual and focus on person-centred goals beyond basic ADL and promote broader participation in life (Department of Health, 2005). As the rehabilitation cycle is ongoing, goal

setting should also be a recurring process to encourage change and ensure treatment is centred around the individual, their specific needs, and considers their views and pre-morbid lifestyle (Turner-Stokes & Wade, 2004). It is important for multidisciplinary teams to work towards a common set of goals for the person with ABI, resulting in a more effective programme and improved outcomes (Turner-Stokes & Wade, 2004).

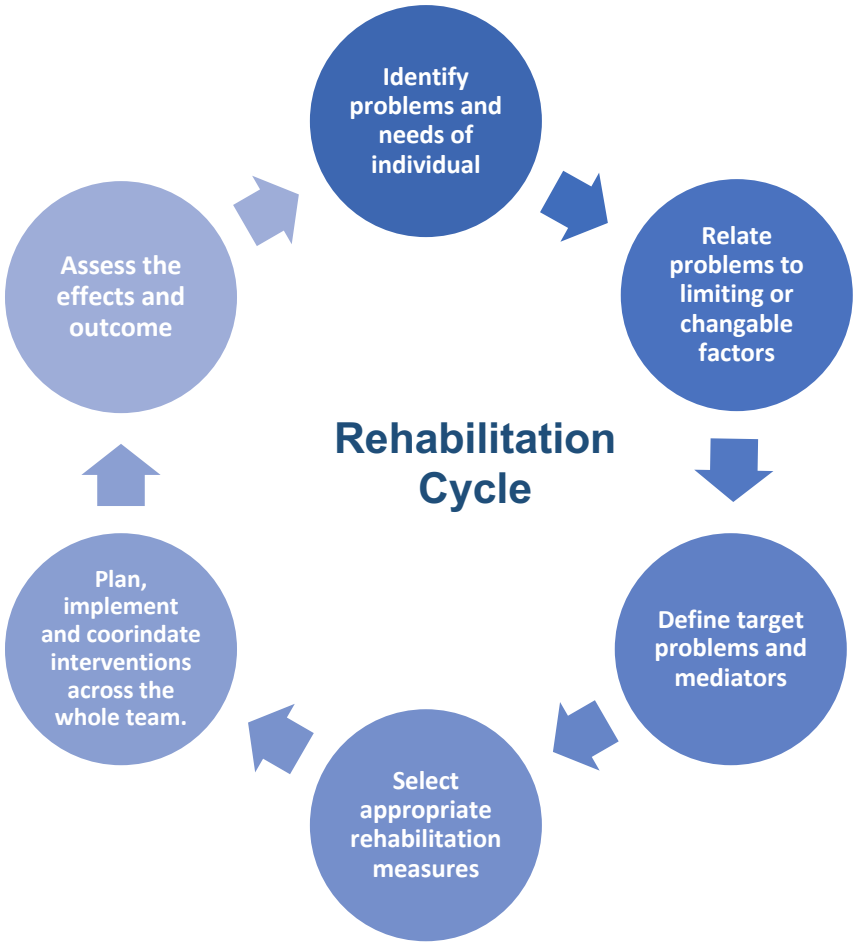


Figure 1-2 Processes involved in rehabilitation following ABI. Adapted from the Rehabilitation Cycle (Steiner et al., 2002; World Health Organisation, 2011)

Goal setting and monitoring takes place across multiple stages of the rehabilitation cycle, from identifying the individual needs to defining target problems, and assessing the outcome. Patient-centred goal setting reflects the biopsychosocial

approach to treating an individual (section 1.9.1), aiming to maximise activities and participation in daily life. However, during the early stages of rehabilitation, goal setting is usually clinician-led, as people with ABI may not be aware of their limitations at this point and have unrealistic expectations (Rosewilliam et al., 2011). Barriers to goal setting may also occur further down the rehabilitation pathway (e.g., post-discharge). This could be a disagreement between the health care professional (HCP) and person with ABI about setting relevant and appropriate goals, a lack of patient understanding of goal setting and rehabilitation, and family opinions that may lead to issues when setting goals (Plant, Tyson, Kirk, & Parsons, 2016).

The ABI rehabilitation team is multidisciplinary and usually comprises an occupational therapist (OT), physiotherapist, speech and language therapist, nurse, support worker, case manager and family members (Turner-Stokes, 2003). Clinicians describe rehabilitation as a process that involves in-depth and broad assessment of individual needs following ABI and the delivery of multifocal interventions (Turner-Stokes et al., 2005). Treatment is often delivered by a multidisciplinary team in a coordinated way, over a period of time (Wade, 2005b). Although HCPs within a rehabilitation team tend to focus on a specific aspect of treatment/care following ABI, it is important that the entire team works together to provide a successful rehabilitation programme for the individual. The wide range of skills and knowledge shared within the team is necessary for success (Wade, 2016a, 2016b). The overall role of the rehabilitation team is to assess the individual with ABI and determine their needs. Rehabilitation following ABI is often a collaborative effort, but can be provided by a single therapist in some cases.

1.8.2. Rehabilitation measures and outcomes.

Outcomes following ABI can be described as improvement or changes in an individual's functioning over a period of time (World Health Organisation, 2011). These changes are attributable to a single outcome measure or set of measures. Outcome measures can assess a person's physical or cognitive impairment, an individual's level of participation (e.g., community integration) or completion of an activity (e.g., activities of daily living). Outcomes are not only important in the clinical context to assess changes in functional ability, but also important in research to evaluate whether an intervention is successful in improving function.

1.8.3. Rehabilitation services and pathways

Rehabilitation services may be delivered as an inpatient, outpatient, or in the community (British Psychological Society, 2005; Daisley et al., 2009; Fleminger & Worthington, 2016). People with ABI can enter the rehabilitation pathway at various points (Figure 1-3). When a person suffers an ABI, they will sometimes receive immediate care, often entering via an accident and emergency (A&E) department. At this point, patients can be transferred to hyper-acute care if their injuries are severe, such as high dependency units, or they may be discharged if no rehabilitation needs are identified (Turner-Stokes, 2003).

Depending on the severity of injury and individual needs following ABI, people will receive different levels of care (1, 2 or 3) (British Society of Rehabilitation Medicine, 2015). However, some individuals may not need any further rehabilitation and therefore exit the pathway. Level 1 care refers to inpatient specialist rehabilitation

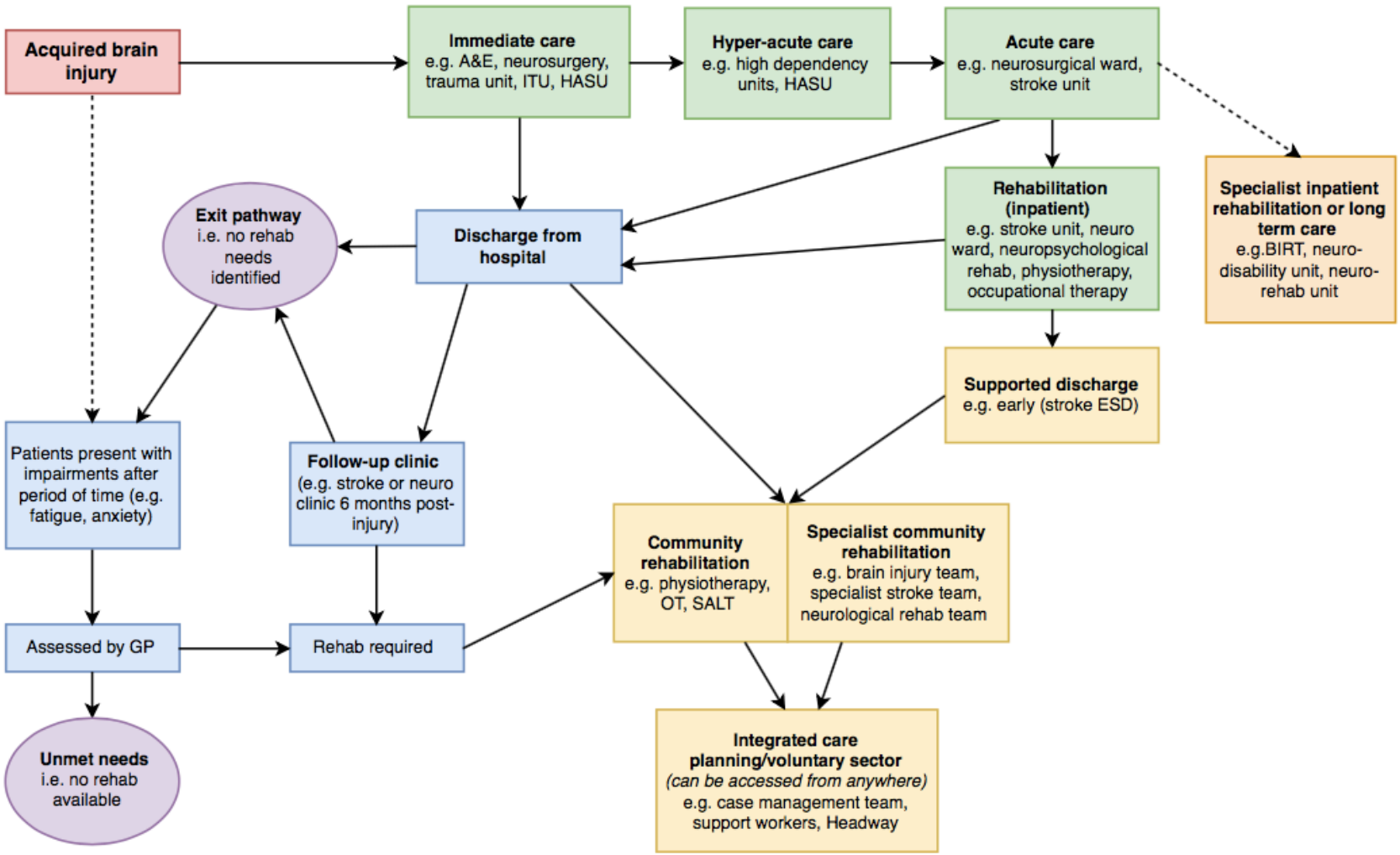


Figure 1-3 Flow diagram of rehabilitation pathways for people with ABI (adapted from (British Society of Rehabilitation Medicine, 2013)

services which are often high cost, and are thinly spread tertiary centres or services across the UK (e.g., Brain Injury Rehabilitation Trust (BIRT), neuro-rehabilitation unit) (British Society of Rehabilitation Medicine, 2015). These services are intended for people who have highly complex needs beyond the scope of local/district rehabilitation services (British Society of Rehabilitation Medicine, 2015). Level 2 care refers to local specialist rehabilitation services which target individuals that have complex needs such as cognitive, behavioural or communicative difficulties and require a longer stay in hospital (i.e. usually more than six weeks to six months) (British Society of Rehabilitation Medicine, 2015; NHS England, 2013b). It can also refer to specialist community services, such as vocational rehabilitation or specialist brain injury teams. This level of rehabilitation is often intended to support a return to productive roles, such as work or parenting (British Society of Rehabilitation Medicine, 2015). Level 3 care refers to local non-specialist services, which provide general multi-professional rehabilitation therapy and support for a range of individual needs (e.g., physiotherapy, speech and language therapy), within the context of community/acute services or immediate care (British Society of Rehabilitation Medicine, 2015). Community rehabilitation often involves health and social services working in close partnership to meet individual needs of the person with ABI (British society of Rehabilitation Medicine, 2003).

1.8.4. Unmet needs following ABI

Some people may not require formal rehabilitation following ABI, as they make a rapid recovery following injury and are discharged from hospital without any further treatment, or have a mild ABI and do not seek medical care (Turner-Stokes & Wade, 2004). However, problems may not be immediately obvious and can become apparent a few weeks or months post-injury. These include hidden disabilities such as fatigue, cognitive impairment and anxiety (Prince & Bruhns, 2017; Turner-Stokes

& Wade, 2004). This poses a challenge for physicians, as they need to identify individuals with rehabilitation needs and appropriately refer them to community services. Given the unpredictable nature of ABI, proactive follow-up appointments are recommended to ensure needs are being met and improve outcomes (Turner-Stokes & Wade, 2004). Also, some individuals do not enter the rehabilitation pathway at all following ABI and their needs remain unmet, i.e., they do not receive any rehabilitation. This may be due to unrecognised impairments at discharge, gaps in local service provision or geographical isolation (i.e., person with ABI lives too far from suitable services) (Turner-Stokes & Ward, 2009). The eligibility criteria for community rehabilitation services post-TBI may lead to the exclusion of individuals with invisible disabilities, such as emotional and cognitive consequences (NICE, 2014b). There are also significant unmet needs in long-term health and social care for stroke survivors, as people often have multiple stroke related problems that may be undetected and undertreated (Hotter et al., 2018). It is important that these individuals who essentially ‘slip through the net’ are recognised and receive the long-term support they need.

Rehabilitation services in the UK are available either via the NHS or private providers. Although the cost of ABI and rehabilitation is expensive, there is evidence to suggest it is a cost-effective intervention (Turner-Stokes, 2004, 2007; Turner-Stokes, Paul, & Williams, 2006). Specialist rehabilitation services can reduce long-term care costs by enabling and supporting individuals to return home and improving care strategies. Rehabilitation funding (private or NHS) for people with ABI needs to be in place prior to receiving treatment. Most rehabilitation units will accept referrals from the NHS, but also from private providers. Insurance or compensation claims can be another funding option for ABI survivors if they want a specific service not covered by an NHS referral. Some people with ABI will need to wait for

compensation or insurance claims to be cleared before proceeding, sometimes having to wait several months before receiving any rehabilitation (Fleminger & Worthington, 2016).

1.8.5. Current issues with rehabilitation

The main issue with rehabilitation in the UK is the lack of financial investment in this service and inadequate provision to ensure people following ABI receive the care they need (Barber et al., 2018; British Society of Rehabilitation Medicine, 2008; Wade, 2016a). Rehabilitation may be essential for some people to enable them to participate in everyday life, work, or education.

Reports by Wade and Turner-Stokes highlight the lack of funding support and insufficient provision available for the rehabilitation of stroke, head injury, multiple sclerosis, and other ABI-related injuries (Turner-Stokes & Wade, 2004; Wade, 2015a, 2016a, 2016b). There is a lack of rehabilitation equipment available for HCPs to provide to their patients, even though many of these interventions have been shown to be cost-effective (Audit Commission, 2000, 2002). This is surprising when evidence-based UK guidelines identify rehabilitation as a fundamental part of healthcare, specifically post-stroke.

There are a large number of people that are inappropriately placed in hospital beds. In 2013, out of the 136,487 beds occupied at any one time, a total of 4226 (3%) were inappropriately occupied, with many of these people (865, 20%) awaiting further non-acute NHS care (NHS England, 2013a; Wade, 2015a). An audit in 2015 found that 23% of inpatients (in the UK and Australia) did not meet the criteria for staying in hospital, and around 40% of these were waiting for or requiring rehabilitation (Reid, King, Mathieson, Woodcock, & Watkin, 2015). This highlights

the unnecessary increase in health care costs due to the unmet needs for disability care, and inadequate provision for rehabilitation services (Wade, 2015a).

Currently, there are unmet rehabilitation needs and inconsistent implementation of care pathways, meaning people with ABI who are discharged sometimes receive little support (Barber et al., 2018). This highlights a lack of awareness of ABI and the magnitude of the problem within rehabilitation. These services require additional attention and funding (Barber et al., 2018)). Accessing support may be problematic for individuals with ABI due to the heterogeneous nature of their injury and subsequent needs, which do not easily fit into the structure of the UK service provision (Holloway & Fyson, 2016).

1.8.1. Policy and guidelines

There are various published policies and standards to guide rehabilitation following ABI. Goal setting is recognised as a key part of stroke rehabilitation and recommended in the National Clinical Guidelines (Intercollegiate Stroke Working Party, 2016). These guidelines also state that people with stroke should be actively involved in their rehabilitation through goal setting and supported in a self-management approach to achieve their goals. This is echoed by the service standards from the British Society for Rehabilitation Medicine (BSRM) and the NHS Five Year Forward View (Maruthappu, Sood, & Keogh, 2014), which advocates self-management. The NSF for long-term conditions and the BSRM highlight the need for local rehabilitation services and recognises that individual needs change over time following ABI, thus a range of services are required (Turner-Stokes & Ward, 2009). The BSRM service standards state that suitable services (e.g., specialist vocational rehabilitation) should be within travelling distance for people post-injury and ensure that individuals can gain timely access to such services (British Society

of Rehabilitation Medicine, 2013). The BSRM guidelines highlight the need for community health and social services to work in close partnership to provide appropriate support to people with ABI and meet specific needs (Turner-Stokes & Ward, 2009). Community services should be relevant and appropriate involving skilled HCPs, be timely and people with ABI should have ongoing access to a rehabilitation team/individual. Family and carers should also be involved in plans (Turner-Stokes & Ward, 2009). Vocational needs should be considered and if the person with ABI has the potential to return to work, they should be contacted by specialist vocational services 4-6 weeks post-referral (Turner-Stokes & Ward, 2009). There are on-going pressures on limited healthcare resources, which is reflected in the Five Year Forward view for the UK National Health Service (Maruthappu et al., 2014), pushing for greater self-management for people with long term conditions. This highlights the need for interventions and rehabilitation strategies to support independence and empowerment.

1.9. Models of Health and Illness

There are various published models of health and illness, including the biomedical and biopsychosocial models. The biomedical model largely governs the medical world, as it is the theoretical underpinning of all decisions made by patients, HCPs and organisations (Wade & Halligan, 2017). This model creates the belief that HCPs should prioritise the diagnosis of disease and focus on curing the ‘unhealthy’ individual. Unfortunately, services that don’t adopt the biomedical approach, such as rehabilitation, will inevitably have lower priority in terms of funding, societal attention, and political importance (Wade & Halligan, 2017). Funding tends to favour services and interventions that aid disease diagnosis and treatment, providing limited provision and attention to the understanding of disability and consequences of

disease (Wade, 2015b). Rehabilitation for disability can be viewed as an external treatment. The biomedical model does not take into account individual subjectivity and the person is often overlooked in the process, with no regard for social, environmental or psychological factors (Wade & Halligan, 2004). It is important that these components be considered when treating individuals with ABI, as rehabilitation aims to achieve an integrated approach, not simply to diagnose and treat. This theory should underpin interventions.

1.9.1. Biopsychosocial model.

The biopsychosocial model was first described in 1977 by Engel, who believed that healthcare should consider the psychological, behavioural and social dimensions that contribute to illness (Engel, 1977). This model of health and illness counters the biomedical model, and is more aligned with rehabilitation. The biopsychosocial model is used widely in clinical practice, especially in rehabilitation and is the basis of the International Classification of Functioning Disability and Health (World Health Organization, 2001), which is a well-known framework. The biopsychosocial model highlights the importance of checking patient history and considering other factors that may influence illness, and the need to recognise relationships as an integral part of healthcare.

Although there is variation in the methods of treatment delivery, there is a consensus among HCPs that a biopsychosocial approach to rehabilitation is taken when considering care plans and treating the individual (Wright, Zeeman, & Biezaitis, 2016). It is important that rehabilitation considers contextual factors (e.g., environment), and social factors (e.g., participation restrictions) and recognises the interrelationships between biological, social, and psychological factors. Clinicians and researchers should aim to identify and understand contributing

environmental/social factors that may affect the success of rehabilitation interventions.

1.9.1.1. International classification of functioning disability and health.

The International Classification of Functioning Disability and Health (ICF) provides a pragmatic and conceptual framework that enables the classification of the health components of functioning and disability (World Health Organization, 2001). The ICF is a World Health Organisation (WHO) framework developed in 1993, which has global applicability and provides a common language about the health and functioning of an individual, and their impairments/limitations. The ICF can be viewed as a medical model, providing a means of classifying disability and health, or an integrated biopsychosocial model describing health at individual, social, and biological levels. The ICF is divided into two parts: functioning and disability, and contextual factors (Figure 1-4).

The first part consists of body functions and structure, and activities and participation. The contextual part includes environmental and personal factors. Each component can interact with another component in two directions, meaning that any intervention affecting one area can potentially affect one or more component. The components can be expressed in positive or negative terms, which corresponds with problematic or non-problematic aspects of health and health-related states. Problematic aspects indicate health problems and are linked with the word ‘disability’, which relates to various components of activity limitation, impairment (body function and structure) and participation restriction. Non-problematic aspects indicate a lack of health problems and are linked with the word ‘functioning’.

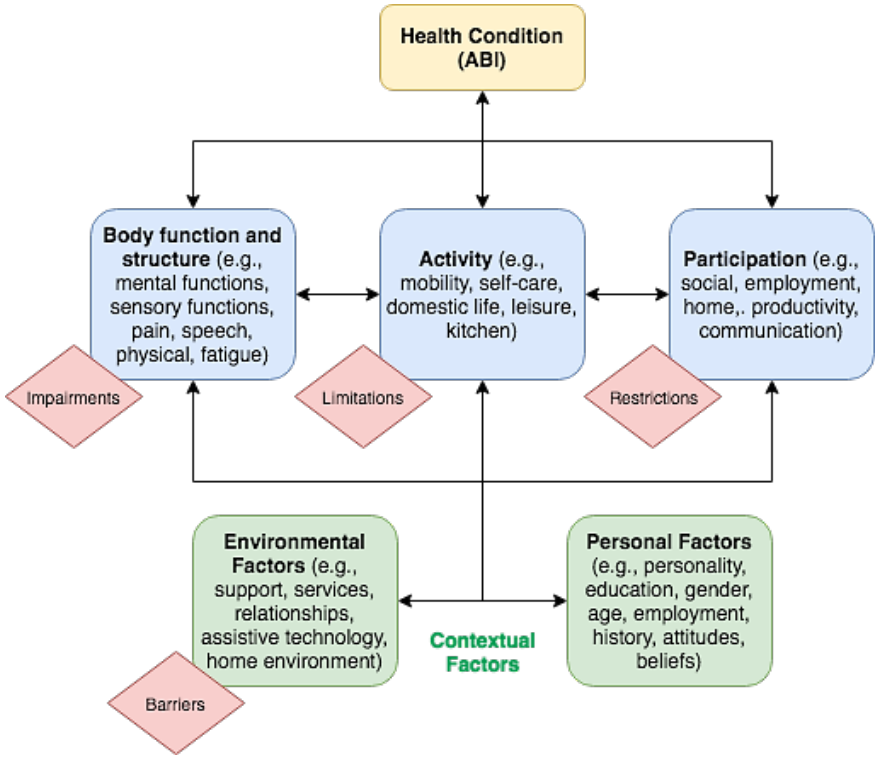


Figure 1-3 Model of the ICF for ABI
(World Health Organization, 2001)

The biopsychosocial model reflects the key elements of the ICF, in that it considers the interrelationship between different components of health-state. The ICF provides a coherent view of the multidimensional aspects of health at biological, psychological, and social levels. It takes the form of a biopsychosocial model as it recognises the importance of contextual factors (environmental and personal) for individuals, but also differentiates between the different contextual factors and how these individually affect other domains. The ICF recognises environmental factors as external influencers of body function and structure, activity, participation, and health condition, and personal factors as internal influencers of these domains (Saleeby, 2007).

1.9.1.2. Appraisal of the ICF.

The ICF is an internationally recognised framework for the description of all aspects of human health and can facilitate intervention studies by clearly distinguishing outcomes that are of interest. The ICF has many strengths. The presence of environmental factors within the framework facilitates the identification of barriers and facilitators within this component, something that is useful in practice and for rehabilitation interventions (Bilbao et al., 2003). Some interventions may focus on modifying the environment by eliminating potential barriers or creating environmental facilitators to increase the completion of ADL. These interventions could be used in the home environment to aid mobility (e.g., walk in shower), or technological aids such as smartphone devices and pagers to aid memory. The ICF recognises that social participation and function are an integral part of life, something that is not highlighted by earlier frameworks (such as The International Classification of Impairments, Disabilities, and Handicaps (ICIDH)) (Jette, 2006). The ICF is also anti-discriminatory compared to other frameworks, like the ICIDH. By removing words like handicap and disability, and replacing with participation and activities, the language is more inclusive and respectful of the disabled population, suggesting they are active individuals with control of their own lives.

Another strength of the ICF is that it provides a holistic view of the individual offering an insight into the complexity of functioning in a quick and easy way (Ptyushkin, Vidmar, Burger, Marinček, & Escorpizo, 2011). It provides a unified language with neutral terminology. The ICF includes both positive and negative expressions of different health dimensions, indicating functioning, or disability. This approach has eliminated the confusion between the biological and social models of disability, each of which present opposing views of health (Beaudry, 2016). The ICF integrates both models to provide a coherent way of classifying ‘disability’ or ‘functioning’ in terms of

biological, personal, and social perspectives of health (Steiner et al., 2002). A final strength of the ICF is providing a framework to plan rehabilitation interventions for people with ABI to achieve specific goals. By using the framework, HCPs can think, assess, and plan their approach with the aim to improve functional outcomes and societal participation.

Despite the multiple strengths identified, the ICF has some limitations. One source felt that the ICF has complicated terminology, which may contribute to assessor subjectivity when completing in practice (Ptyushkin et al., 2011). The ICF does not account for different and rapid variations in functioning which are linked to environmental and personal factors, such as choosing not to complete a specific activity due to a health condition, stage of life and quality of life. However, it offers a quick and easy way of expressing health, disability and functioning, which could be completed at multiple time points, accounting for the changes in functioning. Another issue with the ICF is that the classification of a domain is decided by the user (i.e., nurse, therapist) so there is subjectivity when deciding if something is an activity or participation. Although this may be a weakness of the ICF, a level of subjectivity is somewhat expected. The subjectivity involved when deciding if something is a limitation (activities) or a restriction (participation) is important, but there is a level of overlap between these domains (e.g. inability to complete social activities is a limitation and reduced social life is a restriction). The domains (activities/participation) are often reported together in literature, meaning the classification is sometimes more lenient in a research context. However, it is important to separate these domains when evaluating interventions that encourage participation, to ensure broader reporting of outcomes rather than focusing on functional abilities in ADL.

1.9.1.3. Applications of the ICF.

The ICF is a useful tool in implementation research to design or evaluate interventions. Researchers have successfully used the ICF as a tool to justify the focus on multiple components of disability and on environmental factors of health, but also to identify the desired outcomes of an intervention or service. The ICF can also provide a clear and consistent method for reporting case studies.

The ICF has already been used in this chapter to summarise the sequelae following ABI (Table 1-1) and has guided the selection of case study outcome measures, which will be discussed in Chapter 4. It could be used to inform the development of interview topic guides, to ensure all relevant information is being collected. This is important when evaluating the effectiveness of an intervention following ABI, to identify factors that may affect functional state and whether this change can be attributed to the intervention. The ICF could also be used to analyse qualitative data and inform a coding strategy. By using this unified framework, a common language can be achieved when reporting qualitative findings. In the context of ABI, the ICF could facilitate the identification of barriers and facilitators of interventions and explore their effect on functional states (impairments, limitations, and restrictions). By identifying contributing factors, the framework could help to guide necessary intervention developments.

1.10. Implementation Research

Implementation research or implementation science was borne out of a need to address the challenges faced when translating research into evidence-based practice (EBP) in healthcare (Nilsen, 2015). Over the past decade, there has been an increasing focus on research attention and policy to address this gap between evidence-practice and policy (Grimshaw, Eccles, Lavis, Hill, & Squires, 2012).

Context plays a significant role in this field, as it includes social, cultural, political, environmental, and economic settings, which are integral to the successful uptake of interventions (Grimshaw et al., 2012; Peters, Tran, Adam, & Ghaffar, 2013; Peters, Adam, Alonge, Agyepong, & Tran, 2014). Contextual factors (e.g. environment, services, cultural norms/beliefs) interact with one another and can influence implementation.

There is a growing interest in the use of theories, models, and frameworks within implementation research, to gain an insight into its mechanisms and understand more about whether interventions will work in practice (Nilsen, 2015). It is important to identify key barriers and facilitators early in implementation research and use these findings to inform the development of complex interventions. These interventions are commonly used in rehabilitation and often have multiple interacting components, making them difficult to evaluate (Nilsen, 2015). Early implementation research fits within the MRC framework of designing and evaluating interventions (Figure 1-5). There are three main stages prior to implementation: development, feasibility and piloting, and evaluation (Craig et al., 2008). These stages are essential to understanding how an intervention will work in a ‘real world’ setting and how to manage potential barriers.

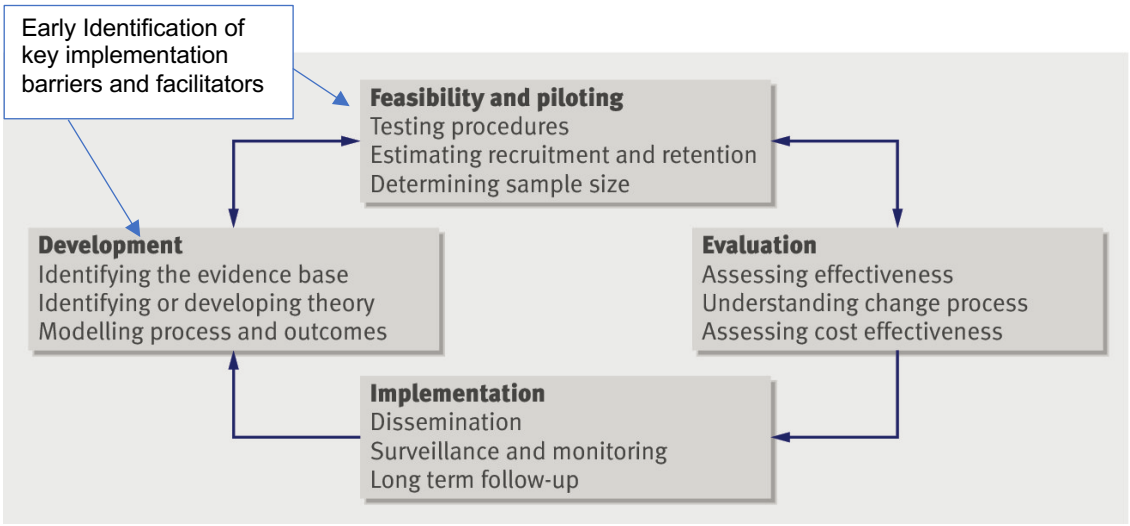


Figure 1-4 MRC framework: Stages of implementation research.
(Craig et al., 2008)

The MRC framework advocates the need to develop interventions systematically using evidence based theory, and test them in a phased approach, starting with a series of smaller pilot studies followed by larger definitive trials (Craig et al., 2008). By using these methods, new interventions are more likely to be successful (i.e., achieve their aims) when used in clinical practice. Stakeholders are integral to the translation from evidence base to practice, by aiding the identification of key barriers and facilitators to long-term implementation (Green & Aarons, 2011). Their involvement should be considered during the early development stages and carried through.

Implementation research often uses quantitative and qualitative methods. Although mixed methods design is not specific to this area of research, it is particularly useful for understanding multiple perspectives and finding potential factors that may influence implementation (Peters et al., 2013). The main outcomes to consider when conducting this research are: acceptability, appropriateness, feasibility, fidelity, cost-

effectiveness and sustainability (Peters et al., 2013). These are important when evaluating the clinical use and effectiveness of an intervention.

The quality of intervention description in publications is remarkably poor (Dijkers et al., 2002), which makes implementation particularly challenging. In order to improve translation from evidence-base to practice, it is important that interventions are described consistently to facilitate their delivery and successful implementation. The Template for Intervention Description and Replication (TIDieR) guidelines were created by an international group of experts and stakeholders to improve intervention reporting. The (TIDieR) guidelines provide a 12 item checklist for better intervention reporting (Hoffmann et al., 2014). The guidelines have been used in this thesis to inform data collection and reporting.

1.11. Assistive Technology for Acquired Brain Injury

Health technology assessment (HTA) is a multidisciplinary process or method of systematically examining the clinical effectiveness and efficacy, safety, cost and the cost-effectiveness, and the impact on social, legal, and ethical outcomes of the implementation of health technologies. The National Institute for Health Research (NIHR) defines technologies as, '*any method used to promote health; prevent and treat disease; and improve rehabilitation or long-term care' (National Institute for Health Research, 2018).* This may be a device, clinical procedure, or drug. In the UK, HTA generally focuses on two areas: clinical effectiveness of the health technology, and its cost-effectiveness in comparison to other interventions. This type of health assessment often acts as a bridge between clinical evidence and policymaking, which is guided by evidence-based research.

Within the definition of ‘health technology,’ there are various types of technology that can be used for rehabilitation. In this thesis, the focus is around assistive technology, which is commonly used in the ABI population. Assistive technology is an umbrella term that describes assistive, adaptive, and rehabilitative devices for people with life limiting or disabling injuries. Assistive technology encourages greater independence by providing individuals with the tools to perform tasks that they were previously unable to complete. Although many assistive technologies exist to support rehabilitation and various symptoms, there is limited technology available to support self-management and functional outcomes of people with ABI (Charters, Gillett, & Simpson, 2015; Jamieson & Evans, 2015). Given the large population recovering from ABI, many with multiple long-term consequences, there is clearly a need for assistive technology to support rehabilitation and promote self-management.

Smart technology is a type of assistive technology and can be defined as an electronic device or system (such as mobile phones, pagers, tablets and laptops), that can be used interactively to serve a particular function. A systematic review by Charters (2015) identified a large number of smart technologies available for people with ABI and the recognised benefit of reminders to improve prospective memory and promote independence in ABI (Charters et al., 2015). ‘Neuropage’ is a well-established, robust paging device that provides scheduled reminders for people with cognitive problems (De Joode, Van Heugten, Verhey, & Van Boxtel, 2010; De Joode, Van Heugten, Verhey, & Van Boxtel, 2013; Dewar, Kopelman, Kapur, & Wilson, 2015; Wilson, Evans, Emslie, & Malinek, 1997). Multiple studies have corroborated the value of reminder devices like Neuropage, electronic calendars, Google calendar and personal digital assistants (PDAs) for people with ABI, demonstrating increased performance of everyday tasks (Baldwin & Powell, 2015; Boman, Tham, Granqvist, Bartfai, & Hemmingsson, 2007; Dowds et al., 2011b;

Jamieson, Cullen, McGee-Lennon, Brewster, & Evans, 2014; O'Neill & Gillespie, 2015).

One study explored the use of a smartwatch as a prompting technology for people with memory impairments post-ABI using an ABA single case design (n=3) (Jamieson et al., 2017a). Usual memory strategies were used in the control phase. The study provided some evidence to support the effectiveness of the intervention, however there was no significant change in memory performance. However, when the smartwatch was removed, memory performance declined for all participants. This is an interesting finding, but given the small number of participants, it is hard to draw clear conclusions about its effectiveness. Similarly, a study using an ABAB design with smartphone reminders (control phase no reminders) showed a significant improvement in task completion when the reminders were provided to people with ABI (n=6) (Ferguson, Friedland, & Woodberry, 2015). Qualitative findings identified an improvement in independence, confidence and coping with memory problems, however no quantitative methods were used to measure this. The intervention period lasted four weeks, however a longer study (i.e., six to 12 months) would have captured more data to explore whether long-term adherence had an impact on task completion. A review of the literature shows a wide range of designs used to evaluate the use and effectiveness of smart technologies in ABI, making it difficult to draw conclusions about these interventions in comparison to usual care, and identify the types of outcomes they could improve. A systematic review by Charters identified 23 studies using assistive technologies in ABI, with only one using a randomised controlled trial (RCT) design and three using a non-randomised control design (Charters et al., 2015). The number of participants ranged from one to 199, with the majority under 20. This suggests the need for larger, higher quality studies.

There is limited research exploring the benefits of smart technology on executive functions such as self-management, navigation, social interaction, initiation of tasks and volition (Charters et al., 2015; Gillespie, Best, & O'Neill, 2012; Jamieson & Evans, 2015). Few studies have explored the impact of smartphone or technology interventions on these functions (Baldwin & Powell, 2015; Jamieson & Evans, 2015; McDonald et al., 2011) and emotional co-morbidities of ABI. However, studies measuring these outcomes recruit small samples making it difficult to draw clear conclusions. One study recruited 12 participants (McDonald et al., 2011) and another study used a single-case design (n=1) (Baldwin & Powell, 2015). This suggests the need for larger studies focusing on these outcomes. The psychological sequelae of ABI are among the greatest unmet rehabilitation needs for this population. Similar studies suggest that psychological disabilities persist longer than physical disabilities, indicating that these symptoms require greater clinical attention (Losoi et al., 2015; Rimel, Giordani, Barth, Boll, & Jane, 1981; van der Sluis, Eisma, Groothoff, & ten Duis, 1998). There is a need for technologies to not only support these functions following ABI, but to promote independence and autonomy of daily activities.

Technology is a rapidly advancing field and there is a need to conduct more high quality studies to evaluate the effect of novel technologies in comparison to usual care. Small studies are useful to identify areas that technologies could potentially target and some of the barriers to use and effectiveness. However, larger more robust studies would highlight areas that require more focus and report some of the long-term issues when implementing such interventions, thus providing researchers with the knowledge to design future trials and avoid making the same mistakes.

1.11.1. Smartphone technology.

The use of mobile devices, such as smartphones within the ABI population has not yet been exploited for fatigue and anxiety management, autonomy or neuropsychological rehabilitation. Smartphones are a valuable assistive tool, with the potential to be implemented in different settings and serve as multifunctional supportive devices. Smartphones may have the ability to benefit various symptoms experienced by individuals with ABI. Many people have access to a smartphone; one study stated that 40% of a UK outpatient population possessed one in 2015 (Migo et al., 2015), and there were an estimated 42.7 million UK smartphone users in 2017, which is expected to grow as technology advances (McNair, Chung, Liu, & Peart, 2017). This highlights the importance of these personal devices to be considered as rehabilitation tools. The only negative predictor of ownership is age; however, this is slowly becoming less prominent (Hussain, Griffiths, & Sheffield, 2017; Johnson, Bamer, Yorkston, & Amtmann, 2009). Smartphone possession is expected to grow as technology advances, highlighting the timely need to utilise this device as a rehabilitation tool. A study by Ferguson suggested that using a smartphone as a memory aid can potentially reduce stigma associated with ABI and allows users to ‘maintain dignity’ (Ferguson et al., 2015) by limiting forgetfulness. However, one study suggested that such compensatory aids may only be used for a short period of time and usage often stops because of stigma, cost and perceived effectiveness (Baldwin, Powell, & Lorenc, 2011). The use of smartphones with multiple reminders may place additional pressure on users, which could increase distress levels for some individuals (Ferguson et al., 2015).

1.11.2. Mobile applications (apps).

Mobile applications, also known as ‘apps’, are a type of software designed to run on a mobile device, such as a smartphone or tablet computer (techopedia.com, 2016). Most apps are designed to serve a specific function and can be an integral part of the smartphone or tablet, or can be downloaded by the user. Apps have created a transition from desktop computers and laptops to small mobile devices, enabling people to connect to the internet and carry out multiple activities on the go. Mobile apps were originally designed to enrich personal and business life, with easy access to emails, maps and social media, but there is an emerging interest in apps as ubiquitous healthcare tools (Anderson, Burford, & Emmerton, 2016). The smartphone apps currently available for people with ABI usually have a calendar or reminder function. Examples include Evernote, Google Calendar, Family Tracker, Pillboxie and Around Me, all of which have planning and reminding functions. There is a well-established benefit of reminding devices to improve task completion and encourage independence (Baldwin & Powell, 2015; Dowds et al., 2011b). One study explored the potential barriers associated with a smartphone reminder app called ForgetMeNot, suggesting it has great potential to support memory rehabilitation, however low motivation and lack of insight were reported as factors affecting use and effectiveness (Jamieson et al., 2017b). Another study evaluated the use of a tablet-based app called iReadMore, which was a novel reading therapy app to support acquired reading disorders (e.g., alexia), often reported in the stroke population (Woodhead et al., 2018). The study reported an improvement in word reading accuracy for trained items in stroke survivors (n=21) following the use of iReadMore over four weeks. However, a larger trial is required to explore its efficacy in a larger sample.

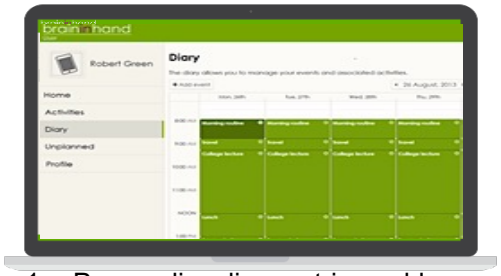
Mobile technology and apps have been successfully implemented in behavioural health for various populations including alcohol and substance users (Bernhardt et al., 2009; Freedman, Lester, McNamara, Milby, & Schumacher, 2006), overweight adults (Patrick et al., 2009) and to support individuals with a TBI and intellectual disability (Depompei et al., 2008). It is important to consider usability and acceptability by service users, when implementing smartphone technology in neuropsychological healthcare or rehabilitation (Jamieson, McGee-Lennon, Cullen, Brewster, & Evans, 2015).

1.12. Brain-in-Hand

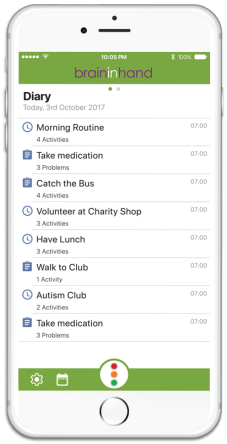
A new assistive technology called ‘Brain-in-Hand’ (BiH) is currently being implemented in various settings for autism and mental health. BiH is web-based software that synchronises with a smartphone app, it is readily available and simple to use. The software helps users create a structured daily routine for difficult to remember tasks or problem situations. The smartphone app gives users instant solutions, which can be easily accessed in real time, thus allowing them to manage their distress levels and improve independence. BiH has a reminder function that enables individuals to set alarms for important appointments and tasks, with the ability to record task completion. BiH also has an online portal, which comprises a diary and timeline. The portal acts as a monitoring system whereby a user, carer, mentor or HCP can track use of BiH. The timeline stores functions selected on the app, whether it be a solution or completion of task.

All data generated from the app are collected, which can then be extracted and analysed. Data are recorded in real time and stored in a cloud, allowing users and HCPs to track and better understand issues that cause distress. An inbuilt alert

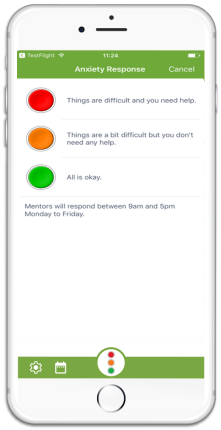
system, also known as a traffic light system, allows users to access telephone support if needed. The traffic light system provides a tool for users to rank their anxiety levels at a specific time, as red (i.e., I am not coping), amber (i.e., I am struggling, but I am coping), or green (I am coping). Together these features may allow for sharing and escalation of issues from carer, to mentor, case manager, or consultant as appropriate. Therefore, BIH may potentially reduce reliance on NHS resources by establishing the right level of support required and improving the focus of NHS clinician-client consultations. Figure 1-6 presents a visual summary of BiH.



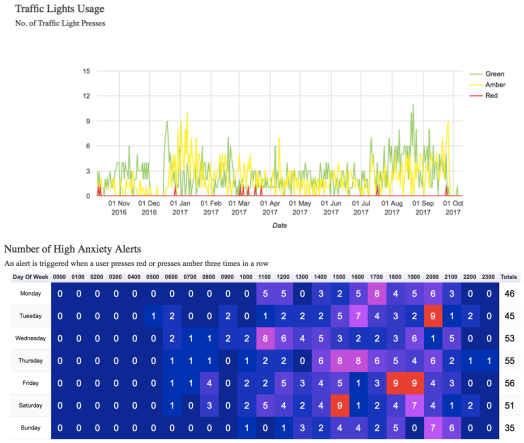
1. Personalise diary entries, add reminders and tailor coping strategies to individual needs.



2. Access anytime, anywhere with predetermined solutions for challenging tasks. Ability to record anxiety or fatigue levels on the go.



3. Users can request additional support when needed by pressing the red button and can self-manage symptoms.



4. Data for records, monitoring by user and HCPs. Provides a tool to identify problems and create strategies for improvement.

Figure 1-5 Brain in Hand (BiH) technology, from planning to data monitoring.

1.12.1. Brain-in-Hand in autism.

BiH has been shown to be successful in autism by helping users to socialise, use public transport, communicate, organise daily life, expressing feelings and managing relationships, and ultimately facilitate independent living (Brain in Hand, 2015). All of these things align with some, if not all, of the areas of support that are required by an individual following ABI. Brain in Hand Ltd. produced an impact report across 21 organisations (Brain in Hand, 2015). They found that out of 162 autism users in 2015 (7 NHS, 76 within social care and 79 within education), 100% found the app easy to use, 88% felt more confident when using BiH, 88% felt they coped better with problems and 94% felt BiH had a positive impact on their life (Brain in Hand, 2015).

However, as this was industry conducted research there was a potential for reporting bias and a lack of reporting negative findings. There was a need for more robust research to evaluate the effect of BiH in this population.

Currently, the BiH users with autism are supported by the National Autistic Society (NAS), which responds if a red traffic light is pressed (8am-6pm Monday to Friday). NAS employees are trained to offer advice and support to the user when they are in a difficult situation, particularly heightened anxiety. The individual user determines the preferred method of contact and the time scale for response from the NAS team, which is discussed during the initial set up.

There are two types of licenses available for BiH: individual and group. Individual licenses are dealt with on more of a personal level, with the BiH trainer going directly to the user. Each individual receives four hours of training, which is delivered by a trained specialist (provided by another company) and this comprises two, two-hour sessions. Individuals are provided with a workbook before the training, which allows

the user to identify potential goals, plan their daily routine, list the problems they experience and think about possible solutions. This is then used to guide the set-up sessions when they receive BiH. Each individual is told to identify a supporter (e.g., family member, friend), who is happy to offer help during use, and also to identify a traffic light responder, which could be someone they know personally, or they can access the support of the National Autistic Society. This would involve the red light response and also proactive contact to ensure everything is working on the app, whether they need any advice, ask if they need help changing their diary, or have other technical queries. Both the supporter and traffic light responder are advised to attend the training sessions.

The group licenses are offered to organisations such as school and universities. The training works differently in this situation, and the staff are trained first rather than the user. Trainers at the organisation receive four hours of training, traffic light responders receive around two to three hours training, and the supporters receive around two hours training. They are also required to attend the set-up sessions. Trainers are encouraged to observe three sessions to ensure their competency; to start they observe a BiH specialist trainer delivering the session, second session they lead the session with help from BiH trainers, and third they deliver the session alone with a BiH trainer observing.

The cost of BiH varies depending on the type of license purchased, whether training is included and if the user requires a red button responder (i.e., someone who contacts the user when they press a red traffic light and provides support). A standard individual license costs £648 for 12 months, which increases to £995 with a red button responder (currently provided by the National Autistic Society for users with autism). The cost of providing this support may be different for individuals with

ABI; however, this information is currently unavailable. The cost of two, two-hour training sessions designed to set-up the app is £336. Detailed intervention costs are presented in chapter 5 as part of a feasibility of health economics evaluation.

1.13. Gap in Acquired Brain Injury Research

There are limited long-term studies that have evaluated the effect of smartphone technology to improve the psychological sequelae of ABI, such as fatigue, anxiety, depression and lack of social participation (Charters et al., 2015). Few studies report the implementation of smartphones to improve functional activities or independence following ABI. There is an established benefit of using reminding devices such as pagers and PDAs to improve task completion in this population (Charters et al., 2015; Gillespie et al., 2012) however, few gold standard studies (i.e., randomised controlled trials) exist. No robust studies were identified that explore the use of smartphone apps to manage fatigue, which is a major problem for many ABI survivors. There appears to be a major gap in rehabilitation research, whereby there is a focus on smart technology to address multiple symptoms. A clear benefit of smart technology in ABI recovery has been identified, with many people already using smartphones for calendar reminders and daily planning (Gillespie et al., 2012). Smartphones have been exploited as ‘health monitors’ or ‘biofeedback sensors’ for various conditions, such as headaches (Nestoriuc, Martin, Rief, & Andrasik, 2008), insomnia (Taylor & Roane, 2010), chronic pain (Palermo, Eccleston, Lewandowski, Williams, & Morley, 2010) or in built accelerometers to monitor movement (Mehta, Zañartu, Feng, Cheyne II, & Hillman, 2012). However, there appears to be limited smartphone interventions that support multiple aspects of ABI rehabilitation (i.e., decision making, anxiety, fatigue, independence, ADL, participation), with the ability to monitor and track progress (Charters et al., 2015). There is a timely need for smart technology, which can address this gap in research and provide a greater

level of support for people with ABI, to encourage autonomy and reduce healthcare reliance.

1.14. Summary

BiH was specifically engineered to support the management of persistent emotional and behavioural problems, which are commonly seen in people with TBI or stroke. However, it has not been systematically evaluated for this population. Research to demonstrate the feasibility and value of this in ABI is timely, as technology currently available to support rehabilitation is limited. BiH has the potential to create a step change in how individuals with brain injury move towards leading more independent and fulfilling lives and become less dependent on scarce NHS and social care resources. This research is necessary to assess whether BiH can promote long-term independence, improve functional outcomes, social inclusion, mood, cognition, and quality of life of people with ABI. The final goal of this study is to evaluate the effectiveness of personal smart technology in improving outcomes for people with ABIs, and BiH is one such technology that will be evaluated in this study. The expectation is that the findings from this study would generalise to other similar personal smart technologies.

1.15. Aim and Objectives

The overall aim of this doctoral research was to explore the perspectives and experiences of people with ABI and healthcare professionals after using BiH for twelve months and determine whether the intervention had any effect on functional outcomes, self-management, mood, fatigue, and cognition. The wider aim was to assess the barriers and facilitators associated with the use of smart technologies like BiH.

The objectives were:

1. To systematically review the current level evidence for the effectiveness of personal smart technologies on the independence and functional outcomes of adults with ABI.
2. To identify barriers and facilitators to the use, effectiveness and acceptability of BiH for the ABI population, carers and HCPs.
3. To determine whether using BiH for up to 12 months is associated with improved functional outcomes, mood, fatigue, quality of life, cognition, and participation in society of people with ABI using appropriate measures.
4. To determine whether BiH increases goal attainment in people who are recovering from an ABI.
5. To collect information about the experiences and perspectives of people with ABI, carers and HCPs after using BiH for six months.
6. To assess the feasibility of collecting resource usage and costs associated with the implementation of BiH, and provide a commentary on suitable economic evaluation framework for a future feasibility randomised controlled trial (RCT).

Table 1-2 presents a summary of this thesis.

Table 1-2 Summary of research objectives and methods

Objective	Method	Chapter
• Identify current level of evidence for personal smart technologies in ABI.	• Systematic review.	Chapter 2
• Identify barriers and facilitators to implementation of BiH. • Evaluate the experiences/perspectives of using BiH.	• Focus groups and engagement work with various stakeholders. • Case studies and semi-structured interviews with ABI participants and HCPs.	Chapter 3 Chapter 4
• Determine if BiH has an effect on outcome measures of interest.	• ABI case studies, n-of-1 design. • Administration of questionnaires.	Chapter 4
• Determine if BiH has an effect on goal attainment.	• ABI case studies. • Goal attainment scaling.	Chapter 4
• Assess feasibility of collecting health economic data. • Suggest a suitable economic evaluation framework.	• Feasibility of health economics evaluation.	Chapter 5

The background information presented in this chapter has highlighted the need to address the given aims and objectives. A mixed method approach will be adopted across this thesis and in subsequent chapters.

Chapter 2 Systematic Review of Personal Smart Technologies used to improve Outcomes in Adults with Acquired Brain Injuries[1]

2.1. Chapter Overview

The previous chapter introduced ABI, its causes and potential outcomes, and the current issues with rehabilitation. Some of the well-researched assistive technologies were introduced, their uses and efficacy, however the literature review did not reveal the extent of high quality studies evaluating the effectiveness of smart technologies in ABI. Although many smart technologies exist to support some of the common problems experienced following ABI, such as cognitive impairment, it was not clear how many studies had measured different outcomes such as independence, function, mood, quality of life and participation. This chapter presents a systematic review to determine the effectiveness of smart technologies on various outcomes, specifically functional independence. The findings of this review have informed the design and focus of subsequent studies in this thesis.

2.2. Background

The long-term nature and often life-changing consequences of ABI mean that significant social and economic burden is placed on individuals, families, and healthcare resources. 'Personal smart technology' (PST), (defined as an electronic device that can be used interactively to serve a particular function to aid everyday activities, which is small and easy to carry) can provide the long-term support needed for ABI survivors, enabling them to lead more independent and fulfilling lives.

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[1] Kettlewell et al., 2018 (in press). A Systematic Review of Personal Smart Technologies used to improve Outcomes in Adults with Acquired Brain Injuries. *Clinical Rehabilitation*.

PSTs have the potential to reduce reliance on scarce health and social care resources. Although many technologies exist to aid cognition and facilitate physical rehabilitation, there appears to be limited PST available to improve or maintain independence and functional outcomes for people with ABI. There are currently several PSTs (e.g., smartphones, tablets, pagers) available to support the multifaceted nature of ABI, with the ability to aid multiple symptoms and facilitate independent living. These are being used in some clinical settings, but the evidence for the effectiveness of such interventions to improve independence and functional outcomes in adults with ABI has yet to be systematically evaluated. Therefore, it was timely to conduct this review, to highlight the level of evidence available and suggest areas of development in technology and research designs to evaluate the effectiveness of these PSTs.

The aim of this review was to determine the effectiveness of PST compared to usual care or other types of intervention (such as rehabilitation programmes), on the independence and functional outcomes of adults with ABI.

2.3. Methods

This review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009) and the protocol was registered on the International Prospective Register of Systematic Reviews (PROSPERO 2016 CRD42016050717).

A search strategy was developed using indexed terms and words relating to acquired brain injury, personal smart technology, and functional outcomes and independence (see Appendix 1 for examples of the search strategy). To minimise

publication and retrieval bias, I did not restrict the search by date or publication status. The search strategy was adapted to the requirements of the databases searched. I searched twelve databases (appendix 2). PROSPERO was checked for other similar reviews and I conducted a hand-search of reference lists. Grey literature searches were conducted using Google, Google Scholar, the British Library Catalogue, PsycExtra, Mednar, CORE (COnnecting REpositories), and theses searches (using British Library EThOS theses online, DART-Europe E-theses Portal and Networked Digital Library of Theses and Dissertations). The last search was conducted on 31/03/2018. Citations for the authors of included studies were undertaken using Google Scholar citation search functions. Search results were exported directly to EndNote X7 and duplicates removed. Additional identified records were manually added.

2.3.1. Eligibility criteria.

All relevant randomised controlled trials (RCTs) were included. Crossover RCTs were included, but only pre-crossover study data was extracted. All quasi-randomised studies were excluded. Studies reporting data from adults (aged 18 and over) who sustained an ABI (traumatic brain injury (TBI), stroke, haemorrhage, anoxia, infection, brain tumours or mixed ABI) were included. Studies delivering personal smart technology interventions, defined as an intervention using an electronic device or system (small and portable, e.g., a smartphone, tablet or personal digital assistant that can be used interactively to serve a particular function) were included. I included studies measuring at least one of the primary outcomes of interest: independence, function (i.e., things that are meaningful to an individual in the context of everyday living and refers to an integrated series of behaviours or skills that allows that person to achieve important everyday goals), fatigue, or quality of life. The secondary outcomes of interest were: use and satisfaction of the

intervention, psychological functioning (including mood, self-esteem, anxiety and self-efficacy), social functioning or participation, and any other benefits or harms.

2.3.2. Data collection and analysis.

2.3.2.1. Selection of studies.

I independently retrieved all titles from the searches and relevant abstracts identified; two other researchers (KR and RdN) then independently inspected all abstracts (50% each) to ensure reliability of selection. Full reports of the abstracts or reports meeting the review criteria were obtained and inspected. A second researcher (KR) inspected 10% of these to ensure reliability.

Data were extracted relating to aspects of study design, participant characteristics, details of the intervention, outcome measures (primary and secondary), and conclusions. A bespoke data extraction form was used (Appendix 3), which was modelled on the TIDieR guidelines (introduced in chapter 1), to extract data from the included studies (Hoffmann et al., 2014).

2.3.2.2. Quality assessment.

The PEDro scale (de Morton, 2009) was used to assess the methodological quality of the included studies. The PEDro scale was chosen, as it has demonstrated high content validity and high inter-observer reliability (Dodd, Taylor, & Damiano, 2002; Verhagen et al., 1998). I assessed the quality of the studies independently, as did another researcher (RdN), using the PEDro criteria. Findings were compared and results tabulated. The inter-rater reliability was analysed using the Kappa statistic (Cohen, 1960), which was performed to determine consistency among the two raters.

2.3.3. Data synthesis.

Meta-analysis was conducted on outcomes of interest where data were available. Data from each study were pooled using a random-effects model, as this takes into account study sample size and the estimate of between-study variation when weighting study effects. If a study reported more than one measure of a specific outcome (e.g., psychological and cognitive function), I chose the measure that was most similar to those used by the other studies, or the one that provided a global measure of function. To avoid bias, this was decided ahead of the quantitative data extraction. Where high scores represented a poor outcome, the valence of the score was changed from positive to negative. Standardised mean difference (SMD) was used as a summary statistic, as various outcome measures were used by the studies. Meta-analytic means were expressed with 95% confidence intervals (CIs). All analyses were performed using Review Manager (RevMan, Version 5.3) (Copenhagen: The Nordic Cochrane Centre, The Cochrane Collaboration, 2014).

2.4. Results

The database search returned 1080 records with 13 additional records identified through hand-searching of reference lists, the grey literature search and through citation searches of primary authors. Following the removal of duplicates, 756 records remained and 650 were excluded after title screening. A total of 106 abstracts were screened and 85 excluded (see Appendix 4 for reasons). The most common reason for excluding a study was that it was not an RCT (n=43), followed by ‘not personal smart technology’ (n=19), as defined in the methods section. A hierarchical approach to excluding studies was taken. A summary of reasons for exclusion is shown in Table 2-1.

Table 2-1 Summary of reasons for exclusion.

Reason for exclusion (in hierarchical order)	Number (n, % total)
Not adults with ABI	14 (14%)
Not original research with results (i.e., reviews, opinion pieces, trial protocols, etc.)	14 (14%)
Not RCT	43 (43%)
Not personal smart technology	19 (19%)
Did not report at least one primary outcomes	7 (7%)
Could not retrieve full text	2 (2%)
Crossover study - no pre data	1 (1%)
Total	**100**

Full-texts were retrieved for 21 records and 15 were excluded following screening. A total of six studies were included in the review (De Joode et al., 2013; Emmerson, Harding, & Taylor, 2017; Gracey et al., 2017; Hart & Vaccaro, 2017; Kim et al., 2012; Lannin et al., 2014). Table 2-2 presents the ID numbers for each study, which will be used throughout this chapter. The reviewers agreed on the included studies. Figure 2-1 presents a PRISMA flow diagram of the selection process. Although a limited number of studies were included in this review and there was some heterogeneity in study measures, I was still able to conduct meta-analyses for three outcomes of interest: goal attainment, cognitive function and psychological function.

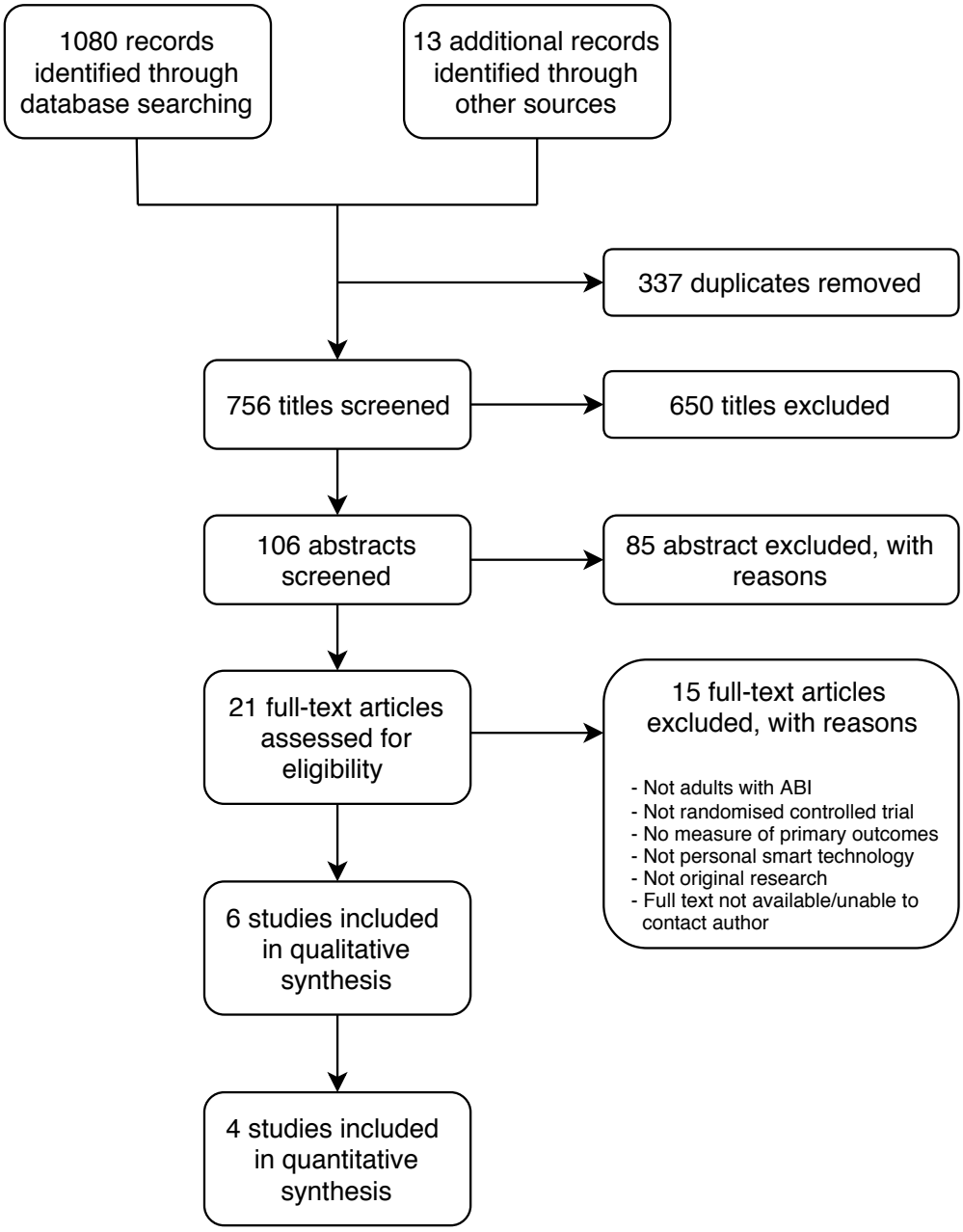


Figure 2-1 PRISMA flow diagram of study selection process

Table 2-2 ID numbers for included studies.

ID Number	Study
1	De Joode, 2013
2	Gracey, 2017
3	Kim, 2012
4	Lannin, 2014
5	Hart, 2017
6	Emmerson, 2017

2.4.1. Quality assessment of included studies

All six included studies were of high quality (≥6) according to the PEDro scale. One study [4] was considered to be of 'excellent' methodological quality and the others [1-3, 5 & 6] of 'good' methodological quality (see Appendix 5). All studies detailed eligibility criteria and random allocation of participants, all provided between-group statistical comparisons for at least one key outcome and provided point measures of variability for at least one key outcome. None of the studies blinded participants or therapists who delivered the treatment due to the nature of the intervention, with only four studies blinding outcome assessors [2, 4-6].

The results for inter-rater reliability between the two reviewers are presented in Table 2-3. The inter-rater reliability was found to be Kappa = 0.962. This value indicates an almost perfect level of agreement on PEDro scoring across the six studies, suggesting the coding is reliable. The raters both agreed that the studies 'satisfied' the PEDro criteria in 47 cases and 'did not satisfy' criteria in 18 cases. The raters disagreed on one occasion, however following discussion with another researcher, they agreed the study did not satisfy the criterion. The final scoring is shown in Appendix 4.

Table 2-3 Inter-rater reliability results.

			Rater B		Total
			Did not satisfy	Satisfied	
Rater A	**Did not satisfy**	**Count**	18	0	18
		% within Rater A	100.0%	0.0%	100.0%
		% within Rater B	94.7%	0.0%	27.3%
		% of Total	27.3%	0.0%	27.3%
	Satisfied	**Count**	1	47	48
		% within Rater A	2.1%	97.9%	100.0%
		% within Rater B	5.3%	100.0%	72.7%
		% of Total	1.5%	71.2%	72.7%
Total		**Count**	19	47	66
		% within Rater A	28.8%	71.2%	100.0%
		% within Rater B	100.0%	100.0%	100.0%
		% of Total	28.8%	71.2%	100.0%
					Kappa = 0.962

2.4.2. Study design and participant characteristics

Five studies used a parallel group design [1, 3-6] and one a crossover design [2] (Table 2-4). Randomisation was performed by computer-generated allocation sequence in one study [4] and blocked sequence allocation in two [2,6]. Three studies [1,3 & 5] did not detail allocation schedule, however one study [5] stated that randomisation was stratified to reduce the effect of memory and emotional factors on outcomes. Studies were conducted in the Netherlands [1], UK [2], South Korea [3], Australia [4,6] and USA [5]. Five studies [1,2 & 4-6] recruited participants from inpatient and outpatient rehabilitation centres and via community/private therapy services. One study [3] recruited people from a stroke inpatient ward, where the intervention was also delivered. Three studies [1,2 & 4] recruited a mixed ABI diagnosis group, two recruited only stroke patients [3,6] and one only TBI patients [5]. Information about participant numbers and demographics was generally well

Table 2-4 Study methods and participant characteristics of included studies

Study ID	De Joode, 2013	Gracey, 2017	Kim, 2012	Lannin, 2014	Hart, 2017	Emmerson, 2017
Aim	Aim of the study was to compare the effects of the PDA with paper based methods in terms of everyday activities after acquired brain injury.	Aim of study to examine the efficacy of Assisted Intention Monitoring (brief goal management training) followed by SMS text messages sent randomly to the participant's phone.	Aim of the study was to examine the effects of gait training using a metronome smartphone application on balance and gait abilities in stroke patients.	Aim of the study was to determine if a PDA was more effective than non-electronic memory aids after acquired brain injury.	Aim of study was to explore if people with traumatic brain injury could create implementation intentions (self-regulatory strategy which aims to promote goal attainment) in line with specific goals and reply to SMS text reminders.	Aim of study was to compare adherence to upper limb home exercise programs provided using video/reminders on touch-screen tablets compared with home exercises provided using a paper-based method for people with stroke.
Design/ Allocation	RCT, parallel group design.	RCT, parallel group, crossover design. Blocked sequence randomisation.	RCT, '*Randomly and equally divided into intervention group and control group*'	RCT, '*Computer generated randomised allocation schedule*'.	RCT, randomisation was stratified.	RCT, blocked sequence randomisation. Allocation concealed.
Blinding	No blinding as it was not possible due to nature of the intervention.	Assessments and primary analyses were conducted blind to group allocation.	No blinding.	Patients and caregivers were aware of allocation, but assessors were blind to group allocation.	Assessors were blind to group allocation.	Assessors were blind to group allocation.
Duration	16 hours training, follow-up 4-6 months after training.	9 weeks, 3 weeks in each phase.	5 weeks.	8 weeks.	8 weeks.	4 weeks.
Setting	7 rehabilitation centres Netherlands and patient homes.	UK community services in East Anglia region.	Stroke inpatient ward at 'S' Rehabilitation Hospital in Seoul, South Korea.	Brain injury rehab unit, community rehab service, and private occupational therapy practice. Australia.	Outpatient brain injury community re-entry programme, patient homes in Pennsylvania, USA.	Community rehabilitation programme sites in Melbourne, Australia.
Participant numbers & demo-graphics	**Diagnosis:** ABI **n =** 40 randomised **Age**: Intervention group mean= 42.2 years; Control group mean= 39.4 years **Gender**: Intervention group = 14 men, 7 women; Control group = 10 men, 3 women **Aetiology**: - Stroke n=12 (intervention n=7, control n=5) - TBI n=11 (intervention n=6, control n=5) - Brain tumour n=3 (intervention n=1, control n=2) - Mixed stroke/TBI n=3 (intervention n=2, control n=1) - Other n=5 (intervention n=5, control n=0) **Mean time post-injury:** - Intervention group = 38.9 months - Control group = 65.9 months	**Diagnosis:** ABI **n =** 74 randomised, 36 in first intervention phase **Age:** Intervention first mean= 46.36 years; Control first mean= 50.18 years **Gender:** Intervention first (intention to treat) = 23 men, 13 women Control first = 23 men, 11 women. **Aetiology**: - CVA n=23 (intervention first n=11, control first n=12) - Infection n=3 (intervention first n=2, control first n=1) - TBI n=33 (intervention first n=17, control first n=16) - Tumour n=10 (intervention first n=6, control first n=4) **Mean time post-injury:** - Intervention first (intention to treat) = 4.89 years - Control first = 8.62 years	**Diagnosis:** Stroke **n =** 20 randomised **Age:** Intervention group mean= 58.3 years; Control group mean= 51.8 **Gender:** Intervention group = 6 men, 4 women. Control group = 7 men, 3 women **Aetiology:** - Infarction n=8 (intervention n=6, control n=2) - Haemorrhage n=12 (intervention n=4, control n=8) **Side of hemiplegia:** - Right side n= 8 (intervention n=5, control n=3) - Left side n=12 (intervention n=5, control n=7)	**Diagnosis:** ABI **n =** 42 **Age:** Intervention group mean= 34 years 8 months; Control group mean= 32 years 5 months **Gender:** Intervention group = 12 men, 9 women Control group = 14 men, 7 women **Aetiology:** - Closed TBI n = 31 - Open TBI n=0 - Initially closed with neurosurgery n=2 - Other n=6 **Mean time post-injury:** - Intervention group = 2363.9 days - Control group = 4379.8 days,	**Diagnosis:** TBI **n =** 8 randomised **Age:** Intervention group mean= 23.8 years, Control group mean = 34.3 **Gender:** Intervention group = 2 men, 2 women. Control group = 3 men, 1 woman **Cause of TBI:** - Motor vehicle n=6 (intervention n=3, control n=3) - Fall n=1 (intervention n=1, control n=0) - Assault n=1 (intervention n=0, control n=1) **Median time post-TBI:** - Intervention group = 2.5 years (0.75-7.0) - Control group = 2.7 years (1.3-4.0)	**Diagnosis:** Stroke **n =** 62 randomised **Age:** Intervention group mean = 68 years; Control group mean = 63 **Gender:** Intervention group = 17 men, 13 women. Control group = 19 men, 13 woman **Type of stroke:** - Infarct n=53 (intervention n=22, control n=27) - Haemorrhage n=9 (intervention n=6, control n=3) **Median time post-stroke:** - Intervention group = 122 days - Control group = 133 days
Inclusion criteria	1. Diagnosis of ABI. 2. Aged between 18-75. 3. Comprehension of Dutch. 4. Experiencing problems in daily life functioning. 5. Clinical judgement that use of external cognitive aids may be beneficial to the participant.	1. Diagnosis of non-progressive brain injury. 2. Aged 18 or over. 3. More than one year post-injury. 4. Clinician, carer or self-reported everyday organisation and memory problems. 5. Ability to use mobile phone.	1. Diagnosis of stroke with subacute hemiplegia. 2. No more than 6 months post-diagnosis. 3. No cognitive impairment (MMSE less than 24). 4. No visual, auditory, or orthopaedic injuries that may influence balance.	1. Diagnosis of ABI. 2. Aged 17 years or over. 3. Functional memory impairment (assessed by RBMT). 4. Emerged from post-traumatic amnesia. 5. Sufficient hand function to use a PDA.	1. Diagnosis of moderate to severe TBI. 2. At least 6 months post-injury. 3. Fluent in English. 4. Confirmation from the participant that at least one of the study goal areas were relevant for him/her following discharge.	1. Diagnosis of stroke. 2. Any degree of upper limb impairment. 3. Referred for occupational therapy.
Exclusion criteria	1. Visual or manual difficulties incompatible with normal PDA use 2. Severe psychiatric comorbidity 3. Progressive neurological disorder	1. Memory impairment of sufficient severity to limit retention of intentions and training information. 2. Patient or carer participant with severe and enduring mental health problem. 3. Substance misuse/dependency. 4. Rehabilitation intervention with significant overlap with study intervention.	Not reported.	1. No memory impairment. 2. Severe physical disability. 3. Living outside metropolitan Sydney. 4. Not English speaking.	1. History of serious mental illness. 2. Current serious psychiatric issues. 3. Significant cognitive disability not as a result of TBI. 4. Enrolment in another intensive treatment programme. 5. No method for receiving voice, email or text messages.	1. Visual or cognitive deficits that would prevent use of the technology. 2. No carer or family member available to provide daily assistance (where necessary).
Control group	• Care-as-usual, aimed at learning skills and strategies to support memory, planning and organisation. • Most centres provided paper based training (e.g. paper diaries). • Received a fixed number of 16 hours of training.	• One-to-one sessions of the same duration as AIM consisting of brain injury information presented using Powerpoint. • Computerised visuospatial game involving increasingly speeded mental rotation ('Tetris'). • Received eight daily SMS text messages reading: 'AIM research study. Please ignore'.	• Thirty minutes of conventional therapy, ten times per week for a period of five weeks. • Conventional therapy was defined as 'one-on-one neurodevelopmental therapy between a patient and a therapist.	• Eight weeks use of a non-electronic memory aid. • Received individual and group sessions which focused on the use of non-electronic memory strategies to support daily living. • Included paper diaries, formation of lists and cueing strategies, integration of mneumonics.	• Received the Goal Review (GR) intervention. • Attended a session that included a brief didactic presentation on the importance of goals, discussion of goals they participant had achieved and goals they still wished to achieve.	• Given instructions for their home exercise programme in a written format, often including diagrams. • Participants who owned or had easy access to a touch-screen tablet were asked not to use video or reminder functions on their device as part of therapy programmes.
Drop outs	**Intervention group:** • Post treatment; no response n=1, unrelated death n=1, questionnaires not received n=2 • Follow-up; burden too high n=1, unrelated death n=1, questionnaires not returned n=9. **Control group:** • Post treatment; burden too high n=1, dissatisfied with allocation n=1, no response n=2, questionnaires not received n=3 • Follow-up; questionnaires not returned n=4.	**Withdrew following baseline assessments and prior to randomisation n=9** Too demanding n=5, memory impaired n=2, phone problems n=1, reason not known n=1 **Intervention first group:** withdrew following allocation n=1, did not complete intervention phase n=6, n=37 randomised to the intervention first group and n=29 completed. **Control first group:** withdrew following allocation n=3, did not complete control phase n=2, n=37 randomised to the control first group and n=30 completed.	**Dropouts n =1** - Participant left hospital halfway through the study	**Dropouts n=0** 100% adherence to study protocol.	**Dropouts n=4** • Withdrew following consent n=1, lost to contact • Withdrew following baseline assessments and prior to randomisation n=1 • Withdrew following introduction of intervention n=2 through agreement, unable to articulate a goal specific enough to create GAS.	**Dropouts n=4** • Died from unrelated medical issues (n=1) • Good progress and self-discharged from the community rehabilitation programme (n=3) -

reported and consistent for all studies, with all reporting age, gender, sample size, and ABI aetiology. Five studies reported average (mean or median) time since injury [1, 2 & 4-6], one reported work status [4] and two reported education level prior to injury [1, 5]. A total of 244 people with an ABI were recruited and randomised across the studies.

Three of the included studies [2, 4, 6] mentioned power calculations and managed to recruit the required number of participants to detect a clinically meaningful change. One study [1] conducted a post-hoc power calculation and concluded that the sample size to detect an effect was insufficient. Two studies [3, 5] did not mention power calculations but indicated the limitation of a small sample size. Dropout rates (range 0-20%) were recorded for all studies, some more detailed than others. Only one study had 100% adherence [4] and another recorded one participant leaving the study early [3]. For the remaining three studies [1, 2 & 5], some dropouts were due to the study procedures being too demanding (e.g., too many questionnaires), other reasons included unrelated death, inability to create specific goals, and phone problems. One study reported that participants were lost to follow-up as a result of self-reported improvement/progress and self-discharge [6].

2.4.3. Intervention details

The duration of the intervention period varied between studies (Table 2-5). The crossover study [2] lasted 9 weeks with 3 weeks in each phase, i.e., 3 weeks in intervention period. One study lasted 5 weeks [3], two lasted 8 weeks [4 & 5] and another consisted of 16 hours' intervention training and then 4-6 months of use [1].

All studies detailed their interventions in accordance with the TIDieR guidelines (Hoffmann et al., 2014). They used different types of personal smart technology: one

Table 2-5 Details of personal smart technology interventions used in the included studies

Study ID	De Joode, 2013	Gracey, 2017	Kim, 2012	Lannin, 2014	Hart, 2017	Emmerson, 2017
Brief description of personal smart technology	PEAT (Planning and Execution Assistant and Trainer) software provided on a PDA (Hewlett-Packard iPAQ HP114, Windows Mobile 6 operating system).	Assisted Intention Monitoring (AIM) which comprised brief goal management training followed by randomly-timed SMS text messages received on Neuropage device.	Rhythmic auditory stimulation (RAS) using metronome app on a smartphone.	PDA.	Implementation intentions created by participants, delivered as SMS text message reminders received on mobile phone.	Home exercise videos and reminders on a touch screen tablet.
Components of intervention	• PEAT was installed on PDA and took control of the device. • PEAT provides reminder function, 'floating task' function to allow automatic planning of specific tasks, and reschedule task if another interferes. • Has a 'wait button' which allows users to postpone the beginning or ending of a task. • Comprises four main modules: cue card, diary, notes section and names section. • Users reminded of start and end of task.	• Main parts of the program presented to participants on Powerpoint slides. • Slides covered the following: 1) utility of setting goals and breaking goals down into steps, 2) absent-mindedness and 'slip-ups', 3) using the 'mental blackboard' to take note of goals and steps, 4) checking status of one's intentions, which was linked to the acronym 'STOP' - Stop, Think, Organise, Plan. • Participants were sent 8 'STOP' texts each day, which was provided via a reminding service call Neuropage, which has the capacity to send SMS messages.	• Metronome application for a smartphone called ZyMi Metronome FREE for Android operating systems and was free of charge. • The metronome beat was provided as auditory stimulation through individual earphones.	• Lowest cost PDA available at the time that had the following features; alarm, calendar, address book and camera, but did not have telephone functionality. • A Windows platform PDA (Palm Z22, HP Palm, HPiPAQ) and a Macintosh platform PDA (MessagePad, ITouch) were available for selection .	• Implementation intentions were developed for each participant to promote goal attainment. • Specific SMS messages containing these implementation intentions were sent to the participants' phones at various times throughout the week and the individuals were required to respond with a phrase.	• During the first therapy session, a home exercise programme was developed by an OT with the participant, in line with usual practice. • An iPad was used to video the participant performing their home exercise programme with a commentary. • A reminder/alarm was set up to provide both a visual and audio daily exercise cue. • Videos updated throughout the programme upon review.
Who provided (and/or set up device)	PEAT training provided by therapists at various rehabilitation centres according to the centre's usual procedure.	Intervention delivered by a member of the research team, '*a qualified occupational therapist with significant experience in providing cognitive rehabilitation interventions both in clinical and research settings with people with stroke and ABI*'.	Not mentioned.	Occupational therapist (OT) provided support in the use of the PDA. All training modules were delivered by an experienced neurological OT.	Therapist(s) worked with each participant in the intervention group to develop implementation intentions that were relevant to their specific goals specified in the GAS.	The home exercise programme was developed by an OT with the participant. The OT provided the commentary for the iPad videos and they also updated the videos when the participant had a review.
Procedures and how it was delivered	• Following baseline, participants were encouraged to use the intervention as much as possible at home or rehabilitation centre, and integrate into daily routines. • Training (using predefined protocol) to use the device was provided for all intervention group participants. • Remainder of the training period was tailored to participants' specific needs. • Following training, participants completed post-treatment measures and given the opportunity to purchase the intervention at a reduced price.	• Brief GMT provided one-to-one in participants' homes or in community setting, over 2 sessions which were no more than 5 days apart. • Training materials were selected from the full GMT program and presented as a PowerPoint presentation with accompanying workbook. • Slides were supported with discussion of examples provided by the participant or in the workbook. • Participants told they would receive 8 texts each day stating the acronym 'STOP'. These would occur at random times between 8am and 6pm each working day. They did not occur within 30 minutes of each other.	• Rhythmic auditory stimulation training sessions were conducted in a rectangular gait training space, 20mx5m. • Training program consisted of 5 stages, each lasting 5 minutes, with a 1 minute break between each stage. • Participants were instructed to walk a 20m course repeatedly for 1 minute of training so they could adapt to the metronome beat. • Stages increased in complexity in time with the metronome beat. • Final stage: forward walking was performed by increasing cadence of a comfortable speed by 5%. When participants were able to maintain this speed for more than 1 minute, they were asked to maintain the speed on their own by gradually turning down the volume of the metronome application until it was muted.	• Participants chose and prioritised meaningful activities that they wanted to improve their independence in or memory. • There were 5 structured training modules provided over study period. • Key features of training modules included: selection of appropriate PDA, awareness of deficit training, training in basic PDA application skills, and use of organisational strategies. • Training sessions also focused on general strategies outside of therapy. Caregivers were involved in the training sessions where possible.	• Participants met therapist(s) to select a goal area from the following: Depression, Anxiety, Anger/Irritability or Social Issues. • Implementation intentions were created by identifying responses that would promote goal attainment. • A message schedule was negotiated with each participant to determine when the SMS texts (with the implementation intentions) would be delivered. • Participants asked to rehearse messages by reading them at least 3 times and reply with a brief phrase so that these could then be logged as received or 'processed'. • After 8 weeks of receiving messages, participant goal attainment was reassessed using GAS.	• During the first therapy session, a home exercise programme was developed by an OT with the participant, in line with usual practice. • An iPad was used to video the participant performing their home exercise programme with a commentary. • A reminder/ from the OT alarm was set up to provide both a visual and audio daily exercise cue. • Videos updated throughout the programme upon review. • Participants asked to complete their exercises for 4 weeks.
Frequency, duration, intensity and fidelity of implementation.	• Total training time was 16 hours with a therapist. • Initial training took between 2-6, 30 minute sessions. Frequency of training sessions varied between 2 times/week and 2 times/month. • Most participants received 30-60 minutes of training each week. • The frequency and intensity of training sessions varied, as this was dependent on routine procedures at the rehabilitation centre, and the specific needs of the individual. • PDA user interface was standardised for all participants as PEAT completely took over the device, meaning individuals could not switch to the Windows environment, thus avoiding confusion.	• The training period depended the individual and their knowledge/abilities to understand the intervention. • Participants received 2 training sessions that lasted between 90 and 120 minutes.	• Participants in the RAS group received 15 sessions of gait training for 30 minutes, three times per week (i.e. 90 minutes per week). • Participants also received 30 minutes of conventional therapy twice a day, 5 times per week. • Conventional therapy was defined as 'one-on-one neurodevelopmental therapy between a patient and a therapist'.	• OT chose the appropriate PDA for the participant from the selection based on their patient's experience with computer platforms/PDAs in the past. • Five structured training modules provided by OT over 8 weeks, with participants taking as long as needed to acquire the skills. • The timing, frequency and duration of the training sessions were consistent, with usual practice in the brain injury unit. • OTs kept records of number, duration and content of training sessions on paper data collection forms.	• A structured protocol was used to develop implementation intentions relevant to participants' specific goals. • Protocol was developed for the study and based on previous literature. • The implementation intention messages were delivered by SMS text over an 8 week period. • The number of daily messages varied between participants (5-7).	• Exercise programmes were based on the National Stroke Foundation Clinical Guidelines. • Content varied depending on individual deficits, as did the number of exercises and number of recommended sessions each day. • A typical recommendation was 1-2 times per day. • Participants used the iPad for 4 weeks.
Tailoring and modifications	• Following initial training, content of remainder of training course was tailored to the patients' specific needs. • PEAT software can be tailored to the individual and users had the control to alter the way they are cued at beginning and/or end of a task.	Not mentioned.	Not mentioned.	The technology changed during the period of the trial.	• A schedule was negotiated with participant as to when messages would be delivered. • Participants had the choice to receive messages on their mobile phone via text, voice or email. Participants' own words were used for the implementation intentions.	• Each participant had an individualised exercise programme which was recorded specifically for them. • Modifications were made to the programme if necessary when the participant was reviewed.

used a personal digital assistant (PDA) [4] to organise daily tasks using inbuilt functions, such as calendar, address book, alarm/reminding function, and one used planning software called PEAT (Planning and Execution Assistant and Trainer) installed on a PDA [1]. PEAT provided users with cue cards, 'floating tasks' (activities that can be scheduled anytime within a specified time window), 'wait button' (enables users to postpone tasks) and the ability to link notes with events, all accessible on the PDA. One study [3] provided a metronome smartphone application (or 'app') for stroke patients, which was used for mobility based tasks, e.g., walking. One used a paging device called Neuropage [2], which received goal management training via text messages and involved the use of the 'STOP' acronym (Stop, Think, Organise, Plan) to encourage goal attainment. The final study used a mobile phone [5], which received goal-specific implementation intentions (a self-regulatory strategy that forms an if-then plan, e.g., '***if** I get angry or nervous, **then** I will put myself in the other person's shoes'*) via text message. This strategy aimed to promote goal attainment in the context of everyday living. Four of the interventions [1, 2, 4 & 5] focused on goal-directed tasks.

Five studies [1, 2 & 4-6] provided details about who delivered the intervention training and/or support. In these studies, a therapist provided this training (specifically OTs in study [4 & 6]). All five studies detailed the procedures involved in delivering the intervention, specifically training and initial set up. Three studies [1, 4 & 5] followed a similar procedure, during which the therapist(s) provided training and/or asked participants to consider meaningful goals relevant to everyday living, and how these can be applied to the intervention. These studies [1, 4 & 5] detailed the individualisation of certain training aspects to meet the needs of the participant. One study [1] initially followed a predefined protocol, then tailored the remainder of

sessions to the person's requirements and abilities. Four [1, 2, 4 & 5] studies focused on goal attainment, one used GAS [1], one used GMT [2], one used implementation intentions based on GAS [5], and another considered goal directed activities [4]. One study [3] followed a completely different procedure and was conducted in a hospital setting. The intervention was delivered as part of a training program, which was divided into five stages. The stages involved different ambulation tasks, accompanied by a metronome beat from the smartphone application. As with this study, one other study [4] divided intervention training into five modules.

Training duration for the participants varied between the studies. One study [1] delivered a total of 16 hours training, which also served as the intervention period. The 16 hours were divided into sessions lasting 30 minutes on average, twice per week. Another study [2] provided two training sessions lasting 90-120 minutes. One study [3] delivered 15 sessions of gait training for 30 minutes, three times per week, and another study [4] provided training over eight weeks in line with the centres' usual practice. Two studies [5, 6] did not detail the amount of time allocated to participant intervention training. In three studies [1, 2, 4], the timing, frequency and intensity of training depended on the individual participant and in two studies [1, 4], the training was dependent on routine procedures at the rehabilitation centres.

Intervention fidelity was not addressed by any study, meaning there was no reference to whether the intervention was delivered as intended and if this was assessed. One study [4] stated that therapists delivering the intervention kept a record of the number, duration, and content of training sessions on data collection forms. One study [3] adhered to a specific duration of training and amount of

conventional therapy alongside the intervention (30 minutes, twice daily, 5 days per week).

One study [4] stated that the technology was changed during the period of the trial, and one study [5] stated that the method/schedule of message delivery to the mobile phone was determined by the participant. Another study [1] provided more detail about tailoring, stating that users had the ability to alter the way they are cued at the beginning and end of tasks.

2.4.4. Comparator interventions.

The control groups varied between studies. Two studies [1, 3] provided the control group with 'care as usual' or 'conventional therapy', a different study [4] provided the control group with non-electronic memory aids, and one provided home exercises in written format [6]. The remaining studies [2, 5] were more complex: control participants in one study [2] received non-intervention based SMS text messages and trained to use a visuospatial game, and in the other study [5] participants attended educational presentations on goal attainment and discussed goals they wanted to achieve. Care as usual/conventional therapy varied between the two studies, with one aimed at teaching skills and strategies for memory [1], sometimes providing paper and pencil aids, the other study provided neurodevelopmental therapy [3].

2.4.5. Primary outcome measures.

2.4.5.1. Functional outcomes.

All six studies assessed functional outcomes, defined as things that are meaningful to the patient in the context of everyday living (Table 2-6). Three studies [1, 4 & 5] assessed goal attainment using the Goal Attainment Scaling (GAS) (Turner-Stokes, 2009), one developed a bespoke measure of intention attainment, while others

Table 2-6 Primary outcome data from included studies

Study ID	De Joode, 2013	Gracey, 2016	Kim, 2012	Lannin, 2014	Hart, 2017	Emmerson, 2017
Functional Outcomes	**Goal Attainment Scaling (GAS) Total** Outcomes at 16-hours post-treatment (between baseline T0 and T2): *Intervention*; mean increase 45.2 points (SD=32.8), p<0.001. *Control*; mean increase 36.7 points (SD= 15.6), p<0.001. Intervention vs. control at T2; p>0.5. **Frenchay Activities Index (FAI)** - Outcomes at 16-hours post-treatment (T2): *Intervention*; mean 23, SD=7.6 (19.3 at baseline), *Control*; mean 20.9, SD=7.3 (23.4 at baseline). - Outcomes at 4-6 months following 16-hour treatment (T3): *Intervention*; mean 25.6, SD=7.4. *Control*; mean 24.3, SD=8.0.	**Intention Attainment** - Outcomes at 6 weeks following intervention phase 2 (intention to treat): *Intervention*: mean 0.64, SD=0.17. *Control*: mean 0.63, SD=0.21. Mean difference 0.01, 95% CI (-0.09-0.11), p=0.87. Missing values intervention n=4, control n=3. - **Mean daily goals achieved (non-phone intentions)** - Outcomes at 6 weeks following intervention phase 2 (intention to treat): *Intervention*: 0.85, SD=0.13. *Control*: 0.83, SD=0.17. Mean difference 0.05, 95% CI (-0.06-0.10), p=0.62. Missing values intervention n=4, control n=3.	**Functional Ambulation Category (FAC)** Outcomes following 15 hours training: *Intervention*; 4.33 (baseline 3.00), p<0.05*. *Control*; 4.56 (baseline 3.67), p<0.05*.	**Goal Attainment Scaling (GAS) Total** Outcomes at 8 weeks: *Intervention*; 53.9 points, SD=16.4 (baseline 14.1). Mean difference within group 45.3, 95% CI (39.1-51.3). *Control*; 54 points, SD=16.4 (baseline 15.4). Mean difference within group 38.4, 95% CI (31.5-45.4). Intervention vs. control (between groups): mean difference 6.3, 95% CI (-2.7-15.4), p=0.165 **GAS functional memory failures goal** Outcomes at 8 weeks: *Intervention*; 53 points, SD=5.2 (baseline 41). Mean difference within group 11.9, 95% CI (9.4-14.5). *Control*; 49.5 points, SD=5.9 (baseline 41.7). Mean difference within group 7.8, 95% CI (5.02-10.6). Intervention vs. control (between groups): mean difference 1.6, 95% CI (1.0-2.2), p=0.0001***	**Goal Attainment Scaling (GAS)** - No significant differences in self-reported GAS change scores between groups at 8-weeks post-intervention. - One participant reported no change, one reported +1, one +2 and one +3. - No significant difference between groups on GAS reported by participant's nominated person (significant other): Mann-Whitney U=4.5, p=1.0	**Wolf Motor Function Test** Outcomes at 4 weeks: Mean time (seconds) *Intervention;* 33, SD=37 (baseline 39). *Control*; 45, SD=44 (baseline 49). Mean difference between group -5, 95% CI (-11-1); p=0.101 Functional score *Intervention;* 3.2, SD=1.4 (baseline 3.1). *Control*; 3.0, SD=1.6 (baseline 2.8). Mean difference between group 0.1, 95% CI (-0.1-0.3); p=0.454
Quality of Life	**MOS Short Form health survey (SF-36): Physical functioning** - Outcomes at 16-hours post-treatment (T2): *Intervention*; mean 43.9, SD=9.9 (44.7 at baseline). *Control*; mean 45.6, SD=7.2 (45.7 at baseline). Outcomes at 4-6 months following 16-hour treatment (T3): *Intervention*; mean 46.7, SD=8.4. *Control*; mean 48.1, SD=12.1. **SF-36: Mental functioning** - Outcomes at 16-hours post-treatment (T2): *Intervention*; mean 39.6, SD=13.2 (38.6 at baseline). *Control*; mean 34.8, SD=13.3 (35.5 at baseline). Outcomes at 4-6 months following 16-hour treatment (T3): *Intervention*; mean 36.9, SD=12.2. *Control*; mean 35.5, SD=11.6. **Life Satisfaction Questionnaire (LISAT-9)** - Outcomes at 16-hours post-treatment (T2): *Intervention*; mean 39.2, SD=6.7 (40.4 at baseline). *Control*; mean 32.3, SD=7.8 (33.9 at baseline). Outcomes at 4-6 months following 16-hour treatment (T3): *Intervention*; mean 40.1, SD=5.3. *Control*; mean 32.6, SD=6.1.	No measure.	No measure.	No measure.	No measure.	No measure.
Independence	No measure.	No measure.	No measure.	No measure.	No measure.	No measure.
Fatigue	No measure.	No measure.	No measure.	No measure.	No measure.	No measure.

assessed functional ambulation [3] and upper limb function [6].

In one study [1] using goal attainment scaling, the intervention group had a significant mean increase of 45.2 (SD = 32.8) points in goal attainment score ($t(20) = 6.31$, $p<0.001$) following the intervention period. However the difference in scores between this and the control group was not significant (mean increase 36.7 points, SD = 15.6, $t(11) = 8.16$, $p>0.05$). The authors suggested that small group size, short intervention duration and low intensity training may have affected outcomes. A second study [4] using goal attainment scaling to measure specific memory failure goals in the context of daily living (i.e., not total goal attainment scaling score) reported a significant difference between intervention and control groups (mean difference 1.6, 95% CI 1.0 to 2.2, $p=0.0001$) at 8 weeks post-intervention, in favour of the intervention. One study [2] developed a bespoke measure of intention attainment, defined as the participants' on-going intentions, seven fixed intentions set at baseline, and *ad hoc* intentions throughout the study. No significant difference (mean difference 0.01, 95% CI -0.09 to 0.11, $p=0.87$) was found between the intervention and control group's intention attainment scores.

Additional functional outcome measures used in the studies were the Frenchay Activities Index (FAI) (Schuling, De Haan, Limburg, & Groenier, 1993), FAC and Wolf Motor Function Test (WMFT). The study did not publish significance results for FAI, presenting only mean values and standard deviations (SD). One study [3] using Function Ambulation Category (pre-post comparison) presented significant improvement in the intervention group following 15 hours training (mean increase 1.33, SD=0.50, $p<0.05$). However, improvement in the control group scores was also significant ($p<0.05$). The study [6] that used the Wolf Motor Function Test presented no between-group differences after four weeks.

2.4.5.2. Quality of life.

Only one study [1] assessed quality of life using two different questionnaires: Medical Outcomes Study (MOS) Short Form health survey (SF-36) (Ware Jr & Sherbourne, 1992) and the Life Satisfaction Questionnaire (LISAT-9) (Boonstra, Reneman, Stewart, & Balk, 2012). This study [1] presented results under the two dimensions of the SF-36 categories: physical functioning and mental functioning. Although a greater improvement in LISAT-9 score (i.e., greater quality of life) was reported in the intervention group (pre-post comparison), no between-group statistical analysis was conducted for this measure or for the Short Form health survey.

2.4.5.3. Other primary outcomes.

None of the included studies used specific measures of independence or fatigue.

2.4.6. Secondary outcome measures.

2.4.6.1. Psychological function.

Three of the included studies [1, 3 & 5] used at least one measure of psychological function; one [1] assessed self-efficacy (General perceived self-efficacy scale; GSES) and depression (Centre for Epidemiologic Studies Depression Scale; CES-D), one study [2] assessed mood state (Profile of Mood states total mood disturbance; POMS-MD), and one [5] assessed anxiety (Brief Symptom Inventory (BSI): Anxiety scale) and depression (BSI: Depression scale) and overall psychological distress (BSI-Global Severity Index (GSI)) (Table 2-7). The study that used GSES [1], presented a mean score of 25 (SD=6.7) in the intervention group at 16 hours' post-intervention, and 25.3 (SD=6.5) in the control group. A higher score indicated more self-efficacy. The same study presented CES-D data, with a mean

Table 2-7 Secondary outcome data from included studies

Study ID	De Joode, 2013	Gracey, 2017	Kim, 2012	Lannin, 2014	Hart, 2017	Emmerson, 2017
Psychological function	**General perceived self-efficacy scale (GSES)** - Outcomes at 16-hours post-treatment (T2): *Intervention*; mean 25.0, SD=6.7 (26.3 at baseline), *Control*; mean 25.3, SD=6.4 (26.5 at baseline). - Outcomes at 4-6 months following 16-hour treatment (T3): *Intervention*; mean 25.9, SD=6.5. *Control*; mean 25.2, SD=6.2. **Centre for Epidemiologic Studies Depression Scale (CES-D)** - Outcomes at 16-hours post-treatment (T2): *Intervention*; mean 18.0, SD=8.9 (18.2 at baseline), *Control*; mean 20.2, SD=6.2 (19.9 at baseline). - Outcomes at 4-6 months following 16-hour treatment (T3): *Intervention*; mean 19.3, SD=7.8. *Control*; mean 19.0, SD=7.7.	**Profile of Mood States total mood disturbance (POMS-MD)** - Outcomes at 6 weeks following intervention phase 2 (per protocol): *Intervention*: mean -0.55, SD=25.6 *Control*: mean 2.83, SD=20.3. Mean difference 3.38, 95% CI (-8.78-15.54), p=0.58. Missing values intervention n=0, control n=1. - Outcomes at 6 weeks following intervention phase 2 (intention to treat): *Intervention*: mean 47.2, SD=40.6 *Control*: mean 47.3, SD=37.9. Mean difference -0.02, 95% CI (-19.37-19.34), p=1.00. Missing values intervention n=2, control n=2.	No measure.	No measure.	**Brief Symptom Inventory (BSI) Depression Scale** - Outcomes at 8 weeks post-intervention. *Intervention*: mean 53.2, SD=7.9. *Control*: mean 52.5, SD=11.9. F=0.3, not significant. **BSI Anxiety Scale** - Outcomes at 8 weeks post-intervention. *Intervention*: mean 52.3, SD=14.7. *Control*: mean 46.5, SD=10.4. F=0.3, not significant.	No measure.
Cognitive function	**Cognitive Failure Questionnaire (CFQ)** - Outcomes at 16-hours post-treatment (T2): *Intervention*; mean 42.2, SD= 15.9 (45.8 at baseline), *Control*; mean 49.2, SD= 14.8 (49.1 at baseline). - Outcomes at 4-6 months following 16-hour treatment (T3): *Intervention*; mean 48.4, SD=10.6. *Control*; mean 45.4, SD=15.1.	No measure.	No measure.	**Memory Functioning Questionnaire (MFQ): Retrospective memory functioning** - Outcomes at 8 weeks: *Intervention*; 15.8, SD=9.7 (baseline 12.5). Mean difference within group 3.2, 95% CI (-0.5-7.0). *Control*; 12, SD=6.1 (baseline 13.4). Mean difference within group -1.4, 95% CI (-3.9-1.1). - Intervention vs. control (between groups): mean difference 4.3, 95% CI (1.6-8.4), p=0.042 **MFQ: Mneumonic usage subtest** - Outcomes at 8 weeks: *Intervention*; 24, SD=10 (baseline 31). Mean difference within group -6.9, 95% CI (-12.8-1.1). *Control*; 25, SD=7 (baseline 26). Mean difference within group-1, 95% CI (-4.4-2.2). - Intervention vs. control (between groups): mean difference -2.7, 95% CI (-8.1-2.6), p=0.301	No measure.	No measure.
Satisfaction & use of intervention	- Outcome at T3 (4-6 months following 16-hour treatment): 57.1% intervention group chose to continue PDA or smartphone use; 76.9% control group chose to continue using paper aid. Three participants in control group (23.1%) stated they would consider buying PEAT software (intervention) or a different PDA or smartphone system. - Intervention group vs. control group satisfaction not significant, x^2 (1, 34) = 1.4, p =0.24. Reasons for participants not to continue PDA use were too expensive to buy for themselves (19.0%) or preferred another or cheaper aid (23.8%).	No measure.	No measure.	- Outcomes at 8 weeks: 14/21 of intervention participants were still using the PDA daily (67%). 3/21 reported they were no longer using at all (14%).	No measure.	Outcomes at 4 weeks: - *How easy was it to follow instructions?* Very easy: *intervention* n=12/27; *control* n=11/37. Very difficult: *intervention* n=2/27; *control* n=1/37; p=0452. Intervention v control p=0.452 - *Did you remember home exercises?* Remembered all the time: *intervention* n=17/27; *control* n=17/37. Forgot all the time: *intervention* n=1/27; *control* n=0/37; p=0452. Intervention v control p=0.485 - *Did you enjoy home exercises?* Always: *intervention* n=8/27; *control* n=6/37. Never: *intervention* n=1/27; *control* n=1/37; p=0864.
Social participation & function	No measure.	No measure.	No measure.	No measure.	**Participation Assessment with Recombined Tools-Objective (PART-O): Social Relations (self-report)** - Outcomes at 8 weeks post-intervention. *Intervention*: mean 2.3, SD=0.6. *Control*: mean 1.1, SD=0.7. F=13.6, p=0.01, η^2=0.09. **PART-O: Out and About (self-report)** - Outcomes at 8 weeks post-intervention. *Intervention*: mean 1.6, SD=0.6. *Control*: mean 1.2, SD=0.3. F=14.7, p=0.009, η^2=0.27. **PART-O: Productivity (self-report)** - Outcomes at 8 weeks post-intervention. *Intervention*: mean 1.7, SD=0.5. *Control*: mean 0.6, SD=0.2. F=0, not significant.	No measure.

score of 18.0 (SD=8.9) in the intervention group at 16 hours' post-intervention and 20.2 (SD=6.2) in the control group. A higher score indicated a greater presence of depressive/anxious symptoms. No significance testing was conducted between the groups for either measure.

One study [2] presented a mean POMS-MD score of 47.2 (SD=40.6) for the intervention group (intention to treat) at 6 weeks' post-intervention and a mean of 47.3 (SD=37.9) for the control group. As with the other measures, a higher score indicated greater presence of symptomatology. There was no significant different between the groups (p=1.0). The final study [5] presented a mean BSI-depression score of 53.2 (SD=7.9) at 8 weeks' post-intervention and a mean of 52.5 (SD=11.9), no significant difference was found between groups. A mean BSI-anxiety score of 52.3 (SD=14.7) at 8 weeks' post-intervention and a mean of 46.5 (SD=10.4), again no significant difference was found between groups. An overall mean BSI-GSI score of 52.7 (SD=11.3) was reported at 8 weeks' post-intervention and a mean of 53.7 (SD=8.9), with no significant difference between groups. For all BSI measures, a lower score represents a better outcome.

2.4.6.2. Cognitive function.

Two of the included studies [1, 4] used at least one measure of cognitive function. One [1] used the Cognitive Failure Questionnaire (CFQ) and the other study [4] used the Memory Functioning Questionnaire (MFQ). One study [1] presented a mean CFQ score of 42.2 (SD=15.9) for the intervention group and 20.2 (SD=6.2) for the control group, at 16 hours' post-intervention. A higher CFQ score indicated greater cognitive failures. No significance testing was conducted between the groups. One study [4] presented MFQ scores in two categories; retrospective memory functioning and mnemonic usage subset. The MFQ retrospective memory functioning mean

score for the intervention group at 8 weeks' post-intervention was 15.8 (SD=9.7) and for the control group was 12 (SD=6.1). A high score indicated greater improvement in memory ability, compared to an earlier period. A significant difference was found between the two groups ($p<0.05$), meaning that the intervention group had a greater improvement in retrospective memory ability than the control group. The MFQ mnemonic usage subset mean score for the intervention group at 8 weeks' post-intervention was 24 (SD=10) and 12 (SD=6.1) for the control group. A higher score indicated less use of memory aids. There was no significant difference between the two groups ($p=0.301$).

2.4.6.3. Satisfaction with use and effectiveness of intervention.

Only two of the included studies [1, 4] assessed satisfaction with and use of the intervention by asking participants whether they would continue PST use, reasons for this and whether they were satisfied with their allocated group. One study [1] reported no significant difference between the satisfaction of treatment ($p=0.24$), which was compared as percentage of people within each group who chose to continue use. At 4-6 months follow-up, this study [1] reported that 57.1% (exact number not stated) of the intervention group chose to continue using the PST (PDA/smartphone). In the control group, 76.9% (10/13) chose to continue using a paper based aid, with 23.1% (3/13) stating they would consider buying the personal digital assistant (PEAT) intervention or other similar smart technology. In the other study [4], at 8 weeks' post-intervention, 67% of intervention participants (14/21) were still using the PST daily (PDA) and 14% reported they were not using the intervention at all (3/21). In the final study [6], after 4 weeks, a total of 71% of the intervention group reported (usually or always) enjoying their home exercises, compared with 67% of the control group.

2.4.6.4. Social participation and function.

Only one study [5] assessed social participation and function, using three different subsets of the Participation Assessment with Recombined Tools-Objective (PART-O): social relations, out and about and productivity. At 8 weeks' post-intervention, the mean PART-O 'social relations' score was 2.3 (SD=0.6) for the intervention group and 1.1 (SD=0.7) for the control group, which presented a statistically significant difference (p=0.01) and improvement in the intervention group. Similarly, a significant difference (p=0.009) was found between groups for the PART-O 'out and about' score: at 8 weeks' post-intervention, the mean score was 1.6 (SD=0.6) for the intervention group and 1.2 (SD=0.3) for the control group. Finally, at 8 weeks' post-intervention, the mean PART-O 'productivity' score was 1.7 (SD=0.5) for the intervention group and a mean of 0.6 (SD=0.2) for the control group. There was no significant difference between groups.

2.4.7. Quantitative synthesis.

Four studies were included in the meta-analysis [1, 2, 4 & 5]. All four studies included subjective measures of goal attainment, however it was only possible to synthesise data from three studies [1, 2 & 4] as the fourth [5] did not report mean and standard deviation values. Figure 2-2 shows the pooled standardised mean differences (SMDs) from the three studies reporting goal/intention attainment measures, using a random effects model. No significant effect of intervention on goal attainment was found shown by the standardised mean difference (SMD) of 0.08 (95% CI of -0.25 to 0.41, p=0.64, Z=0.47, n=141). There was no variation in goal attainment across studies shown by an I^2 value of 0%, meaning there was no heterogeneity.

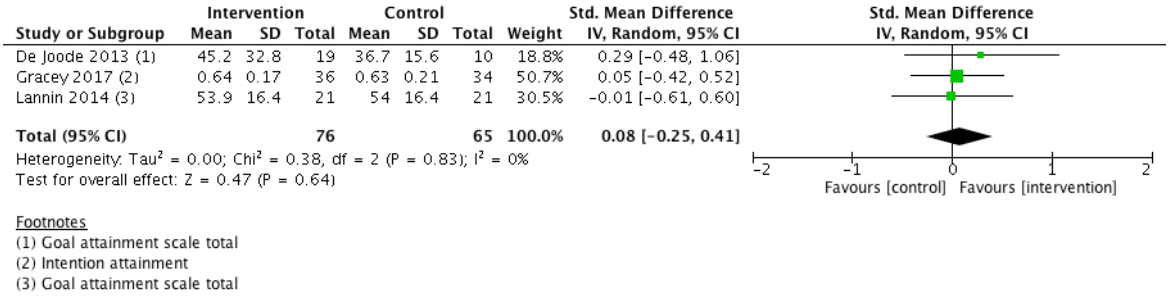


Figure 2-2 Meta-analysis of goal (or intention) attainment outcome measures for three studies.

For each study, the box represents the fixed effects SMD and the line the 95% confidence intervals. The size of each box indicates the relative weight of each study in the meta-analysis.

Three studies [1, 2 & 5] included self-reported measures of psychological function (CES-D, POMS-MD and BSI-GSI), however two of these studies [1, 5] used multiple measures, including anxiety and self-efficacy measures. As I could only use one set of data from these studies, the CES-D was chosen as it was most similar to the POMS-MD, and the BSI-GSI which provided an overall measure of mood or psychological distress. Figure 2-3 shows the pooled SMDs from the three studies using a random effects model. There was no significant effect of the intervention on psychological function (SMD of -0.07; 95% CI of -0.46 to 0.31, p=0.71, Z=0.38, n=107). No variation in psychological function was found across studies, shown by an I^2 value of 0%, meaning there was no heterogeneity in outcomes.

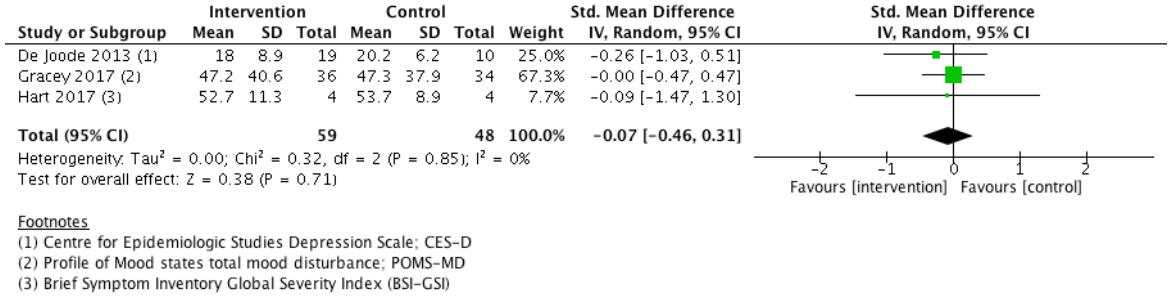


Figure 2-3 Meta-analysis of psychological function for three studies.

For each study, the box represents the fixed effects SMD and the line the 95% confidence intervals. The size of each box indicates the relative weight of each study in the meta-analysis.

Two studies [1, 4] included self-reported measures of cognitive function (CFQ and MFQ), however one of these studies [1] used multiple measures of cognition. As I could only use one set of data from this study, the MFQ (retrospective functioning) was chosen, as it was most similar to the CFQ. The valence of CFQ scores was changed to negative so that a lower score would indicate a worse outcome, as with the MFQ (i.e., a high score indicates better cognitive function). There was no significant effect of the intervention on cognitive function (SMD of 0.45; 95% CI of -0.03 to 0.93, p=0.07, Z=1.84, n=71). There was no variation in cognitive function across studies shown by an I^2 value of 0%, meaning there was no heterogeneity in outcomes.

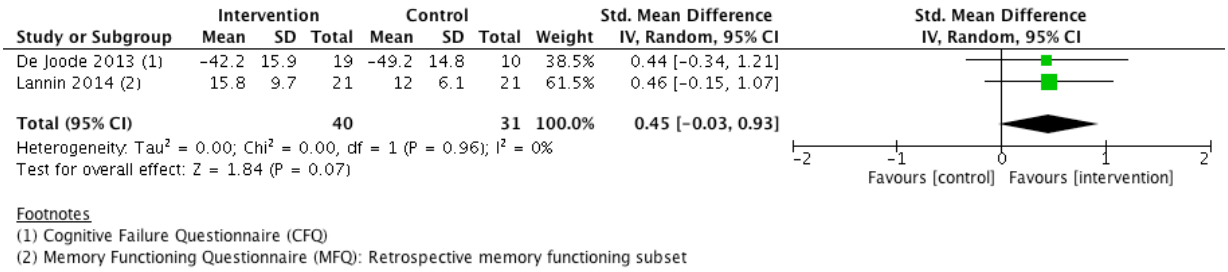


Figure 2-4 Meta-analysis of cognitive function for two studies.

For each study, the box represents the random effects SMD and the line the 95% confidence intervals. The size of each box indicates the relative weight of each study in the meta-analysis.

2.5. Discussion

This chapter systematically reviewed different PSTs and their effectiveness on the independence and functional outcomes of adults with ABI. The review identified six studies that had a focus on function and utilised a range of technology interventions. Given the ubiquity of technology in modern society, specifically smartphones, it was interesting to find that only one study evaluated a smartphone application and only one used mobile phone text messaging. One used an iPad and the remaining studies used different personal smart technologies, all of which are now less commonly used by the general population, such as a pager. It appears there is limited literature exploring the effects of modern personal smart technologies on functional outcomes and independence.

As this is a rapidly growing area of research with limited RCTs, I expected few studies would meet the inclusion criteria and that they would have small sample sizes. Although all studies scored high on quality, the PEDro scale does not take into account power/sample size calculations. Only two studies [2, 4] conducted power calculations prior to recruitment, one [1] conducted a post-hoc calculation, which suggested insufficient power to detect treatment effect. Two had a small number of participants [5, 3]. Perhaps a disadvantage of small sample trials is that it may not be possible to perform further analyses to determine who benefits the most from the use of personal smart technologies, and under what circumstances. Pre-post analysis is not recommended in RCTs and was a limitation of some of the included studies (Bland & Altman, 2011). This highlights the need for larger sample, high quality studies within this area of research.

Although three studies recruited samples with mixed acquired brain injury diagnoses, none of the studies conducted subgroup analyses, based on diagnoses. Whilst such

sub-group analyses could be questioned, particularly with small samples, it is possible that there is greater propensity for certain types of problem in some groups, e.g. hemiplegia in stroke, or diplopia following TBI, which might affect the technology interface and outcomes. However, this can only be conducted if there is sufficient number of participants in the trials.

The quality of intervention description in publications is remarkably poor (Dijkers et al., 2002), which makes replication in practice inevitably difficult. All reviewed studies described their intervention components in detail, providing sufficient information about training procedures, delivery, frequency and duration of use. However, insufficient reporting of specific intervention tailoring and modifications was identified in all studies. Studies have identified the importance of patient-centred/personalised technology in the acquired brain injury population (Cole, 2011; Mawson & Mountain, 2011; Mawson et al., 2014), which should be reported better in future studies to facilitate replication. The TIDieR checklist (Hoffmann et al., 2014) helped me detail the interventions consistently and highlighted areas of reporting that need more attention. It is recommended that researchers make use of this and other checklists when detailing interventions.

Outcome measures varied between the studies, but all presented measures of function and/or goal attainment. The studies used outcome measures that had a level of subjective reporting bias, however this is common for most Patient Reported Outcome Measures. All studies reported significance testing for at least one outcome measure and p values were reported for functional outcomes. Effect sizes were presented for all studies. Four of the studies clearly outlined their primary outcomes, which was a strength. Although some studies presented minor outcome improvement for the intervention groups, and a significant improvement in memory functioning

following the use of personal smart technology, these pre-post findings in an RCT should be treated with caution. Indeed, the meta-analysis did not demonstrate evidence of overall effectiveness of the intervention. There were no significant differences between outcomes of goal attainment, cognitive or psychological function between the interventions (use of personal smart technology) and control.

Only one study specifically reported on whether or not there were any serious adverse events or harms caused by the use of personal smart technologies. This is something that future studies should assess and report.

Despite the focus on functional outcomes, few other effects of personal smart technology were explored. None of the studies reported measures of independence with only one study measuring quality of life and one reporting social participation outcomes. None of the studies reported measures of fatigue. Literature identifies these as some of the more challenging problems to clinically manage following acquired brain injury (specifically fatigue) (Daisley et al., 2009; Lerdal et al., 2011; Maimaris & Worthington, 2012), so it was disappointing to find no high-quality studies exploring these outcomes. Improving social participation and quality of life are often the key foci of rehabilitation interventions (World Health Organization, 2001), and are increasingly being recommended as the primary outcomes from funders such as the National Institute for Health Research; however, it appears that these outcomes are not receiving enough attention in research studies. Researchers need to consider the long-term implementation of their interventions when choosing outcome measures and place more emphasis on the invisible sequalae of acquired brain injury, that are often more difficult to manage, such as fatigue and mood problems. The findings of this review resonate with findings from a 2015 review by Charters et al., which also identified a lack of studies evaluating the effect of technology on the greater needs of

the acquired brain injury population (Charters et al., 2015). This highlights the need for larger RCTs with a focus on different needs of the brain injury population.

A key strength of this review was the use of the TIDieR guidelines to extract information across the different technologies about their key components and potential factors that contribute to their effectiveness (e.g., training, procedures and frequency of use). The guidelines aided our data extraction, and facilitated consistent collection and description of the technologies. The rapid advances in technology and drivers for self-management following acquired brain injury mean that new technologies are emerging all the time. Without understanding and reporting the core components of interventions, and transferring information about factors impacting on their effectiveness, technologists will miss these key findings. Also, researchers will not be able to evaluate the true effectiveness of their interventions if certain factors are not being addressed, therefore delaying clinical implementation.

While this review had robust methodology and used a systematic search strategy to identify relevant trials, it does have limitations. The search was limited to English language only, which may have excluded some relevant studies. Tight inclusion criteria were applied to studies not measuring at least one of our primary outcomes of interest (i.e. functional outcomes, quality of life, independence, fatigue). This led to the exclusion of some interesting studies reporting the use of smartphone based interventions, such as SMS symptom assessment for mild traumatic brain injury (Suffoletto et al., 2013) and goal management training via text messaging (Tornas et al., 2016). These administered various cognitive assessments (Dowds et al., 2011a), neuropsychological tests (Tornas et al., 2016) and one used the Rivermead Post-concussion Symptoms Questionnaire (King, Crawford, Wenden, Moss, & Wade, 1995; Suffoletto et al., 2013). However, one study [3] used smart technology

(metronome app) in a completely different way to the other studies, which suggests our inclusion criteria could have been more specific in terms of intervention use. I suggest altering the study selection criteria in future reviews to exclude certain technologies and focus on those targeting specific problems, e.g., memory impairment, fatigue management, etc. Another limitation is that people with progressive neurological disorders were not included, such as multiple sclerosis that experience similar cognitive manifestations (e.g. difficulties with problem solving, remembering tasks, concentrating).

2.6. Conclusion

Personal smart technology may help to rehabilitate people by facilitating independent living, which could reduce social care costs. However, this can only be achieved if there is more evidence of the clinical and cost-effectiveness of these technologies, and this review suggests that the evidence, as it stands, is inconclusive. To move the field forward, research funders need to commission larger, well-designed clinical trials, and researchers need to describe the interventions better (including tailoring and personalisation), ensure intervention delivery and uptake are accurately recorded, and that outcomes focus on both symptom reduction as well as independence and function. Future studies should also report on the barriers to implementation and measure the potential effects and harms of the intervention, which are often underreported.

As technologies become rapidly outdated, there is a need to identify the core components and transferrable information (i.e. generalisability to other contexts and populations) that contribute to the effectiveness of these interventions. This means that researchers and developers can address the common limitations that impact on

their effectiveness. In the long term, this will contribute to more effective clinical application of personal smart technologies.

2.7. Summary

The review provides a basis for the design of this doctoral research and identifies areas that need addressing when conducting research in this field. The findings from this review have informed the studies presented in the following chapters. i.e. that there is a clear gap in reporting key implementation issues associated with smart technologies, along with limited high-quality studies exploring the effect of these interventions on some of the invisible sequelae of injury (e.g., lack of independence, fatigue, quality of life). This review provided a rationale for the subsequent engagement study presented in Chapter 3 by emphasising the need to better understand the potential barriers associated with smart technologies. It also identified outcomes that are not well reported in studies using technologies like BiH, supporting the measures chosen in the case studies (Chapter 4). Finally, the use of the TIDieR guidelines in this review highlighted the need for consistent reporting of interventions to facilitate delivery and implementation. Thus, BiH has been described using these guidelines in Chapter 4 to ensure all components and processes were detailed sufficiently.

Chapter 3 Informing Evaluation of Brain-in-Hand for People with Acquired Brain Injury: A Stakeholder Engagement Study[2]

3.1. Chapter Overview

The systematic review in the Chapter 2 shed light on the limited reporting of some of the less well-researched outcomes for people with ABI. It also found that key implementation issues (i.e., barriers and facilitators to intervention use and effectiveness) are generally underreported, as most trials focus on the 'acceptability' of an intervention and overlook some of the broader contextual factors. The review found that studies consistently reported functional outcomes, such as goal attainment, cognitive, motor, and psychological function, however there is a clear gap in the reporting of other ABI outcomes (e.g., fatigue, lack of independence, quality of life, and participation). This chapter describes the second element of the thesis, which aimed to understand more about factors that might encourage or prevent BiH use, through stakeholder engagement. The findings were used to identify outcomes for a subsequent study and describe factors that could facilitate or hinder the effective use of BiH in the ABI population. This chapter introduces the Behaviour Change Wheel (BCW) and describes its application as a method for engagement and data analysis.

3.2. Background

Many studies focus on the effectiveness of smart technology interventions for ABI, specifically reminding technologies (Boman, Bartfai, Borell, Tham, & Hemmingsson,

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[2] Kettlewell, J., Phillips, J., Radford, K., & dasNair, R. (2018). Informing evaluation of a smartphone application for people with acquired brain injury: a stakeholder engagement study. *BMC Medical Informatics and Decision Making*, *18*, 33. http://doi.org/10.1186/s12911-018-0611-0

2010; Fish et al., 2007; McDonald et al., 2011; Wilson, Emslie, Quirk, & Evans, 2001), however few address the barriers to use, which is essential to the development and implementation of these technologies (de Joode, van Boxtel, Verhey, & van Heugten, 2012; Jamieson & Evans, 2015; Jamieson et al., 2015; Jamieson et al., 2017b; Wong, Sinclair, Seabrook, McKay, & Ponsford, 2016). It is important to consider the potential use of the technology in clinical practice when designing and evaluating these interventions. Implementation studies attempt to identify the key features of an intervention and consider its applicability in practice, to better inform necessary developments and meet the needs of the target population (Jamieson et al., 2017b; Wong et al., 2016). A report by the Voluntary Organisations Disability Group (VODG) identified problem areas associated with implementing smart technologies, such as a lack of care pathway commissioning, a lack of public awareness of mobile technology, and the unchangeable (and sometimes unhelpful) mind-set of healthcare professionals (HCPs) (VODG, 2013). Some healthcare providers who regard themselves as traditional 'caregivers', might have concerns that physical care and social care may be lost to the increasing use of technology (VODG, 2013, 2016). There may be a certain level of reluctance to change, especially if intervention uptake has the potential to result in the loss of (their) jobs and reduced clinical support. Potential barriers to the uptake of smart technologies may be commissioning of clinical services, technical issues (e.g., poor internet connection), fear of change, lack of leadership, and risk of investment (VODG, 2016). However, increasing staff efficiency, ability to provide information faster, potential cost savings, and increased patient dignity, control and independence may be potential facilitators to the uptake of technology (VODG, 2016).

3.2.1. Behaviour change wheel.

Theories of behaviour change have a significant impact on the underpinning of most, if not all rehabilitation interventions. Improving the implementation of EBP is often

determined by behaviour change, and interventions focusing on these factors are necessary for effective clinical practice. Multiple implementation frameworks exist that focus on the broad implementation process, from development to sustainability, however, few frameworks highlight the importance of behaviour. Innovation in healthcare can be described as "*a novel idea or set of behaviours, routines and/or ways of working that involve a change in practice within a healthcare setting*" (Moullin, Sabater-Hernández, Fernandez-Llimos, & Benrimoj, 2015). It is important to consider and understand the target behaviour during the initial identification and design stage of an intervention, to maximise potential efficacy (Davis, Campbell, Hildon, Hobbs, & Michie, 2015). Michie and colleagues suggest that when identifying interventions that are likely to be effective, it is important to consider all aspects of a system and match the intervention functions to different features (behavioural target, population, context of delivery) (Michie, Van Stralen, & West, 2011). A behavioural model should underpin this decision-making process and identification of influential factors.

Interventions are often designed and developed without having considered this process and do not formally identify a target behaviour. Michie proposed that a systematic method was needed to improve intervention design and overall implementation, which considered the nature of behaviour change and provided a way of characterising interventions and their functions. As a result, the BCW framework was systematically developed based on existing behaviour change frameworks.

The BCW framework suggests that changing behaviour is based on three components: capability, opportunity, and motivation (COM-B; Figure 3-1). Capability refers to an individual's psychological and physical capability to engage in an activity. Opportunity refers to factors not directly linked to the individual, which make

that behaviour possible (e.g., having access to a smartphone). Motivation refers to reflexive and emotional responses that make the behaviour possible (e.g., knowing something will work). In designing the components of an intervention that aims to change behaviour, analysis of the target behaviour is fundamental. The behaviour system exists as a cycle and is an important model to consider when designing and evaluating interventions that aim to change behaviour

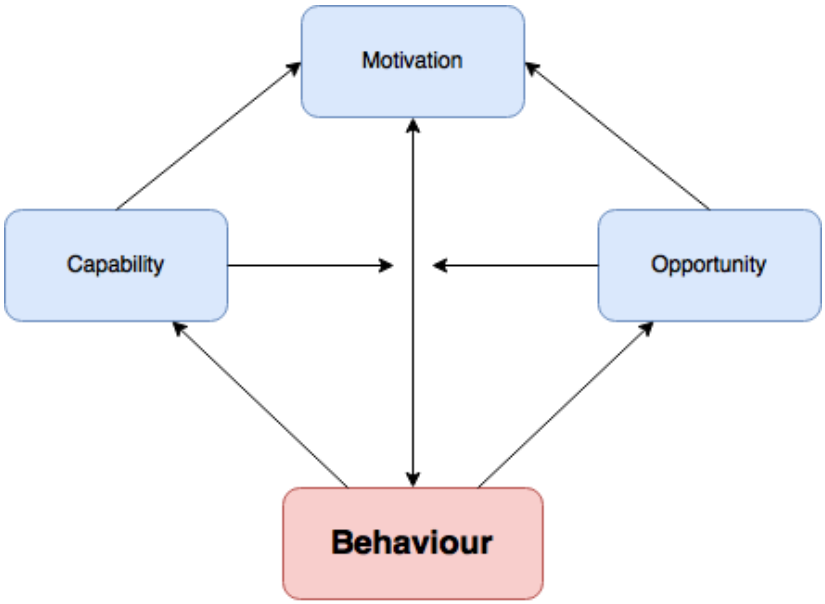


Figure 3-1 Behaviour components (COM-B) model of the BCW.

The BCW can be applied to various contexts to influence future research and direct clinical practice. By using this implementation model, it enables researchers to evaluate core intervention components in a systematic way. It also provides a method for identifying key barriers and facilitators to the use and effectiveness of an intervention in terms of behaviour change. The behaviour components have been successfully applied in a number of settings. One study by Connell et al., used the BCW to guide the iterative development of an upper limb intervention for stroke survivors (Connell, McMahon, Redfern, Watkins, & Eng, 2015). The use of the

model facilitated the identification of target behaviours and changes required to achieve these behaviours. It provided a framework for development, which has also been applied in other studies (Bonner et al., 2013; English, 2013; Fuller et al., 2012).

Examples of anticipated behaviours when using BiH include: activity and medication reminders, fatigue and anxiety monitoring, reminder of strategies to use when a problem occurs. The BCW was appropriate for this study because it considers other factors that might influence use, such as the need for training to use the technology. Although the BCW model considers factors such as environmental restructuring (i.e., changing the physical context and enablement), increasing or reducing barriers to use the app, discussions with experts in the use of BiH felt this did not fully explore the usability and acceptability of the actual technology. Therefore, studies that had evaluated technology and used feedback questionnaires to inform potential views of the app were identified.

3.2.2. Rationale.

There is a need to better understand the use of technology in health, and various studies have identified potential problems with the uptake of mobile technologies, such as adaptability, cost, compatibility with existing systems and complexity (Ross, Stevenson, Lau, & Murray, 2016; VODG, 2013, 2016). However, the systematic review highlighted the need to report key barriers and facilitators to the implementation of smart technologies, like BiH. It is important to identify these factors through early consultation with stakeholders and collaboration (Hartzler et al., 2013; Liddell, Adshead, & Burgess, 2008; Ross et al., 2016). The review also concluded that various outcomes are not reported and it is unclear whether smart technologies like BiH can support different sequelae of ABI. The rationale for this study was therefore to evaluate the usability and acceptability of the smart

technology, explore its potential use in ABI rehabilitation, through early stakeholder consultation, and identify possible outcomes for a subsequent study.

3.3. Aims and objectives

The aim of this study was to obtain early feedback from stakeholders (e.g., people with ABI, clinicians and carers) about the potential barriers and facilitators to BiH use and understand more about the problems it could target in the ABI population.

The objectives were to:

- Explore the barriers and facilitators, and the potential use of BiH in clinical practice with ABI survivors.
- Identify possible adaptations of the technology to meet the needs of the ABI population.
- Identify potential problems BiH could target and inform the choice of outcome measures in a subsequent study.
- Determine if the BCW could be used as model for stakeholder engagement.

3.4. Method

As the aim of BiH technology is to encourage behaviour change, the method of engagement was informed by the BCW model (Michie et al., 2011). Engagement was defined as consulting with people with ABI, carers and HCPs to obtain their views about the technology through different activities. This consisted of verbal engagement with the research team, focus groups, meetings with users and professional groups at their workplace, conferences and completion of questionnaires. A mixed method approach was considered appropriate for this study, incorporating qualitative and quantitative methods of data collection. It was felt that this would enable various perspectives on the potential uses, barriers and facilitators of the technology to be identified. Also provide a way of evaluating the

potential use of the BCW as a tool for engagement, by using both quantitative and qualitative methods. A mixed methods approach would provide a fuller picture of people's experiences, attitudes and feelings about the technology. The data collection process was divided into three stages, with an ongoing iterative approach (Figure 3-2). UK Health Research Authority (HRA) guidance was followed regarding ethics approval via an online assessment tool, and advised that specific ethical approval was not required, as this project was viewed as stakeholder consultation. Participants were identified through voluntary organisations, special interest groups and conferences that had a focus on ABI/technology, and at organised events for the lay public.

3.4.1. Stage 1: Identify stakeholders and develop a format for engagement.

The study management group consisted of academics and clinicians. They identified the stakeholder groups as: ABI survivors who would use the technology, carers or support workers who would mentor people with ABI and support them to use BiH, and HCPs who would potentially recommend using BiH as part of a treatment programme. A pragmatic approach was taken to accessing the identified user groups, and incorporating engagement activities within meetings held by stakeholders. Additionally, focus groups were held to specifically engage both ABI survivors and carers.

As BiH is a novel smartphone app and currently unused in the ABI population, potential stakeholders were provided with information about the system during small groups or presentations, during which the functions of BiH were explained, its potential uses in daily life and in clinical practice. In addition, people were given the opportunity to explore and experience the app themselves using a smartphone or iPad.

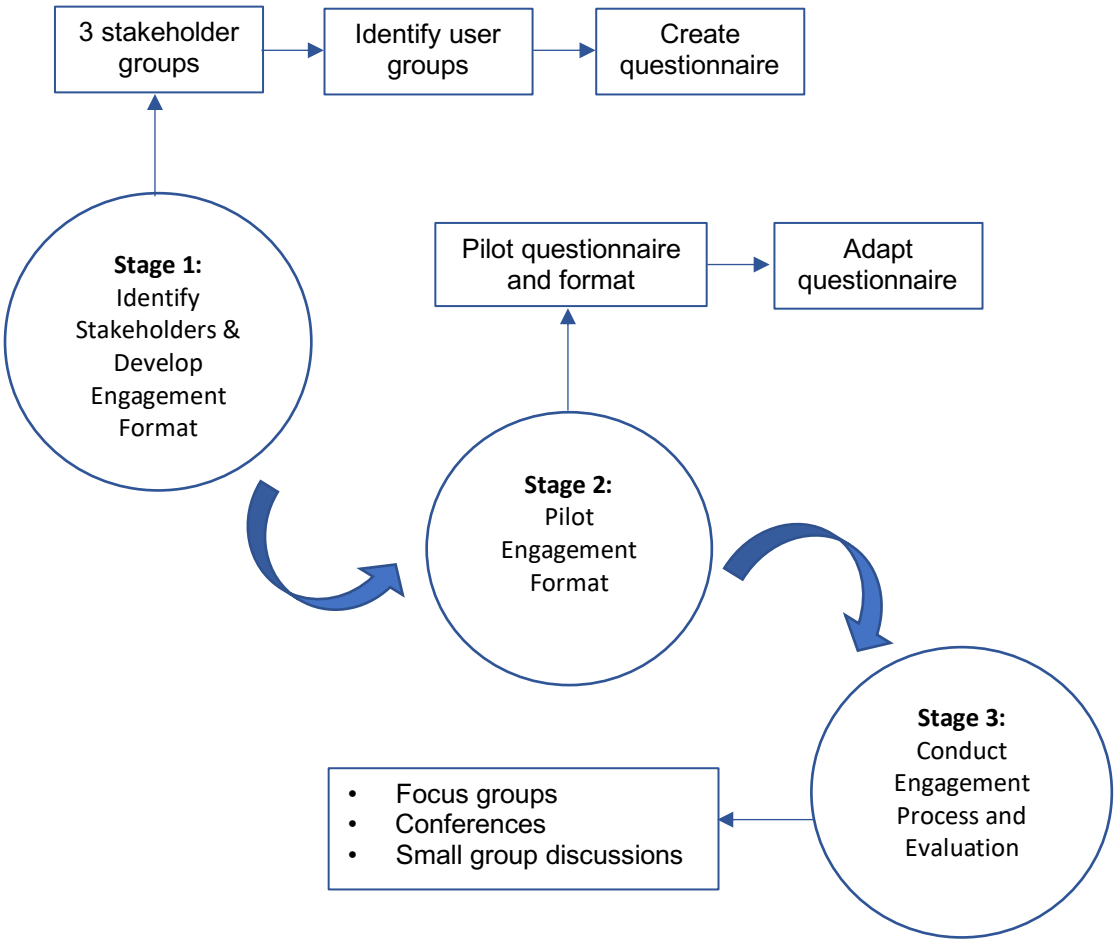


Figure 3-2: Summary of engagement method

3.4.2. The iterative method used to identify stakeholders and carry out engagement activities.

The academic advisory panel suggested using existing technology questionnaires such as the Mobile Application Rating Scale (MARS) (Hides et al., 2014) and the System Usability Scale (SUS) (Borsci, Federici, & Lauriola, 2009) to capture stakeholders' opinions about similar technologies. I evaluated these scales and incorporated the most appropriate elements into a questionnaire. The study management group agreed that a questionnaire would provide further in-depth quantitative data (particularly relating to the technical aspects of the app), and give

people the opportunity to provide feedback outside of a group setting. A questionnaire was designed to be piloted with all stakeholders.

3.4.3. Stage 2: Piloting the engagement format.

The engagement format was piloted with a local ABI technology special interest group (n=6) that had an interest in smartphone apps and were familiar with technology like BiH. To determine if the methods of engagement were appropriate, and would obtain the relevant feedback, the questionnaire and potential focus group questions were piloted with this group of ABI survivors, carers and HCPs. Feedback obtained from this activity informed necessary changes to the engagement approach and questionnaire. The technology special interest group was known to the researchers and contacted to arrange a meeting. Participants were recruited during the group session and questionnaires completed following discussion. Participants were not current UK health department service users.

3.4.4. Stage 3: The engagement process.

The final stage involved identifying opportunities to engage with a wider group of stakeholders. Conferences and meetings where I could present and discuss the technology with professionals were identified. I was invited to present the study and demonstrate the technology at a head injury conference organised by the local brain injury community service, where most of these stakeholders were recruited. This was held in close proximity to the university and comprised a range of professionals (therapists, solicitors, case managers and business owners). The professionals were informed that I was soliciting feedback from them as stakeholders to help identify the potential for the technology to help people with ABIs achieve their rehabilitation goals (and inform outcome measurement for a subsequent study). Professionals were invited to complete questionnaires following discussion if they wished. Further participants were recruited at meetings identified by myself and another researcher

through our existing professional contacts, all of whom had a focus on ABI and/or technology. The conferences and meetings exist to share information about specific aspects of their areas of interest, and to offer support, guidance, and feedback for various projects or cases. As before, stakeholders were invited to complete questionnaires following the meeting.

To ensure ABI survivors and carers were fully involved, focus groups were organised. The APEASE criteria (Acceptability, Practicability, Effectiveness/cost-effectiveness, Affordability, Safety, Equity) (Michie, Atkins, & West, 2014; West & Michie, 2016) along with the BCW was used to create a topic guide for the focus groups. The focus groups were facilitated by myself and another researcher (JP, a research/clinical OT). The group discussions were audio recorded, then analysed independently (myself and JP) and compared. The findings were discussed with the study management group. Views generated in the focus groups and from other engagement activities were mapped onto the BCW behaviour components.

ABI participants and carers were recruited from various sources. Some participants were identified using a database of people with ABIs (who had previously expressed an interest in taking part in brain injury research) at the University of Nottingham. These people had previously consented to being contacted by researchers in our department regarding future research and or being involved in patient and public involvement (PPI) activities. This database is stored securely within the University and accessible only to members of our research team (long term conditions). It was accessed by another researcher (JP) and potential participants were invited by email to take part in a focus group, giving them the opportunity to respond in their own time. Other ABI participants and carers were identified via social media posts by Headway and the Stroke Association (two UK charities), from an existing stroke specific PPI group (University of Nottingham Stroke Partnership Research Group

(UNSPRG)), and local Headway and stroke groups. Purposive sampling was used to ensure a heterogeneous sample, including people who did and did not use technologies.

A pragmatic and opportunistic approach to consult with the stakeholders was taken. In summary, the engagement activities included:

- Two focus groups comprising 8-10 service users and carers in each group.
- A formal presentation followed by a discussion with 30 professionals (therapists, case managers, solicitors) at an ABI meeting.
- Three informal presentations, to discuss and demonstrate BiH to two groups of therapists treating neurological patients, an ABI technology user group, and at a day centre (Headway) specifically for people with brain injury.
- An exhibition stand at a lay stroke conference where information was provided to delegates (stroke survivors, carers and professionals) on a 1:1 basis. The environment was not suitable for questionnaire completion.

3.5. Results

I engaged with 50 stakeholders: 20 ABI survivors (16 completed the questionnaire), 5 carers (4 completed the questionnaire), and 25 professionals (21 completed the questionnaire) who worked with people with ABI including therapists from NHS and private sector, and solicitors. Demographic characteristics of the stakeholders are presented in Table 3-1.

Feedback from the ABI technology special interest group suggested ideas for technological development and identified barriers to uptake, thus indicating that the format did facilitate informed discussion of the smartphone app. Based on their

feedback, the questionnaire was adapted to make it more accessible and easier to complete by creating two versions: one for ABI survivors and carers (Appendix 6) and one for professionals (Appendix 7). Frequently unanswered and irrelevant questions that did not provide useful information about BiH were removed.

Table 3-1 Demographic information of stakeholders

		Age			Gender	
Total = 50		**18-30**	**31-50**	**51+**	**Male**	**Female**
ABI survivors (n=20)	N	3	9	8	15	5
	% total	6%	18%	16%	30%	10%
Carers (n=5)	n	1	0	4	2	3
	% total	2%	0%	8%	4%	6%
Professionals (n=25)	n	2	12	11	4	21
	% total	4%	24%	22%	8%	42%
Overall	n	6	21	23	21	29
	% total	12%	42%	46%	42%	58%

3.5.1. Results from discussion and questionnaires.

The main points identified by the focus groups and other discussions complemented the questionnaire responses. However, the questionnaire approach did not allow individuals to elaborate on their views. For example, during one focus group, a suggestion was to change the word ‘problems’ to ‘issues’ on the app, as the ABI survivor felt the language was negative. Another person suggested linking the app to activity monitoring. The questionnaire enabled us to quantify some responses such as potential uses and reporting on the technical aspects of the app (e.g., appearance of BiH). Over half of stakeholders stated that seeing the app made them want to use it (65%, 17/25) (Table 3-3). This suggests that the app is visually appealing.

3.5.1.1. Capability.

Participants felt they would be confident using the app if they were existing technology users (22/24, 95%), but only a quarter of people felt it was completely appropriate for the ABI population (6/25, 24%) (Table 3-3). This finding is reflected by comments from professionals who felt that users needed an awareness of their problems and an ability to use strategies for the app to be effective (Table 3-2). Most stakeholders identified clear barriers during group discussions: visual and physical impairments, lack of technical skill, poor literacy skills, and cognitive problems faced by ABI survivors, such as memory difficulties and poor executive function. Professionals identified potential problems associated with the use of BiH, such as difficulty switching between screens.

3.5.1.2. Opportunity.

All stakeholders identified the need to have a smartphone as one of the most important facilitators and any potential cost of the app as a significant barrier. Only 24% (9/37) said they would be willing to pay for the app, with a further 54% saying they would consider paying for the app depending on the price (Table 3-3). The groups identified a potential barrier to uptake being competition from apps that have similar functions, but are free or have a one-off cost. Technological problems were identified as major barriers, specifically by individuals who were worried about loss of phones, the battery running down, compatibility with other systems and loss of data following phone updates. There was a concern about use in the work place, as for many people it is not appropriate to use a phone whilst working. With regards length of use, 49% (20/32) of stakeholders thought the app would be used by someone with ABI for more than 12 months and only 15% (6/32) felt it would be used as a short-term aid, between 0-6 months (Table 3-3). The initial questionnaire identified that 53% (8/15) of people felt that training required to use the app was largely suitable for the ABI population, but would need adapting to meet individual

needs. Some stakeholders expressed concern over the amount of time needed to set up, rather than learn to use BiH.

3.5.1.3. Motivation.

Most people said they would be motivated if they could see a use for BiH (39/41, 95%); and after physically seeing the app, 65% (17/26) of people said they wanted to use it (Table 3-3). The questionnaire identified that most people (39/41, 95%) felt BiH would be useful for memory problems, to help with activities of daily living (35/41, 85%) and to support independence (33/41, 80%), such as taking responsibility of appointment planning. Although users in the focus group felt BiH would be useful for self-monitoring such as fatigue or anxiety levels, only 56% (23/41) said they thought it could help with behaviour monitoring. One interesting suggestion was to use the traffic light system to monitor positive behaviours, such as a feeling of wellbeing, rather than focusing on negative behaviours. All stakeholders identified the potential for personalisation to individual needs, one of the difficulties with existing technologies as an important enabler to uptake. ABI survivors felt that using a mobile phone app as an assistive aid was viewed as ‘normal’ behaviour, i.e., reduced stigma, and would be a motivator for use (Table 3-2). The main barriers identified by all stakeholders were the lack of interest in technology, not seeing a personal use/need for it and a lack of existing evidence of its use in ABI, highlighting the need for a further study. If people could not see how BiH would help with rehabilitation or support goal attainment, it would probably not be used. This was identified by all stakeholders as a potential barrier. ABI survivors were concerned about their privacy and a feeling of being monitored, and this was expressed as a potential barrier to uptake. Stakeholders felt that setting up the app may be time consuming and excessive reminders may be annoying. This was kept in mind when conducting the case studies in chapter 4.

Table 3-2 Summary of facilitators and barriers identified by stakeholders mapped onto BCW behaviour components

	Facilitators	ABI	Carers	Professionals
Capability	Physical ability to use smartphone	●	●	●
	Competent at using smartphone	●	●	●
	Awareness of their problems		●	●
	Able to use strategies	●		●
Opportunity	Have a smartphone	●	●	●
	Having the opportunity to personalise use	●	●	●
	Enables users to record symptoms as they happen	●		●
	Computerised record of use (e.g., to track goal attainment)			●
	Offers opportunity to self-monitor and alter use	●		●
Motivation	Using a phone seen as 'normal' behaviour i.e., reduced stigma	●		
	Potential to be personalised to individual needs	●	●	●
	Motivated if they can see a use for it e.g., problem and solution system	●	●	●
	Feeling confident to use the app	●		
	May allow the user to feel like they are taking control of their life again		●	●
	Do not want to use paper diary	●		

	Barriers	ABI	Carers	Professionals
Capability	Visual and physical impairment	●	●	●
	Lack of technical skill	●		●
	Poor literacy skills			●
	Cognitive problems e.g., switching between screens	●		●
Opportunity	Cost and competition from other apps	●	●	●
	Losing smartphone and battery problems	●		
	Technology not reliable e.g., loss of information if phone updated	●	●	
	Incapability with existing systems i.e., will it sync with computer diary	●		●
	Work place restriction not allowing use	●		●
Motivation	No interest in the use of technology or existing systems in place e.g., paper diary	●	●	●
	ABI users do not see a personal use for it (i.e., will not help them)	●	●	●
	Feeling the app is too complicated for them to use or learn to use			●
	Loss of motivation and disengagement with rehabilitation process			●
	Feeling as though they are being monitored	●		
	Too time consuming to set up/edit	●	●	●
	Too many reminders may be annoying	●	●	●
	Lack of existing evidence/use in the ABI population	●	●	●

Additional points were identified by stakeholders (largely picked up by the questionnaire) that did not map onto the components of the BCW. Most of these related to technical aspects of the app, something that is not well reflected by the BCW model. Stakeholders highlighted the inconvenience of having to access a computer to edit the diary and functions of the app, which could be a potential barrier to uptake. If individuals have difficulty remembering events, it is important that they can add or update events easily ‘on the go’. If the system cannot be edited via the app, stakeholders felt BiH offered little additional use than a diary or the 'reminder’ function on a standard smartphone. All stakeholders identified the need for voice recognition and the ability to verbally add things to the diary, along with having visual entries (e.g., adding pictures, diagrams and videos to diary entries, such as therapy exercises, making dinner, etc.). Professionals and carers suggested having an app specifically for mentor use, to monitor user activity without needing computer access. Professionals voiced concern over the use of the red button, the potential for it to be overused and who would be responsible for responding to it. This was fed back to Brain in Hand Ltd. for consideration when setting up the technology with the ABI population in future.

Table 3-3 Summary of questionnaire responses mapped onto BCW behaviour components

BCW component	Question/statement	Response options	Frequency	% total responses
Capability	Would you feel confident using the app? Number scale of 1 (Definitely not) to 5 (Definitely) used.	Definitely or almost	22/24	92%
		Maybe or somewhat	2/24	8%
	How appropriate is the app for a person with an ABI? Number scale of 1 (Inappropriate) to 5 (Appropriate) used.	Appropriate	6/25	24%
		Almost	11/25	44%
		Maybe	7/25	28%
		Less	1/25	4%
Motivation	When seeing the app for the first time, did it make you want to use of it? Number scale of 1 (Definitely not) to 5 (Definitely) used.	Definitely or almost	17/25	65%
		Maybe or less	6/25	23%
		Definitely not	2/25	8%
	What is/are the most appealing parts of the app?	Structured diary	30/41	73%
		Personalised problems and solutions	26/41	63%
		Traffic light system	22/41	54%
		Monitoring progress	15/41	37%
		Feedback online	13/41	32%
		Mentor/support	12/41	29%
	Can you see a use for the app?	Yes	39/41	95%
		No	2/41	5%
	What do you think the app could target or aid?	Memory problems	39/41	95%
		ADL	35/41	85%
		Independence	33/41	80%
		Managing routine	31/41	76%
		Problem solving	26/41	63%
		Self confidence	25/41	61%
		Anxiety/stress management	24/41	59%
		Behaviour monitoring	23/41	56%
		Anger/irritability	14/41	34%
		Goal setting	13/41	32%
		Depression	12/41	29%
Opportunity	Would you pay for the app?	Yes	9/37	24%
		Maybe	20/37	54%
		No	8/37	22%
	How long do you think you (or someone with ABI) would use the app for?	0-6 months	6/32	15%
		6-12 months	6/32	15%
		12+ months	20/32	49%
		Don't know	9/32	22%
	How appropriate is the training (i.e., ease of learning) to use the app? Number scale of 1 (Inappropriate) to 5 (Appropriate) used.	Appropriate	3/15	20%
		Almost appropriate	8 /15	53%
		Maybe	3 /15	20%
		Less	1 /15	7%
	How appropriate is the app when navigating different screens? Number scale of 1 (Inappropriate) to 5 (Appropriate) used.	Appropriate	4/20	20%
		Almost	12/20	60%
		Maybe	4/20	20%

3.6. Discussion

3.6.1. Engagement methods.

The aim of this study was to capture early stakeholder views about BiH and inform the design of a subsequent study to evaluate the effectiveness of the app in the ABI population. Both the BCW and existing technology questionnaires were used as the theoretical basis for the engagement activities. Views of ABI survivors, carers and professional were elicited through a combination of focus groups, presentations, and questionnaires. The mixed method engagement approach provided useful feedback from stakeholders and enabled the identification of different opinions. The quantitative data obtained from questionnaires supported the qualitative feedback from discussions, the latter providing another dimension that would not be picked up with questionnaire responses alone. The format of group engagement was helpful, as it gave stakeholders the opportunity to explore the app in more detail. Group situations also promoted discussion about BiH, and stakeholders were keen to share their views about the app. The questionnaire provided useful quantifiable data, but was not completed by all.

Overall, I was able to engage well with various stakeholders, obtaining a broad range of feedback. A stroke research group was consulted following completion of activities, who agreed that the correct stakeholders had been identified and the engagement format was appropriate. The stroke research group felt the questionnaire was suitable for the ABI population, but should be provided during focus groups or similar discussions. This would ensure stakeholders had the opportunity to explore the technology in greater depth before completing the questionnaire. Feedback from the research group supported the findings regarding the success of focus groups, in comparison to conference presentations, where the environment did not lend itself to discussion and questionnaire completion.

3.6.2. Using the Behaviour Change Wheel model.

Behaviour change techniques (BCTs), defined as ‘active components of an intervention designed to change behaviour’ (Michie et al., 2014; Wood et al., 2015), are specific, complex components of an intervention that are designed to change behaviour, that are observable and replicable (Michie et al., 2014). As I focused on understanding behaviours and intervention functions, rather than techniques associated with changing behaviour, I found that certain stakeholder comments did not easily map onto the BCW, e.g., the potential uses of BiH. Behaviour change interventions operate within a social context, with effectiveness being the primary criteria to consider when implementing an intervention (Michie et al., 2014). Assessing the potential use of BiH was difficult to map onto the BCW, along with the evaluation of specific technological aspects, e.g., was it visually appealing? Therefore, the use of existing technology-specific questionnaires was necessary, alongside the BCW components and APEASE criteria.

The behaviours needed to use the app were more easily mapped onto the BCW, than the potential uses. Due to the type of intervention, the definitions given in the BCW were less rigid, making it easier to categorise feedback from stakeholders. This approach was used in a similar study evaluating the use of the model (Connell et al., 2015). Not all components of the BCW are necessary when evaluating smart technology like BiH. The BCW with the addition of facilitators and barriers, appears to be a useful format that could be replicated to evaluate similar engagement activities or interventions.

The APEASE criteria are important when evaluating interventions that aim to change behaviours, like BiH. All criteria were addressed during discussions, however stakeholders focused more on the ‘practicability’ and ‘acceptability’ aspects during focus groups, as this seemed to be most important. Practicability refers to how

practical the technology would be in a real-life context and whether it is designed appropriately for the target population (Michie et al., 2014; West & Michie, 2016; Wong et al., 2016). Individuals readily identified barriers and facilitators that link with the practicality of use, which also mapped onto the capability and opportunity components of the BCW. Acceptability was addressed by all stakeholders via questionnaires and discussions. The acceptability of BiH differed between groups and the suggested improvements varied when speaking to ABI survivors and professionals. I was keen to ascertain whether BiH would be accepted by all stakeholders and what impact this would have on implementation. Other criteria were addressed, but some points seemed unimportant to ABI survivors and carers, such as the cost-effectiveness and unintended negative consequences of using the app. These stakeholders were interested in the potential cost of BiH for themselves or family members, but when questioned about the cost implications in the healthcare system, their feedback was minimal. As professionals did not attend focus groups, these criteria were somewhat overlooked in other engagement activities, where time and group size was a limiting factor.

It appears the BCW needs to be fully considered prior to engaging with stakeholders and certain criteria should be prioritised depending on the group. The BCW may be used to inform qualitative interviews in further studies, which could serve as feasibility work to inform future implementation.

Feedback highlighted the potential priorities for each stakeholder group. People with ABI mainly focused on the personal facilitators and barriers associated with BiH uptake. They were interested in how useful and appropriate it would be for themselves, as well as the broader ABI population. This resonates with various studies, commonly stating a barrier to use is perceived usefulness and simplicity (Evald, 2015; Jamieson et al., 2017b; Wong et al., 2016). Professionals focused

more on the clinical problems associated with using BiH (e.g., too complicated, misuse of the red button), but also the therapeutic benefits for their patients or clients. Carers were divided about their views on BiH, with some feeling it may reduce anxiety when allowing the person with ABI to have more independence, but others were concerned that it would add more pressure to their role. All stakeholders prioritised certain aspects as expected, but there was a consensus between groups regarding personalisation of the app, ability to use a smartphone, motivation to change from existing strategies. The latter has been addressed by various studies, highlighting the importance of personally relevant reminders to encourage use (Cruz, Petrie, Goudie, Kersel, & Evans, 2016; Ferguson et al., 2015; Jamieson et al., 2017b). A systematic review by Ross et al., 2016 (Ross et al., 2016) identified various factors that influence the implementation of e-health technologies, like BiH. These included cost, complexity, adaptability, stakeholder engagement, training and education for all those involved as key factors in implementation. This study identified the same barriers and facilitators through early stakeholder engagement, suggesting good representation of individuals that would potentially benefit from using BiH.

3.6.3. Limitations.

The study, however, had certain limitations as the iterative approach made it difficult to plan our engagement methods before starting the study. In retrospect, I should have used the BCW to design the questionnaire alongside the existing technology questionnaires, as this would have linked better with focus group discussions. Some BCW domains were not fully explored by questionnaires and discussions e.g., policy categories and intervention functions, as I chose to focus more on the behaviour components. Questionnaires did not capture all intervention and policy areas, as it would have taken too long to complete and may have proven conceptually difficult for some people to grasp. This meant stakeholders were not asked about the

potential for cost savings within rehabilitation services, or to identify potential contraindications associated with BiH use. Professionals did however highlight potential problems associated with the app. Another limitation was that stakeholders had minimal time to use and experience BiH, therefore longer term use in a case study context would provide more useful and in-depth feedback.

3.7. Conclusion

Overall people were keen to use BiH, but wanted it to be personalised, easy and inexpensive (and potentially free). They had concerns about practical issues such as losing the phone, who had access to the data, and losing the information if the phone updated. People who currently fear or avoid using technology did not see any benefits. Most stakeholders said they could see the benefit of this technology for themselves or others. Professionals highlighted their concern over the red button responder and who would take on this role, as it would ultimately add more pressure (especially to a therapist role). They also highlighted the potential for the red button to be overused by the ABI population and the importance of deciding who would use it appropriately.

The BCW is a useful tool for engagement, especially when designing questionnaires and discussion topic guides. The model may help researchers consider a wider perspective than just intervention functions and associated behaviours, especially when identifying barriers and facilitators to use and recommendation. However, the BCW needs additional components that are specific to technology interventions. When designing a questionnaire for this type of stakeholder engagement, researchers need to consider other technology aspects, such as visuals, design and language.

3.8. Summary

This study provided early feedback to support the design of the subsequent case studies (Chapter 4). The use of the BCW to evaluate feedback will be presented in the following chapter. The findings of the engagement work highlighted ABI problems that BiH could target and provided a rationale for the choice of outcomes to be measured in the following study. This explorative study and engagement with stakeholders enabled the identification of potential barriers and facilitators to BiH use. Thus, I was able to consider factors that could potentially affect the success of the next study (e.g., do people with ABI see a personal need for the app and are they competent at using a smartphone?). This study highlighted some of the potential issues with delivering BiH and these were taken into account when designing the subsequent case studies. The red button responder option was not offered to participants in Chapter 4 as it had the potential to be used inappropriately.

Chapter 4 Case Studies

4.1. Chapter Overview

The engagement study presented in Chapter 3 identified outcomes that are important to people with ABI and factors that might impact on the use and effectiveness of BiH in this population. The findings of this study and the systematic review provided a rationale for the design of a series of case studies. Stakeholders identified key problems that BiH could target and potentially support and generated hypotheses, which informed the selection of outcomes measured in this subsequent study. The engagement study also provided a rationale for the inclusion criteria for the case studies, highlighting the importance of being competent at using a smartphone prior to using BiH. Although a number of people felt BiH was not appropriate for people with ABI, this did not alter the inclusion criteria to evaluate its use in this population. The focus of this study was to identify who BiH could be suitable for and how it could be improved. This chapter describes the methodology of a series of case studies (n-of-1 design), including the objectives, recruitment and mixed methods design. The outcome measures used are described and justified, along with the method of conducting and analysing qualitative interviews. The results of the case studies are described and analysed individually, then combined.

4.2. Aim and Objectives

The overall aim of this study was to determine if BiH has any effect on outcomes of interest, and to evaluate the perspectives and experiences of people with ABI and healthcare professionals after using BiH.

The objectives were to:

- Identify barriers and facilitators to the use, effectiveness and acceptability of BiH for the ABI population, carers and HCPs.

- Determine if BiH use is associated with improved functional outcomes, mood, fatigue, quality of life, cognition, and participation.
- Determine if BiH encourages goal attainment in people who are recovering from an ABI.
- To collect information about the experiences and perspectives of people with ABI, carers and HCPs after using BiH for 6 months.

4.3. Methods

4.3.1. Ethics and approvals.

Ethics approval was granted by the NRES Committee East Midlands Nottingham 2, reference number 16/EM/0141. Research and development (R&D) approvals were granted by the three NHS sites: Nottingham University Hospitals (NUH) NHS Trust, Cheshire & Wirral Partnership Trust (CWP) and Derby Teaching Hospitals NHS Foundation Trust (DTHT). The Cheshire site was chosen due to an existing link with supervisors.

4.3.2. Study design.

This study sits between the theoretical development (phase 1) and the feasibility/pilot phase (phase 2) of the MRC framework. These preliminary phases are concerned with developing the underlying programme theory for and identifying the underlying mechanisms of the intervention. The aim of the study was to understand more about who BiH could work for and how, and determine which people would benefit most from using the app following ABI. The findings have been used to design a feasibility trial, which will be discussed in Chapter 6, along with a logic model to explore the mechanisms of the intervention.

The study was an n-of-1 single case design, with multiple participants, used to understand how BiH works in the ABI population and inform the design of a larger

trial to evaluate its effectiveness. It was a single-centre study, recruiting from three NHS sites (NUH, DTHT, CWP) and participant identification centres (PICs): Chesterfield Hospital NHS Trust, Headway (a UK head injury charity) and Stroke Association (a UK stroke charity). ABI participants were not randomised to receive the treatment or not – all who were eligible to participate were offered the intervention. Carers and healthcare professionals (HCPs) involved in supporting or rehabilitating the brain injured person were also recruited where possible. The n-of-1 single case study method enabled the individual participant to be considered as the sole unit of observation in the study to investigate the effectiveness of the intervention and identify potential improvements.

A mixed methods approach was adopted using quantitative and qualitative methods to obtain a comprehensive dataset, which provided different dimensions that would not have been picked up with quantitative methods alone (Creswell & Plano Clark, 2018). The use of different methods enabled the integration of findings, and more meaningful and valid conclusions to be drawn from the data. Using mixed methods provided a breadth, depth, and richness to the findings, as questions arising from one data set could be explored by another (i.e., the qualitative data could explain changes in quantitative data). This approach was successfully used in the previous study (Chapter 3) to obtain early feedback from stakeholders about the use and potential barriers of BiH. It enabled the identification of ABI problems the app could target through quantitative and qualitative methods, providing a clear rationale for the choice of outcomes to measure in this study. The use of mixed methods in the case studies also highlighted resources that need to be evaluated in the economic evaluation (Chapter 5). The design enabled me to achieve the study objectives, but also address the broader aims of the thesis.

4.3.2.1. Sample size.

As this was a series of case studies, no power calculation was performed. It was planned that up to 15 people with ABI would take part in the case studies, a number considered sufficient to reach data saturation (Fusch & Ness, 2015), as enough information would be obtained to inform the design of a subsequent study (e.g., feasibility trial). There appears to be no ideal number of participants to take part in case studies, as study designs are not universal (Fusch & Ness, 2015). Literature reporting case studies that have evaluated smartphone applications or mobile phone use, recruited between five and 23 people (Gentry, Wallace, Kvarfordt, & Lynch, 2008; Stapleton, Adams, & Atterton, 2007; Wade & Troy, 2001). Therefore, I chose to recruit up to 15 participants as this was a median value of similar studies.

4.3.3. Participants.

4.3.3.1. *ABI participants.*

ABI participants were included if they:

1. Were aged between 18 and 65 years of age. The upper age limit was chosen to reflect the potential participants identified by different recruiting sites and the views of people with brain injuries and HCPs, who felt people under potential retirement age would benefit more from the study.
2. Were diagnosed with an acquired brain injury (e.g., TBI, stroke).
3. Were at least 3 months post-injury or stroke.
4. Had at least one problem as a result of the ABI identified by the individual, their carer or HCP that potentially limited their functional independence.
5. Were able to speak and read English sufficiently to complete the questionnaires.
6. Had access to a smartphone before the intervention period started.
7. Were competent at using a smartphone (i.e., they felt comfortable navigating the phone, adding calendar entries or reminders, sending text messages, changing phone settings).

ABI participants were excluded if they:

1. Did not want to take part in the study.
2. Were unable to consent for themselves.
3. Lived more than one hour (or reasonable) travelling distance from the recruiting centre.
4. Had communication difficulties resulting from ABI (e.g., aphasia) and no support from a relative, carer etc.

4.3.3.2. *Healthcare Professionals (HCPs).*

Healthcare professionals (HCPs) were defined as those who are a part of the ABI participant's usual care team with whom they had contact on a regular basis. The HCPs involved in the care of people with ABI (who consented to these members of their care team being approached) received an information sheet informing them about the project. Those that expressed an interest were informed of all aspects pertaining to participation in the study and consented if they met the inclusion criteria. HCPs were included if they:

1. Were treating or supporting a person with an ABI who had been recruited to the study.
2. Were 18 years and over.
3. Were willing to consent to the study.

There were no exclusion criteria.

4.3.3.3. *Carers*

Carers were defined as paid or unpaid persons who were involved in any aspect of the daily care of a person with ABI. Consenting participants with an ABI were asked to nominate a carer, if applicable, (their spouse, partner, parent or the person they have the most contact with) during the baseline assessment visit. Carers were provided with an information sheet informing them about the project, and if they

expressed an interest then an appointment was made to inform them of all aspects pertaining to participation in the study.

Carers were included if they:

1. Were a current carer for a person with an ABI who had been recruited to the study.
2. Were 18 years and over.
3. Were able to give informed consent.
4. Were able to speak and read English sufficiently to complete the questionnaires and interviews.

There were no exclusion criteria.

4.3.4. Recruitment.

ABI participants were recruited from Nottingham University Hospitals NHS Trust (NUH), Cheshire and Wirral Partnership NHS Trust (CWP), Derby Teaching Hospitals Foundation NHS Trust (DTHFT), and from charities Headway and Stroke Association. The initial approach was from a member of the usual care team of the person with ABI, and in most cases, the OT, or by a charity volunteer. They provided the potential participant with a participant information sheet (PIS) and consent form and were advised to contact the research team should they be interested in taking part. ABI participants could also be identified by private providers (e.g., private therapists, solicitors, private case managers) if they felt their patient was suitable for the study. The initial approach was from the private provider, followed by the above procedure. People with ABI could also self-refer. The general public were able to find out about BiH as a result of social media and press releases. Those identifying a potential participant, who directly contacted the study team were approached by the researcher. All potential participants were informed of all aspects pertaining to their participation in the study (quantitative and qualitative data collection methods), and provided with

a PIS and consent form. Participants identified via these routes could be located anywhere in the UK, but within a one hour travelling distance from one of the sites.

For those interested in taking part, a consent visit was organised (face-to-face or over the phone). The researcher explained that entry into the study was entirely voluntary, and that their treatment/care and legal rights would not be affected by their decision. The researcher explained that they could withdraw at any time and in the event of withdrawal, any data collected so far could not be erased and would be used in final analyses where appropriate. At this point participants were asked if they had any questions regarding the study and their involvement. If they wished to participate, consent forms were provided and signed.

Carers and HCPs were recruited after the ABI participants. They were approached by the researcher, after the ABI participant had identified them (i.e., carer or HCP) and were happy for them to be involved. HCPs were provided with a PIS and consent form, and a meeting was organised if they expressed an interest in taking part. The same procedure was followed as with ABI participants.

4.3.5. ABI participant study flow.

Once ABI participants had consented to the study and completed baseline assessments, they completed a further two assessments prior to receiving the BiH intervention (administered at two and four weeks post-baseline). Assessments two and three were administered in person where possible. At six weeks post-baseline assessment, all ABI participants received BiH. At six months post-intervention, ABI participants were interviewed to obtain their views on the acceptability, barriers and enablers to the BiH technology. ABI participants completed a further questionnaire at six months post-intervention, and again at 12 months (Table 4-1). These were

posted to the participants. The flow of ABI participants through the study is shown in Figure 4-1.

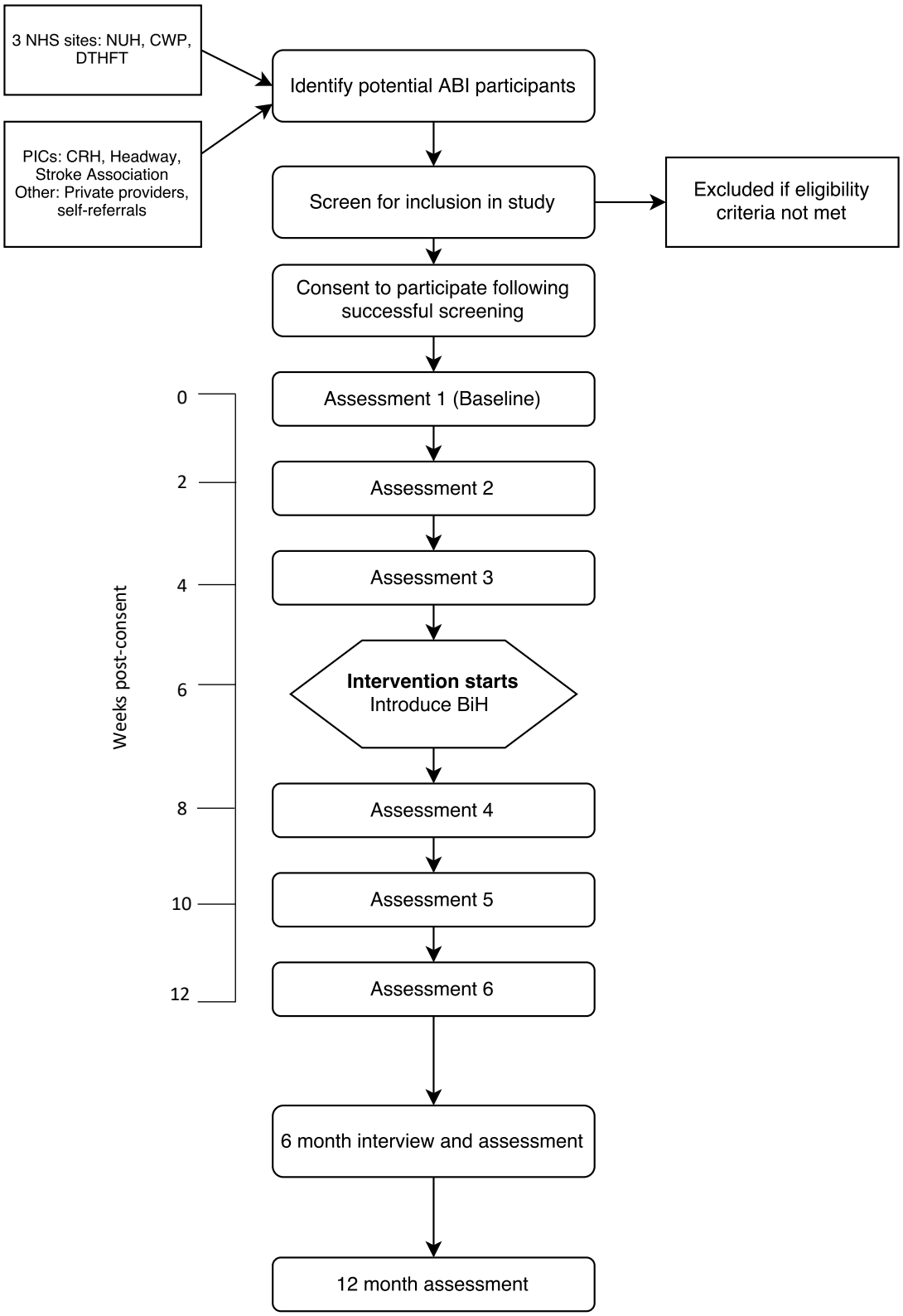


Figure 4-1 ABI participant flow through the study.

Table 4-1 Study assessment schedule

Measure	Assessment Number								
	1 Baseline	2	3	INTRODUCINTRE INTERVENTION BiH	4	5	6	7 6 months	8 12 months
Demographic information	✓								
Service Use Questionnaire	✓							✓	✓
EuroQol EQ-5D-5L (Euro-QOL)	✓							✓	✓
Multiple Sclerosis Neuropsychological Screening Questionnaire (MSNQ)	✓							✓	✓
Goal Attainment Scaling (GAS)	✓							✓	✓
Hospital Anxiety and Depression Scale (HADS)	✓	✓	✓		✓	✓	✓	✓	✓
Nottingham Extended Activities of Daily Living (NEADL)	✓	✓	✓		✓	✓	✓	✓	✓
Community Integration Questionnaire (CIQ)	✓							✓	✓
Fatigue Assessment Scale (FAS)	✓							✓	✓

4.3.6. Endpoints.

4.3.6.1. *Primary endpoints.*

The primary endpoints for each participant were:

- ABI participants: completion of the interview at six months post-intervention and final assessment at 12 months post-intervention.
- HCPs: completion of the interview at six months post-consent.
- Carers: completion of the interview at six months post-consent and final assessment at 12 months post-consent.

4.3.6.2. *Secondary endpoints.*

Measurement of the effectiveness of BiH intervention on improving independence, functional outcomes, social inclusion, mood, cognition, fatigue and quality of life of ABI participants. Secondary measures of effectiveness for ABI participants were collected at varying time points (table 4-1) throughout the study and included:

1) Service Use Questionnaire (end user feedback of BiH intervention)
2) EuroQol EQ-5D-5L (EuroQol; health related quality of life (Herdman et al., 2011))
3) Multiple Sclerosis Neuropsychological Screening Questionnaire (MSNQ; global cognition (Benedict et al., 2003))
4) Hospital Anxiety and Depression scale (HADS; mood level (Zigmond & Snaith, 1983))
5) Nottingham Extended Activities of Daily Living (NEADL; functional ability (Nouri & Lincoln, 1987))
6) Goal Attainment Scaling – Light (GAS-Light; self-management and goal setting (Turner-Stokes, 2009))
7) Community Integration Questionnaire (CIQ; participation (Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993))

8) Fatigue Assessment Scale (FAS; fatigue (Michielsen, De Vries, Van Heck, Van de Vijver, & Sijtsma, 2004).

Justification for measures is presented in section 4.3.9.

4.3.7. Intervention.

The intervention used in this study was introduced in Chapter 1 as BiH, a smartphone application that synchronises with a web-based programme. BiH was provided to ABI participants at six weeks post-baseline. The intervention was chosen as it had the potential to address certain gaps in research by targeting some of the unmet needs of the ABI population, such as interventions to support self-management of invisible sequelae like anxiety and fatigue. It was also fully personalisable, therefore each participant could set specific goals and tailor BiH to their needs. The smartphone app had not been systematically evaluated in the ABI population and although it worked well in autism, its applicability to other symptoms experienced in ABI needed evaluating. Therefore, a range of outcomes were measured to identify who BiH could potentially work for and which problems it could target.

The red button responder was not provided to participants in this study, as the engagement work in Chapter 3 suggested that it had the potential to be overused or used incorrectly. Also, there was no capacity to support this function of BiH as with the autistic population (response provided by the National Autistic Society). The red button was therefore used as a monitoring function, whereby nominated mentors would receive a text message or email when their user (i.e., the participant) pressed a red traffic light.

The TIDieR guidelines provide a set of criteria that guide researchers to report complex interventions in a more systematic way and facilitate replication (Hoffmann

et al., 2014). This method was chosen following the systematic review (Chapter 2), which concluded that interventions are often poorly described, and this set of guidelines should be used to consistently report their interventions. The TIDieR guidelines have been used in this thesis to detail BiH and ensure the processes involved in delivering the intervention can be easily replicated by other researchers. The TIDieR guidelines are split into ten sections, with twelve criteria in total. The intervention has briefly been described using the TIDieR guidelines in Table 4-2.

Table 4-2 Description of BiH using TIDieR guidelines.

Criteria	TIDieR Definition	Description
Brief name	Name or phrase to describe the intervention.	BiH: personal smart technology designed to improve independence and self-management.
Why?	Rationale behind the intervention, goal or theoretical basis.	• BiH was specifically engineered to support the management of persistent emotional and behavioural problems in the autistic population, which are also commonly seen in people with TBI or stroke. • It has not been systematically evaluated in the ABI population. • Research to demonstrate the effectiveness of BiH in ABI is timely, as technology currently available to support patient rehabilitation is limited.
What materials?	What was provided to the participant either before receiving the intervention or while it is being delivered.	• Participants were provided with a workbook (appendix 8) two weeks prior to receiving the intervention and told to complete prior to their training/set-up session. • All participants received a BiH license and used their existing smartphone, which enabled them to download and login to the app, and access the online portal. In most cases, they had a laptop or computer so that they could edit their diary online, via the portal. However, this could also be accessed via a smartphone internet browser. • Participants were provided with a training book during their set-up training session (appendix 10), which provided instructions for adding diary entries to the app and explained the functions of BiH. This was used during the session and left with the participant.
What procedures?	What were the processes involved in using the intervention, describe any supporting activities that were implemented.	• A two hour training session was offered to each participant. Individuals were shown how to use the different functions of BiH by the researchers and this was done in a systematic way using a checklist, which included: overview of the system, adding a diary entry, changing dates, frequency and times of events, duplicating a diary entry, adding unplanned events, how to use the traffic lights and downloading the app. See appendix 9. • Once the researcher had covered each training section, participants were asked if they needed anything repeating. • Following this, each ABI participant was asked to demonstrate adding a diary entry, pressing a traffic light, updating the app and general navigation of the system before the researcher was confident they could competently use BiH. • During the final part of the session, the researcher helped individuals personalise their BiH diaries by adding daily events (such as taking medication) and changed the traffic light labels to suit their specific needs/goals (i.e., monitoring fatigue or anxiety). • The researcher referred to the workbook that had previously been given to the participants and guided the set-up of the system, if it had been completed. If this had not been completed, the researcher used the workbook as a prompt to discuss goals the individuals might want to achieve and think about their daily routine. The researcher allowed the participant to take control at this point and navigate the system, helping where necessary.

Who provided?	For each person that was involved in providing or delivering the intervention.	• PhD student trained to use BiH over a two day period (approximately 8 hours). • If applicable, their therapist attended the set up session or they advised on relevant goals. • Mentor attended set up session if one was nominated by the participant.
How?	Describe how the intervention was delivered or provided.	• The intervention was set up face-to-face, but following this initial session, the app was intended for use by the individual in their daily life at home. • The intervention was ongoing and used by the participant in their own environment.
Where?	Where was the intervention delivered?	• BiH was set up face-to-face with every participant. • This was either in their home or in a hospital setting, depending on their preference.
When and how much?	Amount of time the intervention was delivered for and frequency.	• Participants received two hours training. During this session, the app was set-up and various events, problems and solutions added to the diary. • The participants were provided with BiH to use for 12 months. • At 6 months post-intervention, participants were interviewed and at this point any issues with BiH could be addressed. For all participants, suggested changes were taken on board and problems resolved if possible.
Tailoring	Describe if the intervention was personalised, how, when and why.	• BiH was personalised for each participant depending on their specific needs. • Diary entries could be entered as appropriate for the participant and reminders could be set for any task. The problems/solutions could be completely tailored to the individual by entering any text. • The traffic light system was able to monitor anxiety or fatigue. The participant decided at the set-up session which symptom they would prefer to monitor. • The text beside the traffic lights could be fully personalised so it was relevant to the individual and facilitated their decision when reporting anxiety/fatigue levels (i.e., were they feeling green, amber or red). • The diary, reminders and app settings (except traffic light settings) could be changed at any point throughout the study.
Modifications	Describe if the intervention was modified in any way, how, when and why.	• The app was updated during the study and the appearance changed to make it more visually appealing, however the layout was similar and participants did not require any further training.
How well?	Describe if intervention fidelity and adherence was assessed.	• Intervention fidelity was not assessed as this was a small series of case studies. However, the researcher providing the training to participants used a checklist (Appendix 9) during each session to ensure the same points were covered and all users received the same information. • Participants received up to two hours training and competency was assessed. They were also provided with a workbook two weeks prior to receiving BiH and given a training manual during the set-up session.

4.3.8. Quantitative methods.

The quantitative part of the case studies used questionnaires at baseline, routinely for the first 12 weeks (fortnightly measures), at six months and 12 months post-intervention. An n-of-1 case study design was chosen to ensure a clear set of data was obtained prior to intervention and during use.

4.3.8.1. Baseline assessment.

At baseline, participants were provided with several questionnaires. I supported participants where necessary to complete the questions. Participants took between one to two hours to complete this. The assessment included measures of anxiety and depression (HADS), cognition (MSNQ), quality of life (EQ5D-5L), activities of daily living (NEADL), participation (CIQ), fatigue (FAS) and a service use questionnaire (SUQ). GAS was completed during the baseline visit and used to identify participant goals that were appropriate alongside BiH. Goals were discussed with the participant's therapist (if applicable) before the baseline session, which helped to identify realistic and appropriate goals for the individual. In cases where therapist input was not possible, goals were discussed with a carer, family member or support worker.

4.3.8.2. Routine assessment.

Two questionnaires were administered on a fortnightly basis, which included the HADS and NEADL. This enabled the identification of changes in mood or ADL/independence after receiving BiH. In most cases, these were administered in person, but for some that were located further geographically, they were posted in prepaid return envelopes, or sent via email. If they were sent via email, the assessment documents were edited so that it could be easily completed on a computer and returned.

4.3.9. Justification for chosen outcome measures

4.3.9.1. EuroQoL EQ-5D-5L.

The European Quality of Life – 5 Dimensions (EQ-5D-5L) is a standardised instrument for measuring generic health status, developed by the Euroqol group. The EQ-5D is applicable to a wide range of health conditions and can be referred to as a quality of life questionnaire (Rabin, Oemar, Oppe, Janssen, & Herdman, 2011). The EQ-5D-5L was chosen as it is a simple measure that could be easily completed before, during and after the study. The measure comprises five sections: mobility, ability to self-care, ability to undertake usual activities, pain and discomfort, and anxiety and depression (Rabin et al., 2011). This measure is validated and reliable, with multiple studies implementing use in the stroke, TBI and ABI population (Alderman, Dawson, Rutterford, & Reynolds, 2001; Bell et al., 2005; Golicki et al., 2015; King Jr, Tsevat, & Roberts, 2009; Pinto, Maso, Vilela, Santos, & Oliveira-Filho, 2011). The EQ-5D-5L enabled the identification of perceived changes in quality of life after using BiH.

4.3.9.2. Nottingham Extended Activities of Daily Living.

The Nottingham extended activities of daily living (NEADL) index was originally established as a simple questionnaire to monitor individuals after stroke rehabilitation in the community (Nouri & Lincoln, 1987). It is an instrumental ADL scale and assesses 21 activities within four categories: mobility, domestic activities (e.g., clothes washing), kitchen activities (e.g., washing up) and leisure activities. It is a simple, self-administered questionnaire which takes approximately ten minutes to complete (Yohannes, Roomi, Waters, & Connolly, 1998). The NEADL is a valid measure, reliable (Nicholl, Lincoln, & Playford, 2002) and previously used in studies with ABI survivors (Legg, Drummond, & Langhorne, 2006; Phillips, Gaffney, Phillips, & Radford, 2018; Reavenall & Blake, 2010; Wu, Chuang, Lin, & Hong, 2011). In chapter 3, stakeholders identified ADL, independence and managing routine as

things BiH could potentially target/support, and the systematic review (chapter 2) identified poor reporting of these outcomes. Therefore, it seemed appropriate to use the NEADL. The questionnaire was administered on a fortnightly basis for the first 12 weeks of the study, as a potential indicator of change in functional activity, before and whilst using the intervention. The Rasch analysed version of the NEADL was used to score the returned questionnaires (das Nair, Moreton, & Lincoln, 2011). The NEADL reflects the proposed changes set out in the objectives and secondary endpoints, to identify if the BiH intervention had any perceived effect on functional outcomes and ADL.

4.3.9.3. Hospital Anxiety and Depression Scale.

The Hospital Anxiety and Depression Scale (HADS) was originally developed by Zigmond and Snaith in 1983 (Zigmond & Snaith, 1983) and is a common tool used to determine the levels of anxiety and depression experienced by an individual. The HADS is a 14-item scale that generates ordinal data, allowing a ranking order to be deduced. The HADS has been evaluated within the ABI population in several studies, demonstrating validity and reliability when measuring emotional distress (Schönberger & Ponsford, 2010; Whelan-Goodinson, Ponsford, & Schönberger, 2009). A review by Herrmann stated that the HADS provides, ‘clinically meaningful results as a psychological screening tool, in clinical group comparisons and in correlational studies with several aspects of disease and quality of life’, (Herrmann, 1997). This measure was chosen as stakeholders (chapter 3) suggested that BiH could support anxiety management and behaviour monitoring. The HADS was administered routinely for the first 12 weeks of recruitment to gain a clear indication of anxiety and depression levels prior to BiH intervention, and during use. It is quick and easy to complete, and has been used successfully in studies with the ABI population (Dawkins, Cloherty, Gracey, & Evans, 2006; Hodgson, McDonald, Tate, & Gertler, 2005). The HADS was a good choice of assessment to indicate potential

alterations in emotional behaviour during the study, without the need for an in-depth questionnaire. The Rasch analysed version was used to score the assessment (Gibbons et al., 2011; Pallant & Tennant, 2007).

4.3.9.4. Community Integration Questionnaire.

The Community Integration Questionnaire or CIQ was developed in 1993 by a panel of experts and included people with TBI (Willer et al., 1993). The CIQ was anticipated as a brief assessment of community integration, which could indicate the degree to which an individual after a TBI is able to perform relevant roles within the home and community (Willer & Corrigan, 1994). The CIQ uses behavioural markers of integration and does not include items that focus on feelings or emotional status (Dijkers, 1997). The rationale was to increase levels of reliability. The CIQ was used in this study as the scale is short and easy to complete, representing little burden. It required no special training to administer. There is reported concurrent validity between CIQ scores and specific items from reliable measures of disability and handicap, such as the Functional Independence Measure and Disability Rating Scale (Sander et al., 1999). The CIQ appeared to be a good indicator of integration and social participation, thus fulfilled the study objectives. The systematic review (chapter 2) identified few studies reporting measures of participation, therefore the CIQ was included as an outcome measure in this study.

4.3.9.5. Multiple Sclerosis Neuropsychological Screening Questionnaire.

The Multiple Sclerosis Neuropsychological Screening Questionnaire (MSNQ) is a brief, self-administered, 15 item test that reflects neuropsychological competence with ADL (Benedict et al., 2004). Cognitive impairment is prevalent following ABI, therefore I needed to implement a measure of this. Neuropsychological testing is often time consuming and difficult to complete. Neuropsychiatric conditions, like multiple sclerosis and ABI are often complex and have the potential to induce

secondary changes to cognitive functioning (Harvey, 2012). These changes reflect those experienced following brain injury, thus a neuropsychological test was appropriate for this study. The cognitive domains typically affected in ABI are: attention, memory, executive functioning (i.e., planning, prioritising) and information processing (Harvey, 2012). The mini mental state exam (MMSE) is often used to screen for cognitive impairment and used in various studies (Arevalo-Rodriguez et al., 2015; Mitchell, 2009; Monroe & Carter, 2012), as it is short and easy to complete. However, it does not assess all of the aforementioned affected domains and tends to provide a gross indicator of cognitive capacity (Folstein, Folstein, & McHugh, 1975). Some of the MMSE may be too simple for less impaired individuals. The MSNQ appeared to be the most suitable assessment to use in this study, as it reflects the daily impairment of functioning I was interested in. The MSNQ is short, thus limiting participant burden and indicated competence with ADL. Also, stakeholders (Chapter 3) identified memory as the key problem BiH could potentially target, therefore, a measure of cognitive function was needed.

4.3.9.6. Fatigue Assessment Scale.

HCPs highlighted fatigue as something that is sometimes unrecognised and receives less support following ABI. Therefore, it was important to include a measure of fatigue in this study. The fatigue assessment scale (FAS) is a short questionnaire that is easy to complete (Michielsen et al., 2004). Corroborating studies have suggested the FAS as the best indicator of fatigue following stroke (Lerdal et al., 2009; Mead et al., 2007) and it has been validated in the ABI population, unlike some other measures, such as the FIS: Fatigue Impact Scale (Mead et al., 2007; Michielsen, De Vries, & Van Heck, 2003; Michielsen et al., 2004; Vries, Michielsen, Heck, & Drent, 2004).

4.3.9.7. Goal Attainment Scaling.

Goal attainment scaling (GAS) provides an overall outcome measure by setting individual goals and assessing the level of attainment of these over a certain period of time. Goal-setting has become a routine procedure and is evident in multiple areas of clinical care. There is substantial literature which demonstrates its usefulness as a person centred outcome measure. GAS was first introduced in the 1960s by Kirusek and Sherman to assess outcomes in mental health settings. The GAS identifies 3-4 goals which can be weighted to reflect importance. This method of goal setting has been used successfully in studies with the ABI population to measure goal attainment (Bouwens, Van Heugten, & Verhey, 2009; De Joode et al., 2013). The GAS-Light tool was used in this study, as it enabled me to identify changes in goal attainment as a result of BiH intervention. An overall GAS-Light score was calculated at baseline, six and 12 months post-intervention using the GAS calculation spreadsheet (Turner-Stokes, 2003). Although stakeholders (chapter 3) did not highlight goal setting as a key target for BiH in the ABI population, it does form an important part of rehabilitation and something that seemed relevant to include in the case studies. BiH also uses a goal-directed approach for their users with autism.

The SUQ will be described in Chapter 5.

4.3.10. Quantitative analysis.

4.3.10.1. *Statistical analysis.*

The data obtained from all questionnaires were statistically analysed. The Rasch analysed versions of the HADS and NEADL were used. The suggested clinical cut-off scores were identified from published sources. Clinically relevant change in mood was determined by an increase or decrease of HADS scores resulting in a change of their perceived clinical status (Gibbons et al., 2011), e.g., if a participant moved into

the probable depression range (Rasch converted score 7 or greater) from the borderline range (Rasch converted score 5-7) of the HADS scale. These thresholds are presented in individual case figures, clearly illustrating if boundary crossover occurred. Published sources were also used to determine the clinical threshold for cognitive impairment measured by the MSNQ (O'Brien et al., 2007) and for fatigue measured by the FAS (Cumming & Mead, 2017).

In line with the objectives of the study, data were analysed to present the perceived change of memory, mood, fatigue, cognition, quality of life, participation and functional independence for the ABI participants measured using questionnaires. Overall response rates and completeness of questions returned were assessed. For parametric tests, mean averages and standard deviations were presented for comparison between measures with associated p values. All analyses were completed on IBM SPSS version 22.0 and GraphPad Prism version 6.0.

4.3.11. Qualitative methods.

4.3.11.1. Semi-structured interviews.

At six months post-intervention, participants took part in semi-structured interviews, directed by a theory driven topic guide. These were audio recorded, transcribed and analysed using qualitative methods. The qualitative part of the study sought to understand the experiences, opinions and motivations of the participants after using BiH for six months, and the barriers/facilitators to use and effectiveness. Semi-structured interviews were chosen, as the sample was small and this approach provided additional information to support the quantitative data. It also provided context and meaning to the quantitative results. I used a topic guide so that interviews were not overly structured and allowed participants to speak naturally. Questions were open ended where possible, thus not limiting the choice of answers the participant could provide to the interviewer (Gubrium & Holstein, 2002).

It was anticipated that the qualitative study would provide a way to understand the feelings, values, and perceptions that underlie and influence the behaviour of participants. The information obtained from the interviews hoped to influence the development of BiH and inform future improvements of the intervention, and/or similar technologies. I wanted to explore the acceptability of BiH for people with ABI, carers and HCPs, and potential barriers and facilitators to use.

The topic guides were informed by two models: BCW and ICF (appendices 13 & 14). I successfully used the BCW in Chapter 3 as a method of stakeholder engagement; something that delivered interesting and useful results. As BiH was designed to change behaviours, using the COM-B components of BCW seemed a logical choice to guide the interview questions. The core components of the ICF were used to direct questioning, to ensure the necessary topics were covered and data gathered fulfilled the study aims.

A coding matrix was developed prior to analysis, and additional codes added as new themes emerged. Each code was defined and a summary of the matrix is shown in Appendix 11. Table 4-4 presents the commonly used codes and definitions. The codes were split into two overarching themes of barriers and facilitators, then broken down into different subthemes. All of the codes had a theoretical source, which were associated with the quantitative outcome measures used in the study (CIQ, NEADL), BCW or ICF.

Table 4-3 Summary of interview codes used and their rationale/source.

Main codes	Sub-codes	Definition	Rationale/ source
1) Barriers or 2) Facilitators (each sub-code had a main code)	Behaviour Components - Capability - Opportunity - Motivation	**Capability:** Having the skills and/or understanding, strength and/or stamina to do something. **Opportunity:** The ability to do something due to the environment, social cues, resources and cultural norms. **Motivation:** The ability to achieve something due to emotional reactions, desires, self-conscious intentions and beliefs about what is good and bad.	BCW
	Body Function/structure - Sensory functions - Speech - Fatigue - Medication - Type of injury - Time since injury - Severity of injury - Mental functions	Impairments that affect body function or structure. **Type of injury:** Instances relating to facilitators with the specific injury and symptoms. **Time since injury:** Instances relating to how the injury and/or symptoms have improved over time. **Severity of injury:** Instances involving how little the injury effects daily functioning. **Mental functions:** Instances involving improved functioning in the brain, such as memory.	ICF
	Environmental factors - Aids o Technology o Non-technology - Environment - Services - Relationships - Support	**Aids:** Physical aids within the environment. **Non-Technology:** e.g. paper based diaries and to do lists. **Technology:** e.g. BiH and mobile phones. **Environment:** The surrounding environment and how this impacts on daily living or tasks. **Relationships:** Relationships within families, with friends or carers. **Services:** Services that are available to the individual and how they work with that person. **Support:** Any support that the individual receives, such as support workers, friends or therapists.	ICF
	Participation - Productivity - Employment - Home - Social	**Productivity:** Tasks that are completed during the week and how often these things are completed without support. **Employment:** Things that happen in the workplace and current educational or work status. **Home:** Tasks within the home, i.e., daily running of the household. **Social:** Social activities in the community	CIQ
	Personal factors - Independence - Acceptance - Goal attainment	**Independence:** The state of being independent and not having to rely on other people. **Acceptance:** Acknowledging or accepting the changes in the individual's physical or psychological functioning. Moving forward. **Goal attainment:** Working towards and achieving goals in the context of everyday living.	ICF
	Activities - Domestic - Mobility - Leisure - Kitchen	**Domestic:** Household tasks, such as cleaning and making the bed. **Mobility:** Moving around on foot, such as running and walking. **Leisure:** Hobbies and things the individual does for fun. **Kitchen:** Tasks in and around the kitchen, such as cooking.	NEADL

4.3.11.2. Framework analysis.

There are a number of approaches that can be used for qualitative analysis depending on the desired outcome and specific focus of research. The framework approach is a type of thematic analysis, which involves the tabulation of results to facilitate the interpretation of data and enable the researcher to easily identify emerging themes. Framework analysis was used to identify key themes arising from the interviews. This method was chosen to enable in-depth exploration of qualitative data, while maintaining a systematic analysis path. This approach improved the consistency of analysis and enhanced the credibility of findings (Spencer, Ritchie, Lewis, & Dillon, 2003). Analysis was split into five stages as shown in Table 4-4. The qualitative data were coded and analysed using NVivo version 10.0.

Table 4-4 Stages of qualitative analysis.

Analysis Stage	Description
1 - Transcription	All interviews were conducted, voice recorded and transcribed.
2 - Familiarisation	• I read through the transcripts once to familiarise myself with the data and get a general feel for the information. • The transcripts were read a second time and notes were taken for each participant, identifying the key messages of the interview.
3 - Coding	• The transcripts were initially coded using a pre-defined list, which was based around the BCW components and the ICF. Codes were broadly split into barriers and facilitators. • Following the coding of all transcripts, additional codes were generated for other themes that had emerged from the interviews. This was an iterative process and applied to all transcripts. • Additional codes were generated following discussion with other researchers and comparison of coding. The final coding matrix is shown in Appendix 11.
4 – Developing framework	• Once transcripts had been coded, the findings were discussed with other researchers and the key themes identified. • The codes were categorised and a framework developed for analysis.
5 – Applying framework	The framework shown in Appendix 12 was systematically applied to all interviews. The framework used the key themes and helped me to identify quotations for each participant, which have been used in the qualitative results.

4.4. Case Study Results

In total, 19 people were assessed for eligibility and 14 consented to the study; 11 of these were people with ABI and three were healthcare professionals (HCPs). A CONSORT diagram is presented in Figure 4-3. One participant withdrew following baseline assessment due to an ABI-related medical issue, something which the participant felt would compromise their commitment to the study. The remaining ten ABI participants completed all routine questionnaires up to 12 weeks post-baseline, and received BiH at six weeks post-baseline. One participant was withdrawn from the study following assessment six due to a participant dying (which was deemed not to be attributed to being part of the study or intervention). Subsequently, nine ABI participants were interviewed at six months post-intervention. Another participant withdrew from the study following the interview, as he was advised by his rehabilitation team to stop using BiH due to persistent technical problems. All six month assessments were completed and returned (n=8). At 12 months post-intervention, eight final assessment booklets were sent to participants; six were completed and returned. Every effort was made to contact the participants who did not return questionnaires via telephone and email, but this was unsuccessful.

4.4.1. Participant characteristics.

The details of the 11 participants recruited to the study are shown in Table 4-5. There were more men (n=9) than women (n=2), and the mean age was 43.45 years (SD=13.15), ranging from 24 to 66 years. Seven participants had a TBI, one a stroke and the remaining three had different types of ABI as a result of hypoxia, aneurysm haemorrhage and brain tumour surgery. The exact time since injury was not collected, however participants were asked to put themselves in a time category (i.e., under 12 months, 12-18 months, 18-24 months, 2-3 years etc. post-injury). The majority of participants were 12-18 months post- injury (n=5), three were 18-24 months post-injury, one was 3-4 years post-injury and two were over four years post-

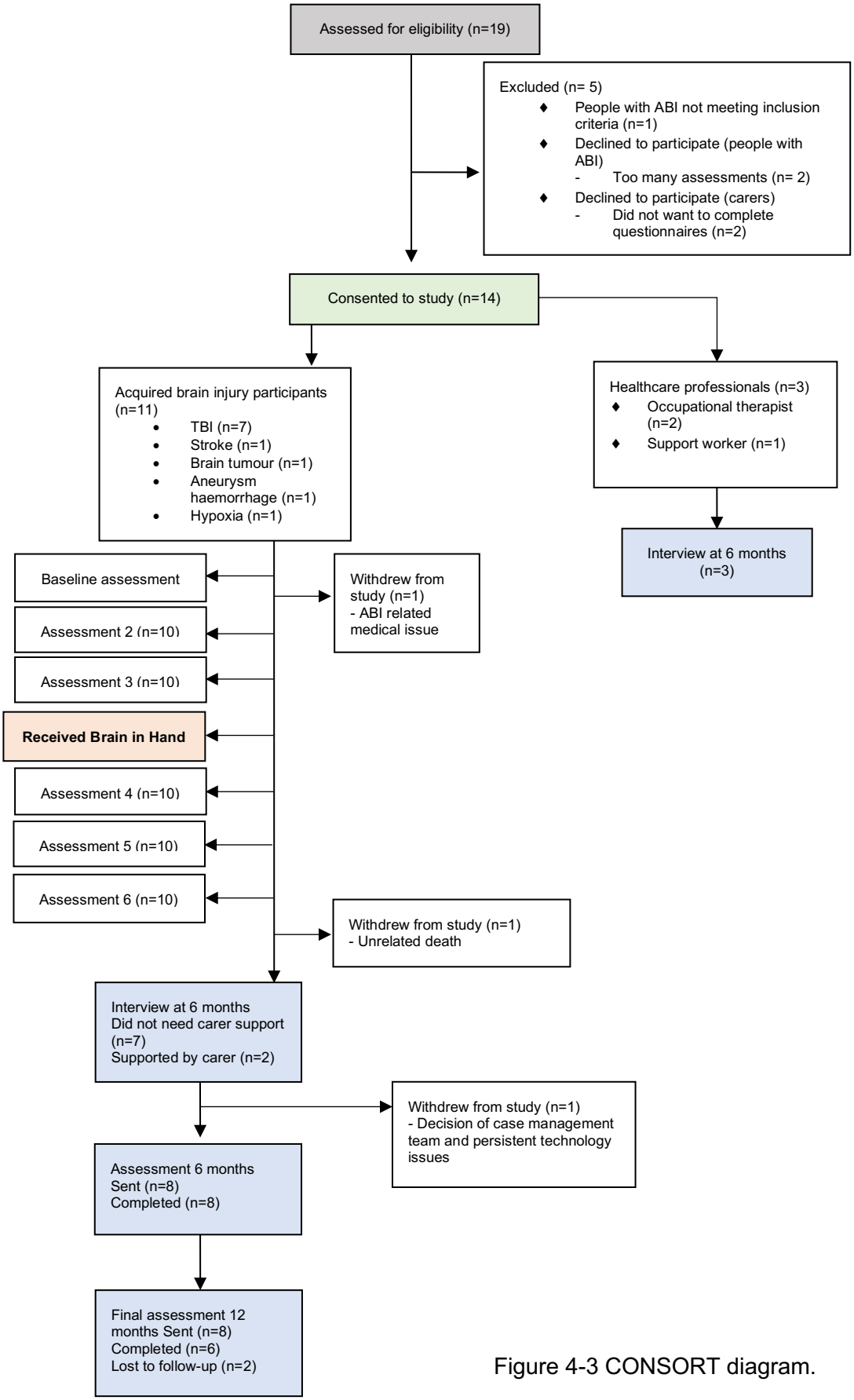


Figure 4-3 CONSORT diagram.

injury. Further discussion at baseline identified that one participant was over 25 years post-injury and had received no rehabilitation until a year prior to recruitment. Eight of the participants were receiving occupational therapy at the time of recruitment, four were receiving neuropsychological therapy, two were receiving physiotherapy and two speech and language therapy.

4.4.1.1. Baseline characteristics.

Participants varied considerably in their clinical baseline measures. Some experienced anxiety, depression and/or fatigue. The sampling strategy was to obtain a diverse range of participants to fully explore the effectiveness and use of the intervention in the ABI population. The baseline data shows the variation in people recruited in terms of injury severity, time since injury, age, gender and baseline measures. The mean HADS anxiety score (Rasch converted) was 7.5 (SD=6.04, 95% CI 3.18-11.82) at baseline. A higher score indicated a greater level of anxiety, with a suggested cut-off score (Rasch converted) of ≥9 for 'probable anxiety' (see red numbers in Table 4-6) (Gibbons et al., 2011). Four participants were in this 'probable anxiety' range at baseline, suggesting that some participants were experiencing anxiety. The mean HADS depression score (Rasch converted) was 4.5 (SD=3.24, 95% CI 2.18-6.82) at baseline). A higher score indicated a greater level of depression, with a suggested cut-off score of ≥8 for 'probable depression (see red shaded boxes in Table 4-6) (Gibbons et al., 2011). Only two participants were in this 'probable depression' range at baseline, however most participants did not score highly on this measure, suggesting that the majority were not depressed.

The mean NEADL score (Rasch converted) was 40.4 (SD=10.5, 95% CI 32.92-47.88) at baseline. A higher score indicated a greater level of independence and functional ability in the context of ADL. The results were heterogeneous, with some

Table 4-5 Baseline characteristics for ABI participants.

Case ID	Gender	Age (years)	Injury	Time since injury	Current Rehabilitation	HADS Anxiety*		HADS Depression*		NEADL♦		EQ5D-5L Index♦	CIQ♦	MSNQ*	FAS*
						Standard	Rasch converted	Standard	Rasch converted	Standard	Rasch converted				
1	Man	32	TBI	3-4 years	OT	0	0	1	0	63	51	1.00	25	22	11
2	Man	48	Brain tumour surgery	18-24 months	NP	2	1	2	2	65	53	0.84	27	32	21
3	Woman	24	TBI	12-18 months	OT, PT, SLT	12	10	6	5	37	27	0.59	8	33	32
4	Man	48	TBI	Over 4 years	OT, NP	9	8	9	5	58	46	0.66	15	40	27
5	Man	38	TBI	12-18 months	OT, NP	18	16	10	7	62	52	0.55	11	48	32
6	Man	50	TBI	18-24 months	OT	16	16	15	10	39	31	0.32	11	59	41
7	Man	32	TBI	12-18 months	OT	5	4	3	2	57	47	0.84	17	30	20
8	Man	58	Hypoxia	12-18 months	OT	6	5	7	5	37	32	0.65	14	39	33
9	Woman	52	Aneurysm haemorrhage	12-18 months	NP	14	13	14	8	49	37	0.71	17	47	42
10	Man	66	Stroke	Over 4 years	PT, SLT	2	2	2	1	39	28	0.73	10	23	17
11	Man	30	TBI	18-24 months	OT, PT	17	**	7	**	46	**	0.26	15	49	NC
Mean (SD)	-	43.45 (13.15)	-	-	-	9.18 (6.57)	7.5 (6.04)	6.91 (4.78)	4.5 (3.24)	50.2 (11.2)	40.4 (10.5)	0.65 (0.22)	15.5 (5.97)	38.4 (11.6)	27.6 (10.2)
95% CI	-	34.62-52.29	-	-	-	4.77-13.6	3.18-11.82	3.70-10.12	2.18-6.82	42.68-57.69	32.92-47.88	0.50-0.80	11.44-19.47	30.55-46.18	20.27-34.93
Outcomes Measure Range	-	-	-	-	-	Min 0 Max 21	Min 0 Max 18	Min 0 Max 21	Min 0 Max 15	Min 0 Max 66	Min 0 Max 54	Min -0.59 Max 1.00	Min 0 Max 29	Min 0 Max 60	Min 10 Max 50
Score Range	-	24-66	-	-	-	0-18	0-16	1-15	0-10	37-65	31-53	0.26-1.00	8-27	22-59	11-42

♦ lower score indicates a negative outcome * lower score indicates a positive outcome.
HADS: Hospital Anxiety and Depression Scale; NEADL: Nottingham Extended Activities of Daily Living; EQ-5D-5L: EuroQol 5-dimensions 5-levels; CIQ: Community Integration Questionnaire; MSNQ: Multiple Sclerosis Neuropsychological Screening Questionnaire; GAS: Goal Attainment Scaling; FAS: Fatigue Assessment Scale; SD: standard deviation; OT: Occupational therapist; NP: Neuropsychologist; PT: Physiotherapist; SLT: Speech and language therapist; NC: Not completed.
Red coloured numbers indicate probable clinical impairment/presence of the outcome in question (i.e., anxiety, depression, cognitive impairment).

participants scoring low on domestic and leisure sections of the questionnaire. Three participants scored highly on the NEADL (greater than 50) and two scored slightly lower (46 and 47), suggesting they were relatively independent in some aspects of daily living.

The mean CIQ score was 15.5 (SD=5.97, 95% CI 11.44-19.47) at baseline. A higher score indicated a greater level of participation in society. This baseline measure was more consistent across the group compared to other measures. The MSNQ scores at baseline varied between participants, with some scoring low (less than 25/60) and others scoring highly (more than 45/60). The mean MSNQ score was 38.4 (SD=11.6, 95% CI 30.55-46.18) at baseline, with a range of 22 to 59 (maximum possible score = 60). A lower score indicated a greater level of memory function and cognition, with a proposed cut-off score of 24 suggesting possible cognitive impairment (O'Brien et al., 2007). Only two participants were below this threshold and the remaining had possible cognitive impairment (red numbers, Table 4-5). Four participants had moderate to high scores of 47 and above, suggesting they had some cognitive impaired. The mean FAS score was 27.6 (SD=10.2, 95% CI 20.27-34.93) at baseline, with a range of 11 to 42 (minimum - maximum possible score = 10 - 50 respectively). A higher FAS score indicated a greater presence of fatigue and a suggested cut-off score of 24 or above indicating possible post-injury fatigue (Cumming & Mead, 2017). Six participants were above this threshold at baseline, suggesting that the sample experienced high fatigue.

Table 4-6 summarises the findings across cases and will be referred to throughout the individual case study results. As case 11 did not continue after the baseline assessment and minimal information about their personal life was collected at this point, they were not included in any further results.

Table 4-6 Summary of qualitative data obtained between baseline and 12 months across the 10 cases.

Measure		Case 1	Case 2	Case 3	Case 4	Case 5	Case 6	Case 7	Case 8	Case 9	Case 10	Mean	SD
HADS anxiety	Baseline	0	1	10	8	16	16	4	5	13	2	7.50	6.04
	6 months	2	1	12	WD	15	16	NR*	6	10	4	8.25	5.82
	12 months	3	1	11	WD	NR*	18	WD	NR*	12	2	7.83	6.85
HADS depression	Baseline	0	2	5	5	7	10	2	5	8	1	4.50	3.24
	6 months	1	5	4	WD	10	12	NR*	4	6	2	5.50	3.78
	12 months	1	4	4	WD	NR*	8	WD	NR*	6	4	4.50	2.35
NEADL	Baseline	51	53	27	46	52	31	47	32	37	28	40.40	10.46
	6 months	45	54	20	WD	43	19	NR*	36	46	21	35.38	13.91
	12 months	55	51	14	WD	NR*	20	WD	NR*	48	20	34.67	18.52
GAS-Light	Baseline	37.7	37.1	36.2	-	36.2	37.7	38	38	36.4	37.6	37.21	0.76
	6 months	60.6	74.7	54.2	-	NR*	37.7	58	46	50	50	53.9	11.02
	12 months	64.1	38.9	71.2	-	NR*	25.5	WD	38	50	62.4	50.01	16.68
CIQ	Baseline	25	27	8	15	11	11	17	14	17	10	15.50	6.29
	6 months	19	21	11	WD	11	14	NR*	12	19	10	14.63	4.37
	12 months	18	23	19	WD	NR*	12	WD	NR*	19	6	16.17	6.11
MSNQ	Baseline	22	32	33	40	48	59	30	39	47	23	37.30	11.68
	6 months	18	26	27	WD	45	55	NR*	39	28	35	34.13	11.91
	12 months	23	22	31	WD	NR*	57	WD	NR*	30	38	33.50	12.91
FAS	Baseline	11	21	32	27	32	41	20	33	42	17	27.60	10.24
	6 months	11	24	27	WD	32	40	NR*	25	37	23	27.38	9.09
	12 months	16	19	33	WD	NR*	42	WD	NR*	37	27	29.00	10.22
EQ5D-5L	Baseline	1	0.836	0.592	0.657	0.549	0.32	0.837	0.649	0.714	0.727	0.69	0.19
	6 months	1	0.951	0.67	WD	0.496	0.46	NR*	0.816	0.812	0.62	0.73	0.20
	12 months	0.906	0.837	0.62	WD	NR*	-0.016	WD	NR*	0.812	0.691	0.64	0.34

The coloured boxes represent the valence of the score based on the clinical measure. Green shaded boxes represent a positive/higher level outcome. Red shaded boxes represent a negative/lower level outcome. Amber/yellow shaded boxes represent a moderate level outcome. The colours range from green to amber to red.
HADS: Hospital Anxiety and Depression Scale, NEADL: Nottingham Extended Activities of Daily Living, GAS-Light: Goal Attainment Scaling-Light, CIQ: Community Integration Questionnaire, MSNQ: Multiple Sclerosis Neuropsychological Screening Questionnaire, FAS: Fatigue Assessment Scale, EQ-5D-5L: EuroQol 5-dimensions 5-levels NR: questionnaire not returned/unable to rate goal attainment, WD: withdrew from study; SD: standard deviation. *contacted twice via phone/email to obtain missing data but no response.

4.4.2. Case 1.

The results from case 1 (Liam[3]) will be presented in this section. Liam completed all questionnaires and the interview at six months post-intervention.

4.4.2.1. Pen portrait.

Liam was a 32-year-old man who had a TBI in 2013 (three years post-injury when recruited). He was a trained chef and college lecturer prior to injury, having previously worked as a head chef for a successful restaurant. Liam was receiving occupational therapy at the time of recruitment, but was discharged from the TBI rehabilitation service in 2017 (9 months post-consent). Liam had just moved into his own accommodation at the beginning of the study and was starting to live independently with minimal support. He had a buddy that visited twice a week and enjoys the social contact he has with this person, describing him as more of a friend than support worker. Liam's parents lived nearby and were largely involved in his life prior to the move. He was determined to reduce contact with them, try to self-manage and live alone with minimal help. Liam was going through a divorce at the time of his injury and was not in a relationship during the study. Liam was a high functioning individual, with no significant cognitive impairments, anxiety or depression. He had a positive outlook on life and is a sociable person. However, he did lack a little insight especially when planning meals or tasks. His main goals were to live alone with minimal help, manage his finances and regain independence. Liam was already using a smartphone for reminders at baseline. (See appendix 15 for detailed summary of case study).

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[3] Pseudonyms used throughout

4.4.2.2. Clinical outcome measures.

The outcome data presented in Table 4-6, shows that Liam did not improve on any outcome measures over the 12 months apart from ADL/functional outcomes (NEADL). The intervention appeared to have no initial effect on the anxiety or depression scores (Figure 4-3), or on the NEADL score (Figure 4-3). However, at six months, Liam's anxiety and depression scores increased by 2 and 1 points respectively, and his NEADL score dropped from 51 to 45. At 12 months, his anxiety score increased by a further 1 point and his depression score remained the same. At 12 months, his NEADL score increased sharply from 45 to 55, which was higher than his baseline score. Although the HADS scores increased following the use of BiH, they were still within the normal clinical range (0-5).

At six months, there was a decrease in participation (shown by a decrease in CIQ score of 25 to 19). There was an improvement in cognition, shown by a decrease in MSNQ score from 22 to 18. This may have been a result of increased BiH use. All other scores remained the same at six months post-intervention.

At 12 months, there was an increase in fatigue levels from six months shown by higher FAS score (11 to 16). There was a further decrease in participation shown by a lower CIQ score (19 to 18), a decrease in quality of life (lower EQ5D-5L index from 1 to 0.906), and a decrease in cognition (higher MSNQ score, 18 to 23). Overall, at six months post-intervention there appears to be a worsening of most measures and this continues at 12 months. The change in outcomes suggest that Liam was becoming depressed, however he was not taking any medication for this and did not mention any change in mood.

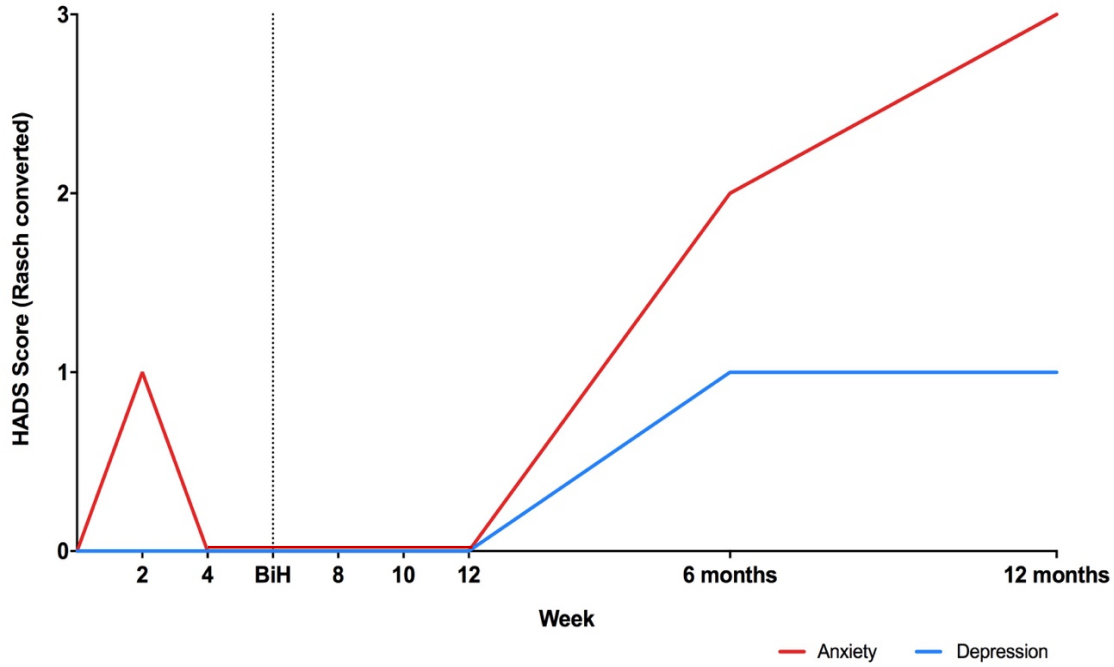


Figure 4-4 Case 1 HADS (Rasch converted) scores over 12 months.

Blue (depression) and red (anxiety) lines represent the HADS scores over the 12 month study period, showing the initial 12 week fortnightly measures. The dotted line indicates the time BiH was introduced.

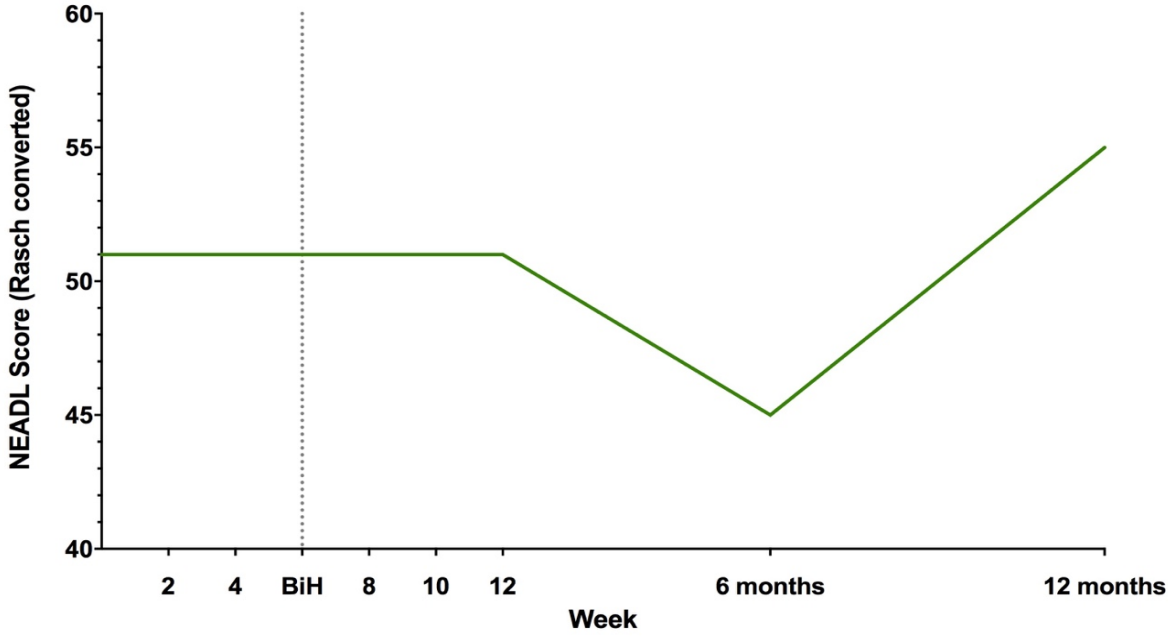


Figure 4-5 Case 1 NEADL (Rasch converted) scores over 12 months.

The green line represents the NEADL scores over the 12 month study period, showing the initial 12 week fortnightly measures. The dotted line indicates the time BiH was introduced.

4.4.2.3. Brain-in-Hand data.

Data collected from the BiH app shows that Liam did not use all its functions and was using it as more of a reminding tool than a monitoring or problem-solving tool. Liam only pressed green traffic lights throughout the study (Table 4-8). He was using the traffic lights to monitor anxiety. It is interesting to note that even though his anxiety levels increased according to HADS measure, there was no change in the traffic lights pressed. Liam was already using his phone for reminders before the start of the study and this was reflected in his use of BiH. He completed a large number of tasks throughout the study and was consistent over the 12 months. He completed slightly more tasks in the first six months. Liam only used one solution, which was accessed in the first week of use.

Table 4-7 Case 1 data over 12 month period exported from the BiH app.

		First 6 months	Last 6 months	Total
Traffic lights (anxiety)	**Green**	655	209	864
	Amber	0	0	0
	Red	0	0	0
Tasks Complete (% total)		241 (73.5%)	171 (66.5%)	412 (70.5%)
Tasks Incomplete		87	85	172
Solutions Used		1	0	1

His use of the traffic lights is shown in Figure 4-5, which is consistent between October 2016 and May 2017. However, there is a significant decline in use around the middle of May even though tasks were still being completed at this point, up until August 2018.

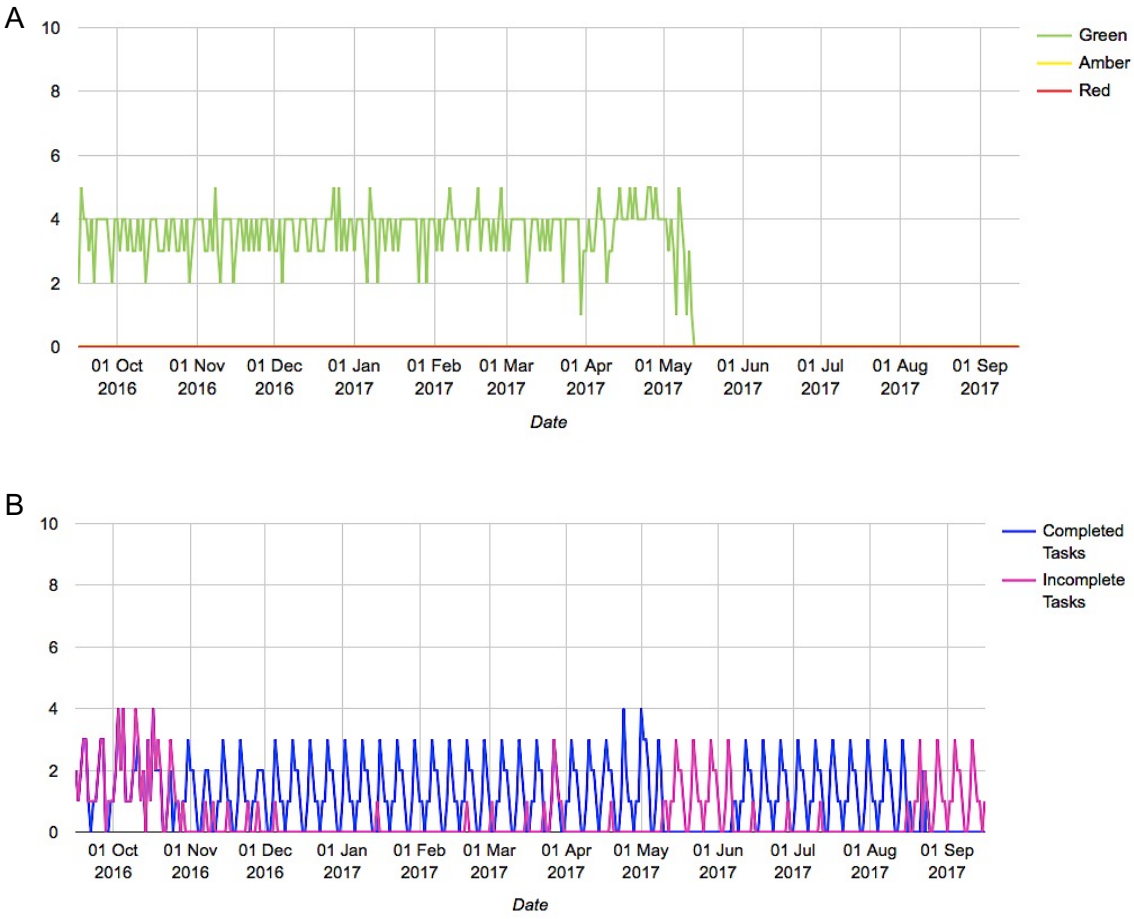


Figure 4-6 Case 1 data exported from the Brain in Hand cloud.

Graph A shows the total number and colour of traffic lights pressed between September 2016 (BiH intervention introduced) and September 2017 (12 months post-intervention).

Graph B shows the number of tasks completed (blue) and not completed (pink) over the 12 month period.

4.4.2.4. Goal attainment.

The following goals were set at baseline with the help of Liam's OT:

1. **Participant stated goal**: Live independently with minimal support in new apartment and manage household tasks with little help from parents.

   SMART goal: To self-manage in new home with minimal help and complete all necessary household tasks and food shopping, using BiH diary to provide this structure. He will not call his parents every day to ask for help and try to resolve any problems himself first. He will complete at least 70% all tasks over six months measured by BiH app.
2. **Participant stated goal**: Begin to manage money himself and pay all bills for his new apartment, take control of his finances which at baseline were controlled entirely by his parents.

   SMART goal: No missed payments on rent or bills over the 12 month study period. Start taking control of finances by doing food shopping himself and using reminders on BiH to take specific cards to the shop. Reduce his non-essential spending over six months.
3. **Participant stated goal:** Start running again and try to enter half-marathon.

   SMART goal: Join a local running club within six months and aim to run three times per week. Use BiH for running reminders and possibly add training plan. Enter half-marathon for the following year.

Table 4-8 presents Liam's progress over 12 months and identifies whether goals were achieved. Liam achieved two of three goals and exceeded expectation in both cases. His GAS-Light score increased over the 12 months. BiH appeared to help him achieve these goals by using the BiH reminder function. By using data from the app, I was able to determine if Liam had completed the required percentage of tasks over a specific period.

Table 4-8 Goal attainment for Case 1 over 12 months.

Goal	0-6 months	6-12 months	Baseline-12 months
1	Yes – better than expected. Completed 73.5% tasks added to BiH diary (data exported from BiH app). Called his parents 3 times per week and only when necessary.	No - Partially achieved Only completed 66.5% tasks on BiH diary (data exported from BiH app). Still only contracting his parents when necessary and not asking for help as much as he used to. Usually only 2-3 times per week.	Yes - better than expected. Completed 70.5% tasks on BiH diary over 12 month period (data exported from BiH app). Therapist agreed that he self-managed much better than expected and needed little help. Independent living has been successful.
2	Yes – as expected. Taking control of money and finances. Did not miss any rent payments and all bills paid on time. Successfully used BiH to remind him to take his store card when food shopping. Has bought a few non-essential items but less spending than at baseline.	Yes – better than expected. All bills paid for on time and no rent payments missed. Managed to save enough money for a trip to New Zealand. Set most of his travelling budget independently with minimal help from his parents.	Yes – better than expected. Over 12 months there were no missed rental payments and all bills were paid on time. Managing finances much better. Successfully travelled to New Zealand and managed money while abroad. Overall, a great improvement from baseline.
3	No – partially achieved. Joined local running club and running at least three times per week. He stated that he felt much healthier and was socialising more as a result. However, he was not using BiH to add running reminders, he was using phone reminders instead as he could not change the diary.	No – partially achieved. Still a member of the running club and tries to run three times per week but started volunteering again so has less time. Cannot enter half marathon as he was travelling to New Zealand when it the event was taking place. Still not using BiH reminders.	No – partially achieved. Joined the running club and although running less than at the start of the study, still tries to run twice each week. Will enter the half marathon next year. He is happy using phone reminders for running not BiH.
GAS- Light score (baseline = 37.7)	+22.9	+26.4	+49.3

4.4.2.5. Qualitative data.

A face-to-face interview was conducted with Liam at six months post-intervention. He talked about potential improvements that could be made to BiH, along with his opinions about the app, the barriers he faced while using BiH and whether he thought it was suitable for his needs/goals. Figure 4-7 summarises the findings from the interview with Liam.

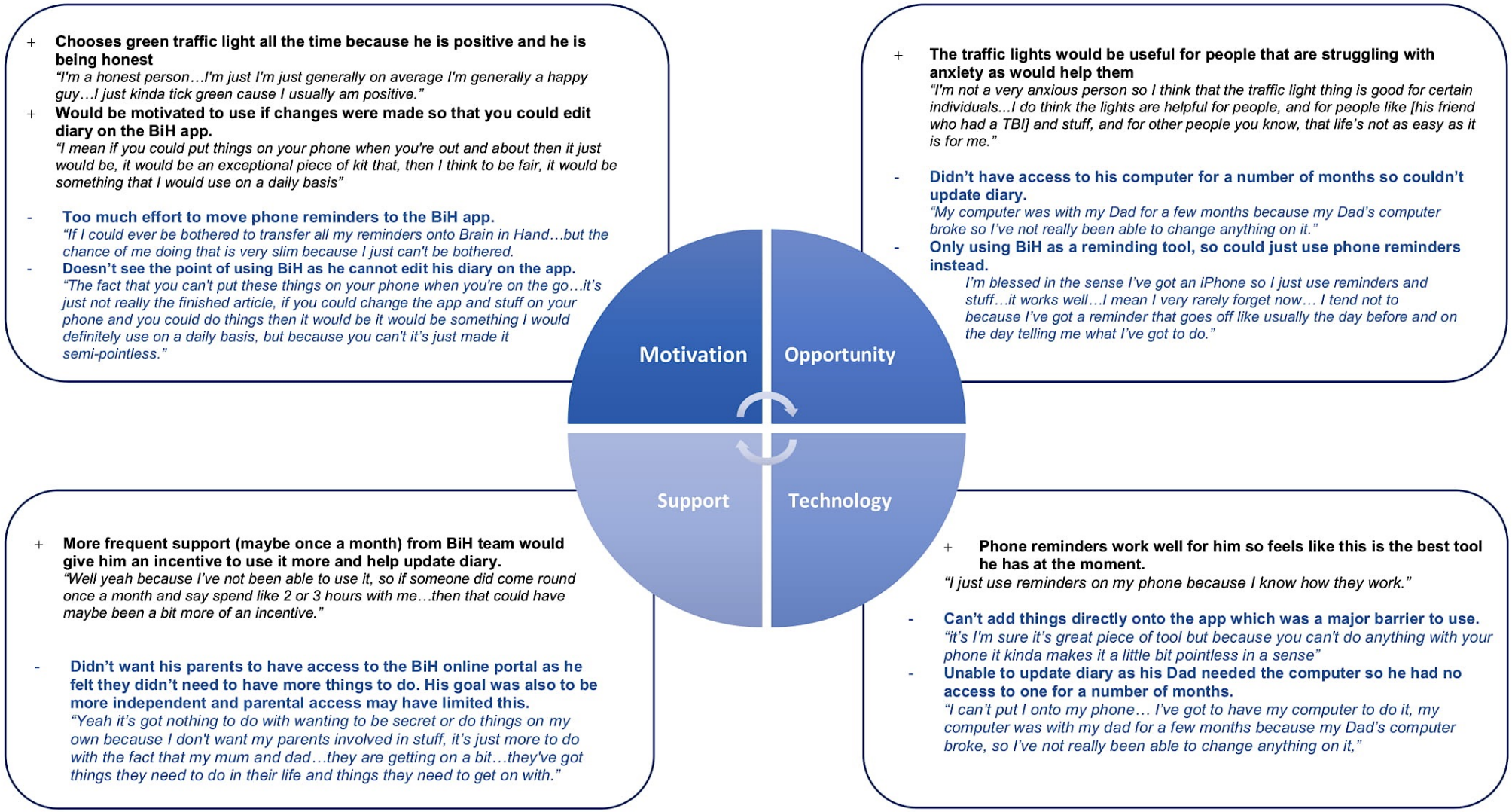


Figure 4-7 Summary of the qualitative findings from the Case 1 interview.

4.4.3. Case 2.

The results from case 2, Daniel are presented in this section. He completed all questionnaires and the interview at six months post-intervention.

4.4.3.1. Pen portrait.

Daniel was a 48-year-old man who had an ABI in 2014, as a result of brain surgery (two years post-injury when recruited). He had his own photography business and continued to work following injury. Daniel was receiving rehabilitation at the time of recruitment with a neuropsychologist, however was discharged shortly after consenting to the study. He lived at home with his wife and daughter. He suffered from high levels of fatigue and found it difficult to rest during the day, or pace activities. He reduced his working hours and responsibilities within the business as a result of his ABI, and was helping around the house to support his daughter and busy wife, who was a surgeon. Daniel had minor cognitive impairment, which sometimes interfered with daily life, as he could be easily distracted or forget to do tasks. He had a positive outlook on life and did not suffer from anxiety or depression. He had minor issues with mobility as a result of ABI, but it did not limit his daily life. Daniel's main goals were to manage fatigue, take planned rests and to structure his day better to ensure all necessary tasks were completed (e.g., take daughter to school, cooking, food shopping). Daniel was already using a smartphone and electronic calendar before starting the study to remember tasks and synchronise his daily routine with other family members. (See appendix 16 for summary).

4.4.3.2. Clinical outcome measures.

There was improvement in some outcome measures over 12 months (Table 4-6). The intervention appeared to have a negative effect on Daniel's anxiety levels, which increased from 2 to 4, however this was still within the 'normal' clinical range (Figure

4-8). As his anxiety levels increased, his NEADL score decreased (Figure 4-9), showing a slight negative effect on ADL and functional outcomes. His depression score stayed the same following the introduction of BiH. At six months post-intervention, Daniel's depression level stayed the same, but his anxiety levels decreased again. As his anxiety score decreased, Daniel's NEADL score increased from 46 to 54, which was higher than his baseline score. At 12 months, his HADS depression and NEADL scores decreased.

At six months, there was a decrease in participation (shown by a decrease in CIQ score of 27 to 21), and an increase in fatigue levels shown by a FAS increase of 21 to 24. There was an improvement in cognition at six months, shown by a decrease in MSNQ score from 32 to 26 and NEADL score, as mentioned above. There was an improvement in quality of life between baseline and six months, measured by the EQ5D-5L index (0.836 to 0.906).

At 12 months, there was a further improvement in cognition shown by a decrease in MSNQ score from six months (26 to 22) and an overall improvement from baseline (32 to 22). There was also a decrease in fatigue levels between six and 12 months, which was an overall improvement from baseline (21 to 19). There was a further decrease in participation between six and 12 months (CIQ score) and an overall decrease from baseline. A small increase in quality of life was observed between baseline and 12 months. Overall, there was an improvement in cognition, fatigue, and quality of life at 12 months post-intervention.

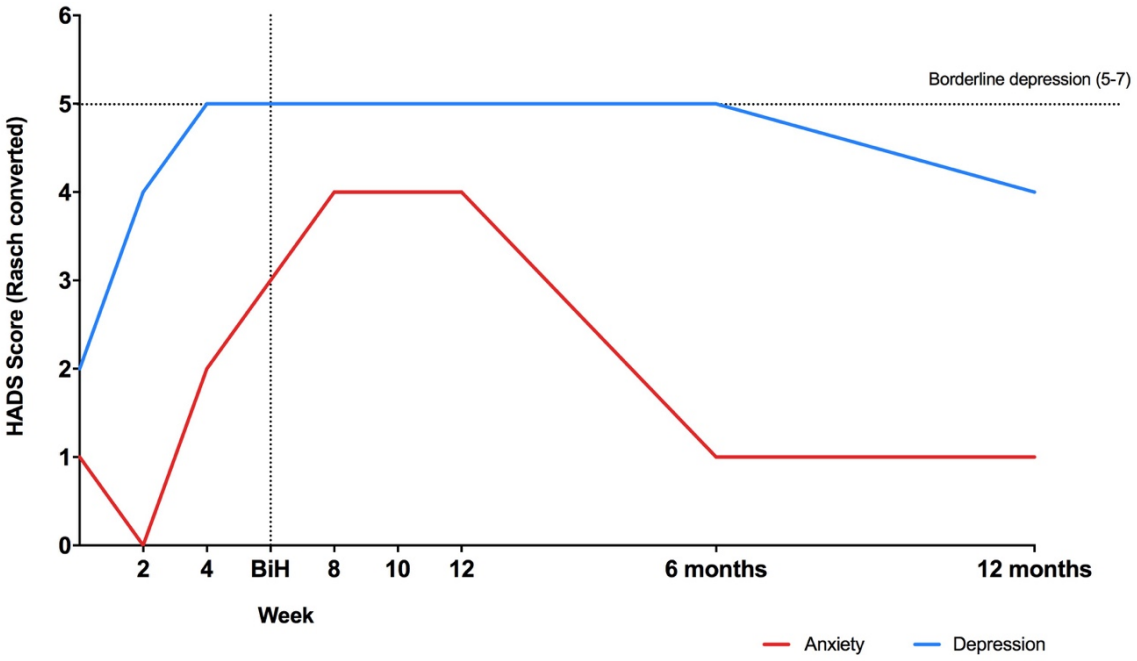


Figure 4-8 Case 2 HADS (Rasch converted) scores over 12 months.

Blue (depression) and red (anxiety) lines represent the HADS scores over the 12 month study period, showing the initial 12 week fortnightly measures. The vertical dotted line indicates the time BiH was introduced. The horizontal dotted line indicates the clinical cut off for borderline depression (Rasch converted HADS depression score 5-7).

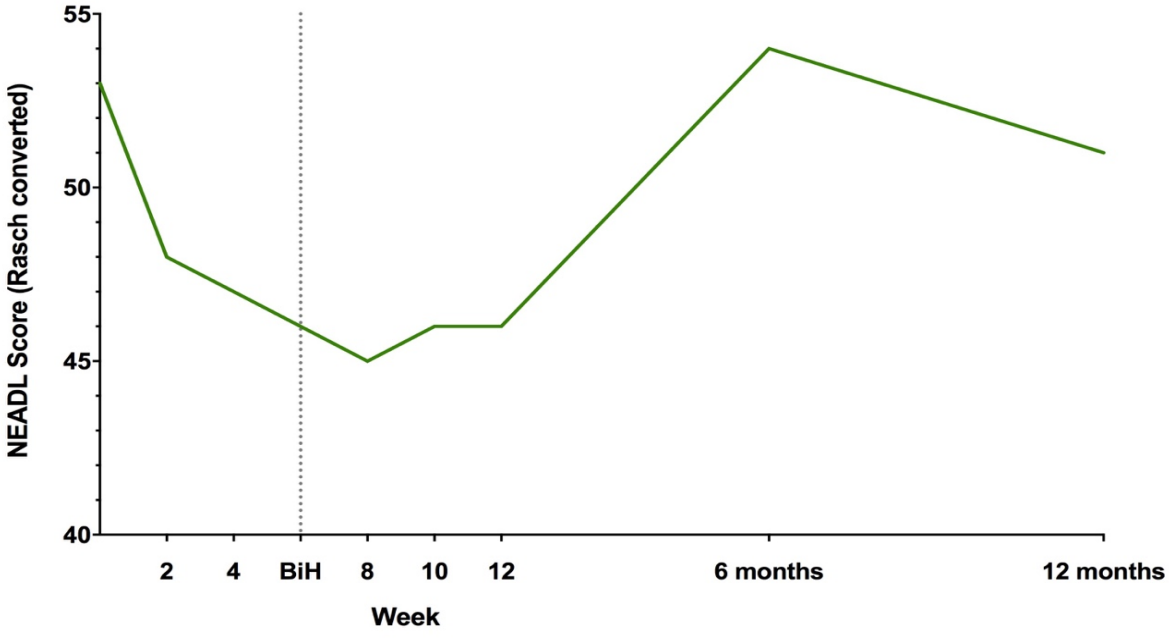


Figure 4-9 Case 2 NEADL (Rasch converted) scores over 12 months.

The green line represents the NEADL scores over the 12 month study period, showing the initial 12 week fortnightly measures. The dotted line indicates the time BiH was introduced.

4.4.3.3. Brain-in-Hand data.

Data collected from the BiH app shows that Daniel was using it as a symptom monitoring tool and to structure his day better, such as managing the housework and his daughter. Daniel pressed mostly green traffic lights throughout the study (n=131), fewer amber presses than green (n=61) and less red presses (n=12) (Table 4-9). The majority of green traffic lights were in the first six months (n=109). He was using the traffic lights to monitor fatigue, and a number of 'rest' reminders were added to his diary to encourage fatigue management.

Daniel was already using iCalendar for reminders and planning before the start of the study, as he could sync this with his wife's calendar, making it easier to plan events. These reminders were added to his BiH diary, which accounts for the large number of tasks he had to complete over the initial six-month period, some of which were deleted after the six month interview. Although he completed a large number of tasks during the study (32.7%, 438/1338), BiH registered more incomplete tasks during the study. In the first six months, he completed 38.6% tasks (325/843) and 22.8% tasks (113/495) in the final six months. Out of the 843 tasks set in the first six months, 110 of these were 'rest' tasks, with the aim to manage fatigue by taking some time out and resting his mind. He pressed green frequently in the first six months, suggesting his fatigue levels were low as he only completed 35.5% (39/110) of rest tasks. However, he also pressed red eight times during this period, which may be due to some of the missed rests. In the final six months, Daniel completed even less 'rest' tasks; 24.4% (31/127). Over 12 months, Daniel used nine solutions, eight of these were in the first six months.

Table 4-9 Case 2 data over 12 month period exported from the BiH app.

		First 6 months	Last 6 months	Total
Traffic lights (fatigue)	**Green**	109	22	131
	Amber	38	23	61
	Red	8	4	12
Tasks Complete (% total tasks)		325 (38.6%)	113 (22.8%)	438 (32.7%)
Tasks Incomplete		518	382	900
Total tasks		843	495	1338
Completed 'Rest' tasks (total rest tasks, % total)		39 (110, 35.5%)	31 (127, 24.4%)	70 (237, 29.5%)
Solutions Used		8	1	9

Daniel's traffic lights use is presented in Figure 4-9A, showing an increase in green presses during the first four months (October 2016 to February 2017). However, there was a clear decline in use between March and April 2017, and again between May and June 2017. The decreased traffic light use between these periods corroborates with an increase in incomplete tasks at these time points, as shown in Figure 4-9B.

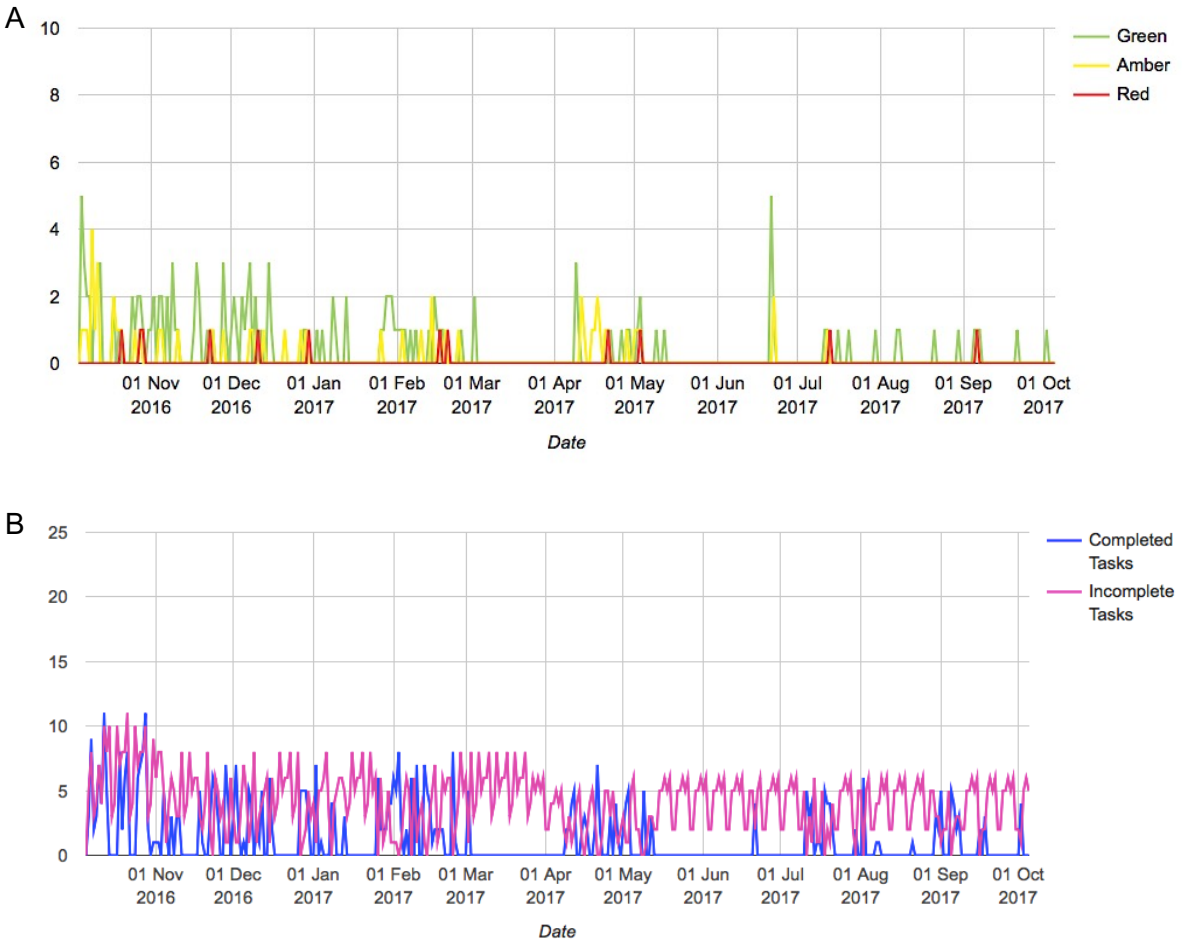


Figure 4-10 Case 2 data exported from the Brain in Hand cloud.

Graph A shows the total number and colour of traffic lights pressed between October 2016 (BiH intervention introduced) and October 2017 (12 months post-intervention).

Graph B shows the number of tasks completed (blue) and not completed (pink) over the 12 month period.

4.4.3.4. Goal attainment.

Three goals were set at baseline with the help of Daniel's wife, who was also his mentor[4]:

1. **Participant stated goal**: Manage fatigue better.

   SMART goal: Rest more during the week and complete at least 60% of BiH 'rest' tasks. Use traffic lights every day to monitor fatigue levels.
2. **Participant stated goal**: Structure day better and do more household tasks.

   SMART goal: Use BiH to structure day better and set reminders for resting and household tasks. Complete at least 70% of all tasks on BiH diary.
3. **Participant stated goal:** Do more cycling for himself.

   SMART goal: Add a reminder to BiH to go cycling once each week as some time out for himself and make sure he has a rest after this. Use traffic light to monitor fatigue

Daniel only achieved one of his goals set at baseline and partially achieved two of his goals (Table 4-11). The attainment of two goals was measured using BiH data collected from the app, concluding that Daniel did not complete as many tasks as expected during the study period. His GAS-Light score increased more in the first 6 months and there was a slight increase in the final 6 months.

[4] Each participant was asked to nominate a mentor to support them in their use of BiH throughout the study. This could be a family member, carer, therapist etc. The mentor had access to the online BiH portal (explained in Chapter 1) and received an email or text alert when the participant pressed a red traffic light.

Table 4-10 Goal attainment for Case 2 over 12 months.

Goal	0-6 months	6-12 months	Total 12 months
1	No – partially achieved. Only completed 35.5% of 'rest' tasks in the first six months but stated that he had started ignoring them and was feeling worse. He was using the traffic lights Partially achieved the goal.	No – partially achieved. Only completed 24.4% of 'rest' tasks in the remaining six months. He was continuing to use the traffic lights to monitor his fatigue levels but not as much as expected.	No – partially achieved. Over the 12 months, he only completed 29.5% 'rest' tasks, however, did use the traffic lights to monitor fatigue levels for the majority of the study, He also recognised that not following the 'rest' reminders led to higher fatigue levels.
2	No – partially achieved. Used BiH to structure his day better and complete more household tasks in the day, however, he could not use the app for meal planning which was his main focus so less tasks achieved. Only 38.6% total BiH tasks achieved.	No – partially achieved. As with the first six months, he tried to use the app in different ways to structure day and although successful in some ways, he could not use it in others. As a result, only 22.8% tasks completed in the final six months. Clear gaps in app use during this period of time.	No – partially achieved. Only 32.7% tasks completed over the 12 month study period.
3	Yes – better than expected. Started cycling again and was going at least once each week usually on a Thursday. He added this to his BiH diary. Started running after school cycling club again. Stated that BiH was helping him organise and prepare for lessons.	Yes – as expected. Continued cycling once a week and helping with cycling club when he had time. He used BiH to monitor his fatigue levels but could have used it more to plan rests after cycling.	Yes – slightly better than expected. Managed to achieve his goal to return to cycling over the 12 months and also helped out with the school cycling club, using BiH to plan lessons.
GAS-Light score (baseline = 37.1)	+37.6	+1.8	+39.4

4.4.3.5. Qualitative data.

The interview at six months post-intervention was conducted via telephone. Daniel talked about his experience of BiH and the barriers he faced, specifically the inability to use the app for meal planning in the way he wanted. He also talked about the benefits of BiH and how the traffic lights had helped him become more aware of his fatigue. The analysis of qualitative data obtained from case 2 identified the main emerging themes as barriers and facilitators linked to motivation, opportunity, support and capability. Figure 4-11 summarises the findings from the interview with Daniel.

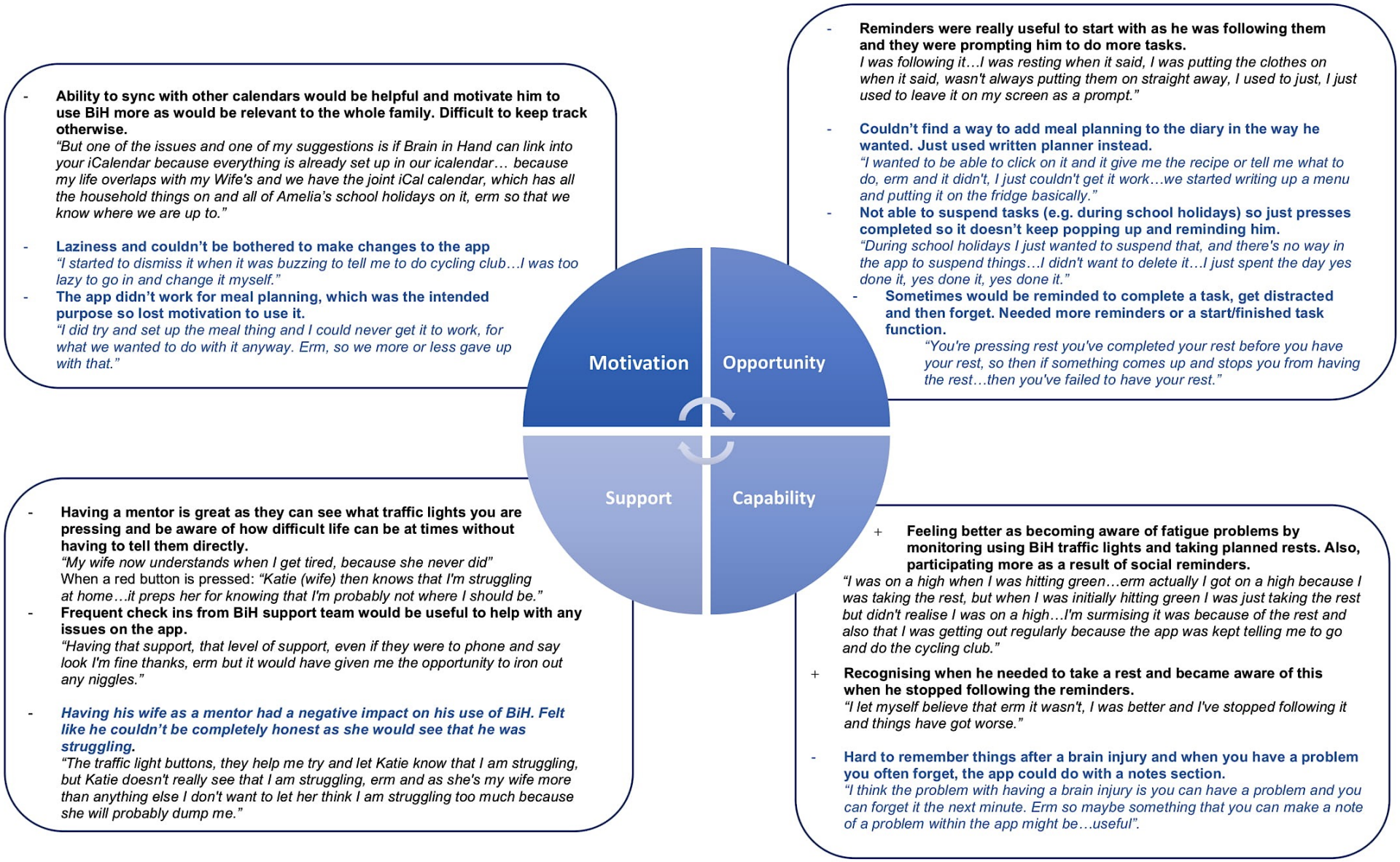


Figure 4-11 Summary of the qualitative findings from the Case 2 interview.

4.4.4. Case 3.

The results from case 3 (Hannah) are presented in this section. She completed all questionnaires and the interview at six months post-intervention.

4.4.4.1. Pen portrait.

Hannah was a 24-year-old woman who had a TBI in 2015 (12-18 months post-injury when recruited). She was in the final year of a university degree at the time of injury and was hoping to return to finish her degree. Hannah lived at home with her parents who were very supportive. She was receiving various types of rehabilitation throughout the study: occupational therapy, physiotherapy, and speech and language therapy. Hannah and her family were very proactive and liked to be involved in research. She was a happy, positive individual, who seemed motivated to achieve goals, but often experienced anxiety and fatigue. Hannah struggled to concentrate for long periods of time and prioritise tasks when she was feeling tired. She experienced some mobility issues and needed help when travelling on public transport. Hannah volunteered at least once a week and liked to leave the house every day. Her main goals were to manage fatigue better and have more frequent rests, take medication consistently and a long-term goal to return to university. Hannah was using her smartphone for reminders before starting the study. (See appendix 17 for summary).

4.4.4.2. Clinical outcome measures.

There was improvement in some clinical measures over 12 months (Table 4-6). Initially, BiH appeared to have a positive effect on Hannah's anxiety levels (HADS; Figure 4-12), which decreased after two weeks of using the app, however this then increased after four weeks. After four weeks of using BiH, her depression score decreased. As Hannah's anxiety score decreased, her NEADL score increased from

13 to 18 showing an initial positive effect on ADL and functional outcomes (Figure 4-13). However, as her anxiety score increased again, her NEADL score decreased. Over the first six months, the NEADL and HADS anxiety scores follow a similar pattern; as one improved the other did. Between six and 12 months, Hannah's anxiety score decreased slightly and her NEADL score decreased. Her depression level remained the same over the final six months of the study.

At six months (table 4-6), there was an increase in participation (increase in CIQ score), a decrease in fatigue levels (decrease in FAS), and an improvement in cognition (decrease in MSNQ score from 33 to 27). There was a small decrease in quality of life between baseline and six months, measured by the EQ5D-5L index (0.592 to 0.548).

At 12 months, there was a slight decline in cognition shown by an increase in MSNQ score from six months, however there was an overall improvement from baseline. There was an increase in fatigue levels at 12 months compared to the six-month measure and an overall increase from baseline. There was a further increase in participation shown by a higher CIQ score and an increase in participation from baseline. A small increase in quality of life was observed between baseline and 12 months (increased EQ5D-5L index from 0.592 to 0.62). Overall, there was an improvement in cognition, participation and quality of life at 12 months post-intervention.

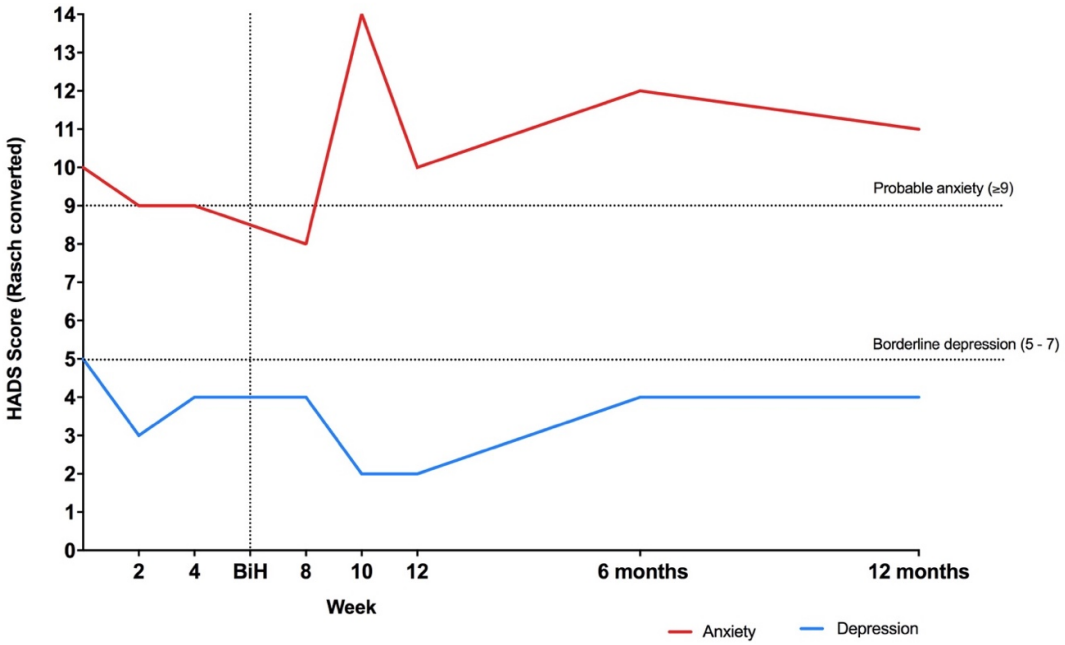


Figure 4-12 Case 3 HADS (Rasch converted) scores over 12 months.

Blue (depression) and red (anxiety) lines represent the HADS scores over the 12 month study period, showing the initial 12 week fortnightly measures. The vertical dotted line indicates the time BiH was introduced. The horizontal dotted lines indicate the clinical cut off for borderline depression (Rasch converted HADS depression score 5-7) and probable anxiety (Rasch converted HADS anxiety score greater than or equal to 9).

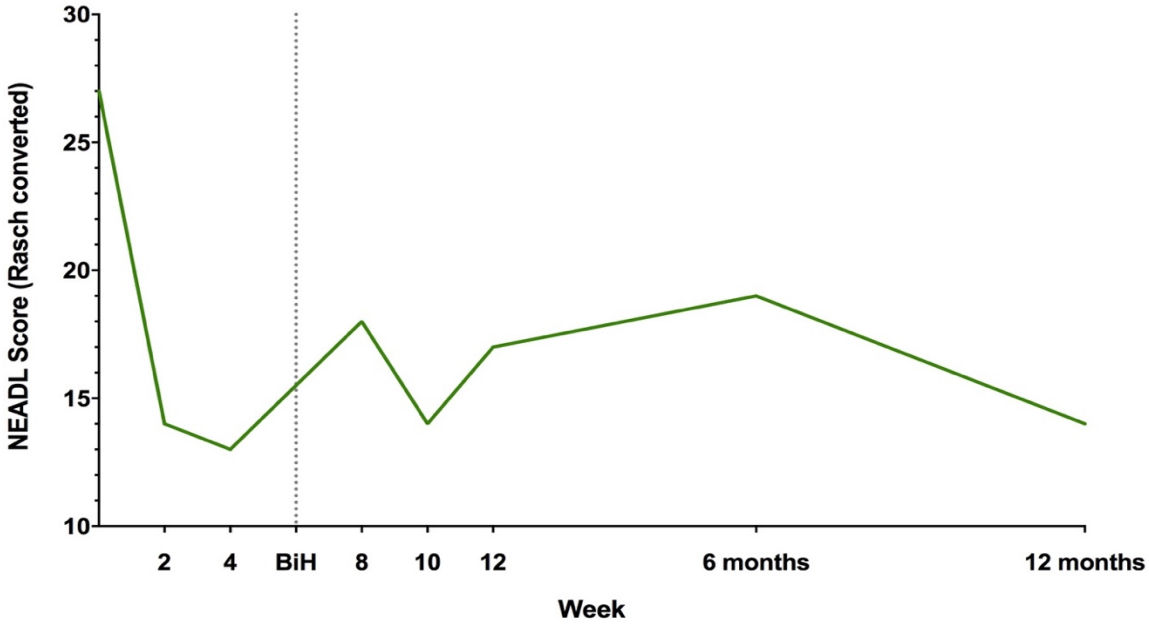


Figure 4-13 Case 3 NEADL (Rasch converted) scores over 12 months.

The green line represents the NEADL scores over the 12 month study period, showing the initial 12 week fortnightly measures. The dotted line indicates the time BiH was introduced.

4.4.4.3. Brain-in-Hand data.

Hannah was frequently using the BiH traffic light system to monitor her fatigue levels and for daily reminders (table 4-11). Hannah pressed a similar amount of green (n=886) and amber traffic lights (n=745) over 12 months, and rarely pressed red (n=10). The number of the green traffic lights was similar during the first and final six months, however, there seemed to be an improvement in the final six months as she pressed 86 more green buttons, and six fewer red buttons. She was using the traffic lights to monitor her fatigue levels. It appears that this was working well for Hannah and she was using this function of the app consistently.

Table 4-11 Case 3 data over 12 month period exported from the BiH app.

		First 6 months	**Last 6 months**	**Total**
Traffic lights (fatigue)	**Green**	400	486	886
	Amber	372	373	745
	Red	8	2	10
Tasks Complete (% total tasks)		685 (68.2%)	635 (53.8%)	1320 (60.4%)
Tasks Incomplete		319	546	865
Total tasks		1004	1181	2185
Completed 'Medication' reminders (total medication reminders, % total)		182 (214, 85.0%)	232 (256, 90.6%)	414 (470, 88.1%)
Completed 'exercises' reminders (total exercises reminders, % total)		120 (209, 57.4%)	80 (182, 44.0%)	200 (391, 51.2%)
Solutions Used		0	1	1

Hannah was also using BiH as a reminding tool and a way to take control of her daily life, so she could rely less on her parents. A number of important reminders were added to the BiH diary such as 'take medication,' 'do speech therapy exercises,' 'do physiotherapy exercises,' along with tasks that would encourage independence, such as cooking for herself and buying ingredients for a meal.

Hannah was keen to self-manage and fill her day with more activities. She completed a large number of tasks over the 12-month period, equating to 60.4% total tasks (table 4-11).

Hannah's main focus was to cook more for herself, so a number of these types of tasks and reminders were added to the BiH diary. Initially, this included a few cooking sessions with a therapy assistant, so that she could regain confidence in the kitchen. Hannah only added cooking tasks/reminders in the first six months, as it became part of daily routine in the final six months. In total, 19/67 cooking tasks were completed on the app, which is only 28.4% total tasks. Hannah used one solution during the 12 months.

Hannah's use of the traffic lights is shown in Figure 4-14A. There was an increase in amber traffic lights around three months post-intervention. The number of green and amber traffic lights remained quite consistent over the next six months and there was an increase in green traffic lights between August and September 2017 (10 months post-intervention). There is an increase in completed tasks at various time points, as shown in Figure 4-14B. Hannah appeared to be competing more tasks in the two months, which was shortly followed by a burst in amber traffic lights in January 2017. There does not appear to be a relationship between increased fatigue and number of incomplete tasks.

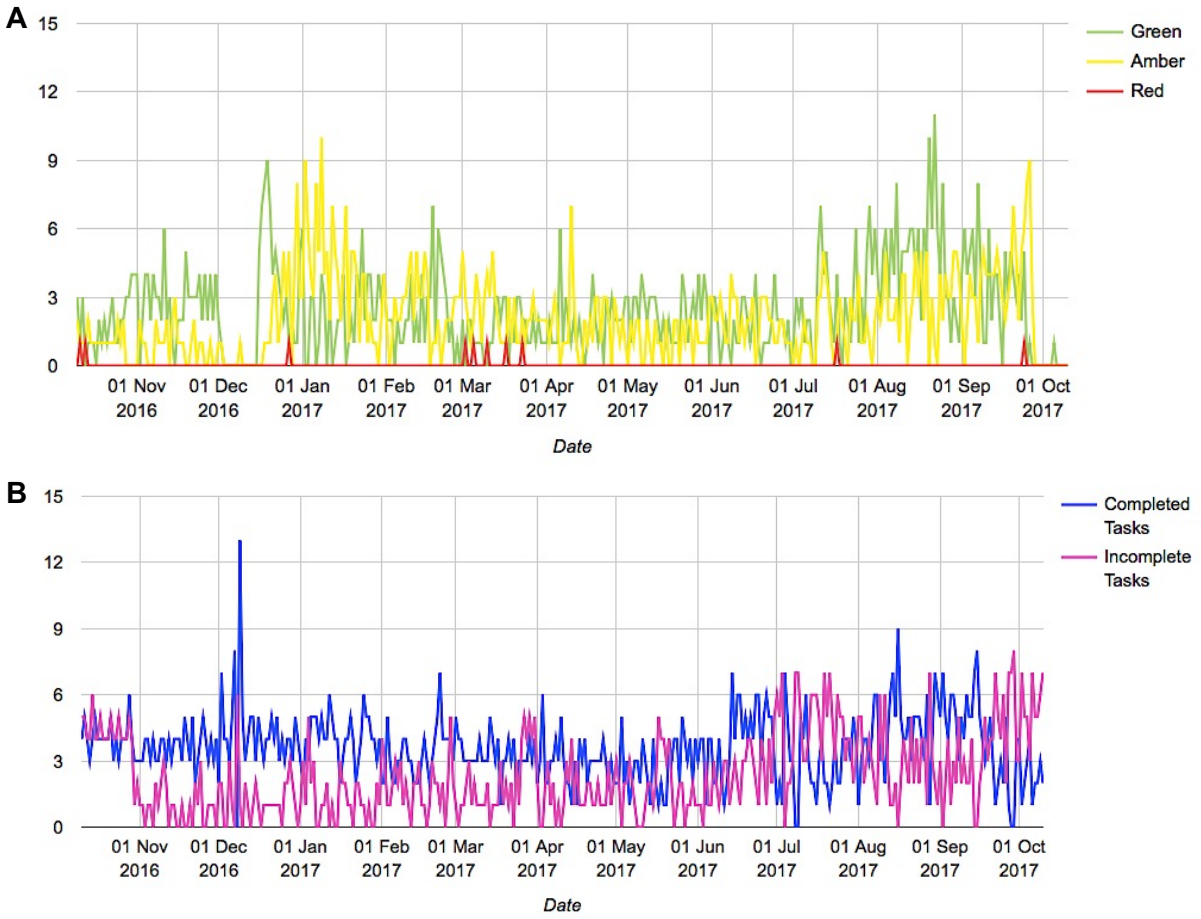


Figure 4-14 Case 3 data exported from the Brain in Hand cloud.

Graph A shows the total number and colour of traffic lights pressed between October 2016 (BiH intervention introduced) and October 2017 (12 months post-intervention).

Graph B shows the number of tasks completed (blue) and not completed (pink) over the 12 month period.

4.4.4.4. Goal attainment.

Three goals were set at baseline with the help of her OT:

1. **Participant stated goal**: Return to university.

   SMART goal: Return to university within 12 months and use BiH to start practicing study time, learn to plan ahead and pace herself as necessary.
2. **Participant stated goal**: Complete core stability exercises every day.

   SMART goal: Use the BiH diary to remind her to do her core stability exercises every day. Do at least five days out of seven, so around 70% should be completed.
3. **Participant stated goal**: Take medication at the correct time each day.

   SMART goal: Use BiH to remind her to take medication every day, specifically the 2pm dose, and monitor this use the app. Should have completed at least 70% medication reminders over the study.
4. **Participant stated goal:** Cook more for herself.

   SMART goal: Cook for herself twice each week and use reminders to prompt her to do this.

Hannah achieved three of her four goals set at baseline and exceeded expectation in all cases (table 4-12). The attainment of these two goals was measured using the BiH app data. Her GAS-Light score increased greater over the 12 months, and more in the final 6 months.

Table 4-12 Goal attainment for Case 3 over 12 months.

Goal	0-6 months	6-12 months	Total 12 months
1	No – partially achieved Over the six months, she had contacted the university and started the process of her returning to complete her third year in October 2017. We made a plan to add reminders to the BiH diary to prepare her for the return to university life.	Yes Hannah was returning to university the week after her final assessment and was confident she would be able to manage the work load and her fatigue. She had been practicing pacing herself with BiH over the past six months.	Yes Hannah returned to university as planned when the study period ended and used BiH to help with preparation.
2	No – partially achieved. Only completed 57.4% of 'exercise' tasks in the first six months but stated that she was trying to complete them daily. Partially achieved the goal.	No – partially achieved. Only completed 44.0% of 'exercise' tasks in the final six months. She stated that she was still trying to complete them daily but was prioritising her university preparation and often felt too tired.	No – partially achieved. Only completed 51.2% of 'exercise' tasks in the 12 months.
3	Yes Completed 85% of 'medication' tasks in the first six months.	Yes Completed 90.6% of 'medication' tasks in the final six months.	Yes Completed 88.1% of 'medication' tasks over the 12 months.
4	Yes Hannah was keeping track of the amount of times she was cooking each week and stated that she was cooking lunch at least twice each week. She had started going to the supermarket with her mum to buy ingredients.	Yes Hannah continued to cook for herself over the next six months, and more so in preparation for living alone at university. She was now cooking for the family at the weekends and shopping for ingredients herself.	Yes Hannah achieved her goal to cook more for herself and was really pleased that she had stuck to this over the 12 months. She was frequently cooking in the week and used BiH to motivate herself.
GAS -Light score (baseline= 36.2)	+18.0	+34.9	+52.9

4.4.4.5. Qualitative data.

A face-to-face interview was conducted at six months post-intervention. She had a positive opinion about BiH and had enjoyed using the app. Hannah talked about some of the technical problems she faced while using BiH, but focused more on how it had helped her achieve goals. She talked about how the traffic light system had helped her manage fatigue better and used the traffic light idea within her BiH diary to assign a colour to tasks (i.e., a red task would be highly fatiguing, green task would require less mental/physical energy). The analysis of qualitative data obtained from case 3 identified the main emerging themes as barriers and facilitators linked to motivation, capability, support and technology. Figure 4-15 summarises the findings from the interview with Hannah.

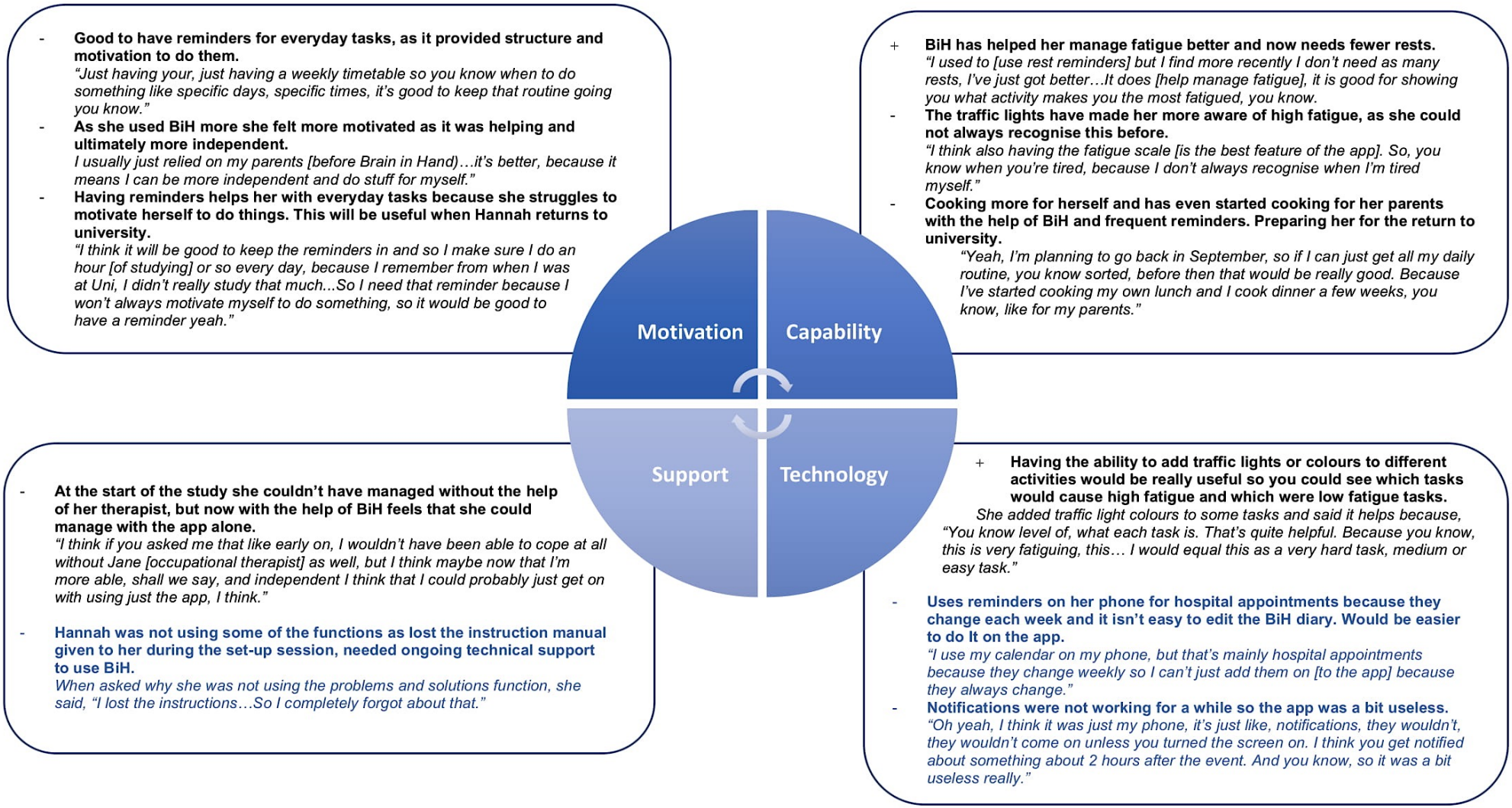


Figure 4-15 Summary of the qualitative findings from the Case 3 interview.

4.4.5. Case 4.

The results from case 4 (Peter) are presented in this section. He only completed the routine questionnaires (baseline to 12 weeks) and did not take part in the interview.

4.4.5.1. Pen portrait.

Peter was a 48-year-old man who had a TBI over 25 years ago (1990s) as a result of a motorbike accident. He did not receive any rehabilitation at the time of injury. Prior to recruitment, he had been receiving occupational therapy and neuropsychological therapy for around a year. He lived at home with his son and his Uncle regularly visited to care for him. His Uncle had control of his finances and helped him manage money, although Peter wanted to be more independent and regain this control. He took his son to and from work every day, which he enjoyed doing. He appeared to have a positive outlook on life and was happy to be taking part in some research. He had cognitive impairment, and often needed reminding to do tasks and attend appointments, something which caused problems at the hospital. He missed a few appointment that I arranged with him. He admitted he was not very organised and found it hard to structure his day. He was taking medication for epilepsy at the time of recruitment and experienced moderate levels of fatigue. He had borderline anxiety and depression. He did not like going out socially and did not have any hobbies. He was not in work at the time of recruitment, but wanted to find some voluntary work and was actively looking. One of his goals was to find voluntary work. His other goals were to use a brain training app at least 2-3 times per week and cook at least two meals per week. He was using a calendar on his phone at the time of recruitment to structure his day and remember appointments.

Unfortunately, Peter withdrew from the study prior to the six month assessment and interview (See appendix 18 for summary).

4.4.5.2. Clinical outcome measures.

Peter withdrew from the study before the six-month assessments and therefore no further data was collected. Overall, the data show improvement in some clinical measures over the 12-week period (table 4-6), although it is difficult to see any patterns in this short period of time. Initially, BiH appeared to have a negative effect on Peter's depression levels, as the HADS depression score increased after two weeks of using BiH, however it then decreased again to his baseline score (Figure 4-16). BiH appeared to have no effect on his NEADL score or anxiety score (Figure 4-17). Over the 12-week period, Peter's NEADL score improved, however this increase occurred prior to receiving BiH.

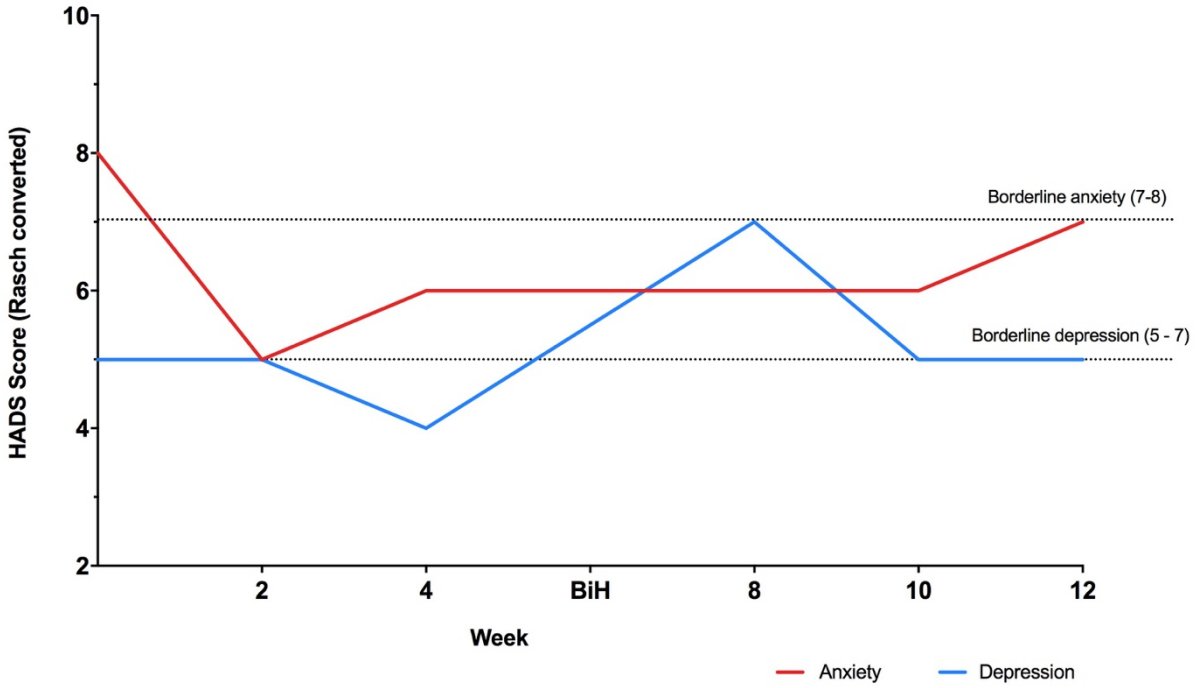


Figure 4-16 Case 4 HADS (Rasch converted) scores over 12 weeks.

Blue (depression) and red (anxiety) lines represent the HADS scores over the initial 12 week fortnightly measures. The vertical dotted line indicates the time BiH was introduced. The horizontal dotted lines indicate the clinical cut off for borderline depression (Rasch converted HADS depression score 5-7) and borderline anxiety (Rasch converted HADS anxiety score 7-8).

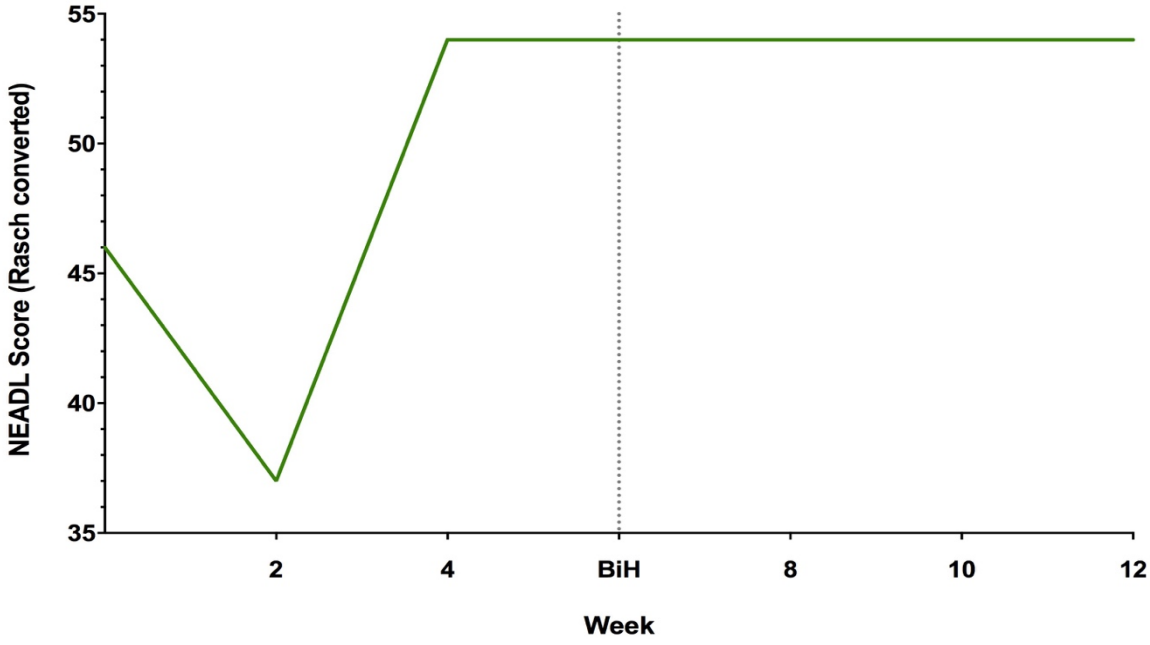


Figure 4-17 Case 4 NEADL (Rasch converted) scores over 12 weeks.

The green line represents the NEADL scores over the initial 12 week fortnightly measures. The dotted line indicates the time BiH was introduced.

4.4.6. Case 5.

The results from case 5 (Colin) are presented in this section. He completed all but one of the assessments (12 month questionnaires not returned) and the interview at six months post-intervention.

4.4.6.1. Pen portrait.

Colin was a 38-year-old man who had a TBI in 2015 (12-18 months post-injury at time of recruitment). He had a job as a support worker at the time of injury, but was unable to return to this role due to the nature of his work. Colin lived at home with his partner and daughter, and his mother lived nearby. He did not need a carer or support worker, but his mother regularly visited to help when needed and provide support. Colin was receiving rehabilitation at the time of recruitment, which included occupational therapy, specifically focusing on vocational rehabilitation. He was also receiving neuropsychological support. Colin was a friendly, but anxious individual and appeared to be struggling with accepting his injury at the time of recruitment. He had cognitive impairment and found it difficult to solve problems, needed to be reminded of tasks and appointments, and found it difficult to control impulses. Colin experienced fatigue. Colin found it difficult to go to bed at a normal time as a result of his fatigue, and struggled to manage the inconsistent amount of sleep he had each night. He was actively looking for work at baseline and a couple of months after recruitment, he returned to work as an occupational therapy assistant. He then went on to work in an office role within a rehabilitation team. Colin's main goals were to manage his fatigue better by taking more rests each day and monitor the time he goes to bed, to return to work and structure his day better. He was not using any assistive technology at the time of recruitment and relied on his partner to remember events or appointments. (See appendix 19 for summary).

4.4.6.2. Clinical outcome measures.

The data presented in table 4-6 shows improvement in some clinical measures over 12 months. BiH appeared to have a negative effect on Colin's depression levels (Figure 4-18), as his HADS score moved from the borderline range (5-7) at baseline, to the probable depression range by six months post-intervention (≥8). His depression levels decreased at 12 weeks (6 weeks post-intervention) and it seemed that BiH was having a positive effect on his mood, however this then increased again. Colin's anxiety levels remained the same for two weeks post-intervention. His HADS anxiety score then decreased at ten weeks and was consistent for the remainder of the study. However, his anxiety score was still in the 'probable anxiety' range. Following the introduction of BiH, his NEADL score decreased and remained the same for six weeks post-intervention, then increased slightly at six months (Figure 4-19). There was a bigger decrease in NEADL score from baseline to two weeks post-baseline (52 to 44), however there were only minor changes in scores after this point.

At six months, there was no change in fatigue levels (FAS score 32 throughout study) or participation (CIQ score 11 throughout study). There was a minor improvement in cognition at six months, shown by a decrease in MSNQ score from 48 to 45. Colin also scored worse on the EQ5D-5L measure at six months suggesting a decrease in quality of life (EQ5D-5L index score 0.549 at baseline to 0.478 at six months).

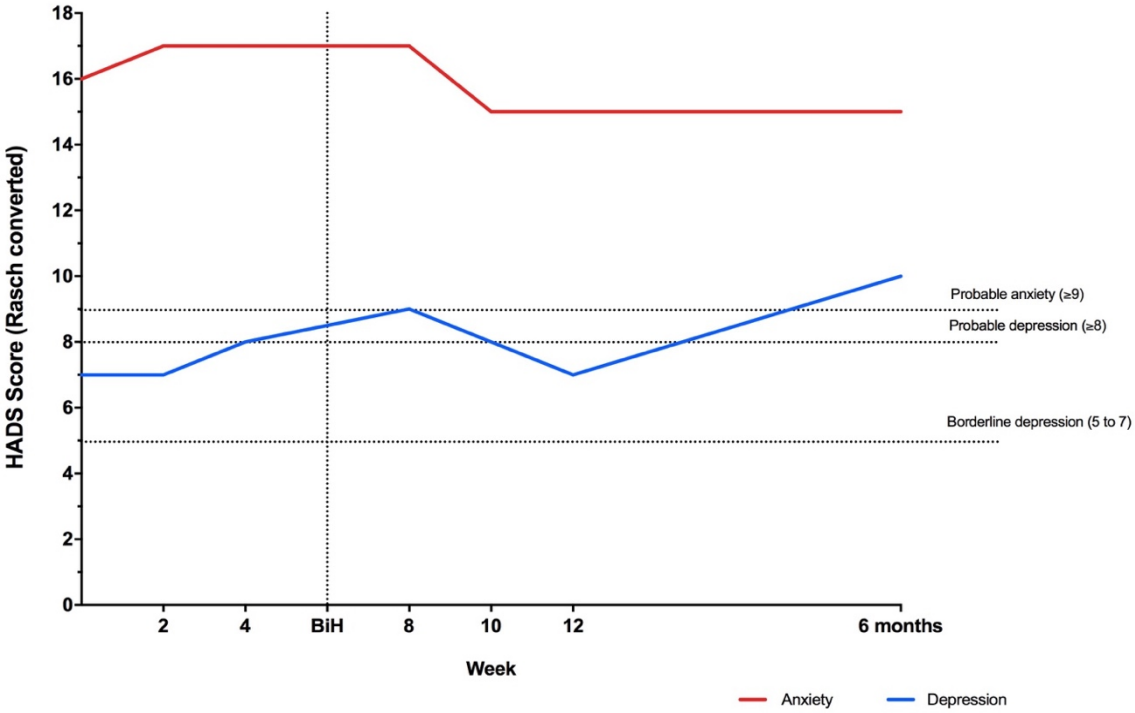


Figure 4-18 Case 5 HADS (Rasch converted) scores over six months.

Blue (depression) and red (anxiety) lines represent the HADS scores over the first six months, showing the initial 12 week fortnightly measures. The vertical dotted line indicates the time BiH was introduced. The horizontal dotted lines indicate the clinical cut off for borderline depression (Rasch converted HADS depression score 5-7) and probable depression (Rasch converted HADS depression score greater than or equal to 8), and probable anxiety (Rasch converted HADS anxiety score greater than or equal to 9).

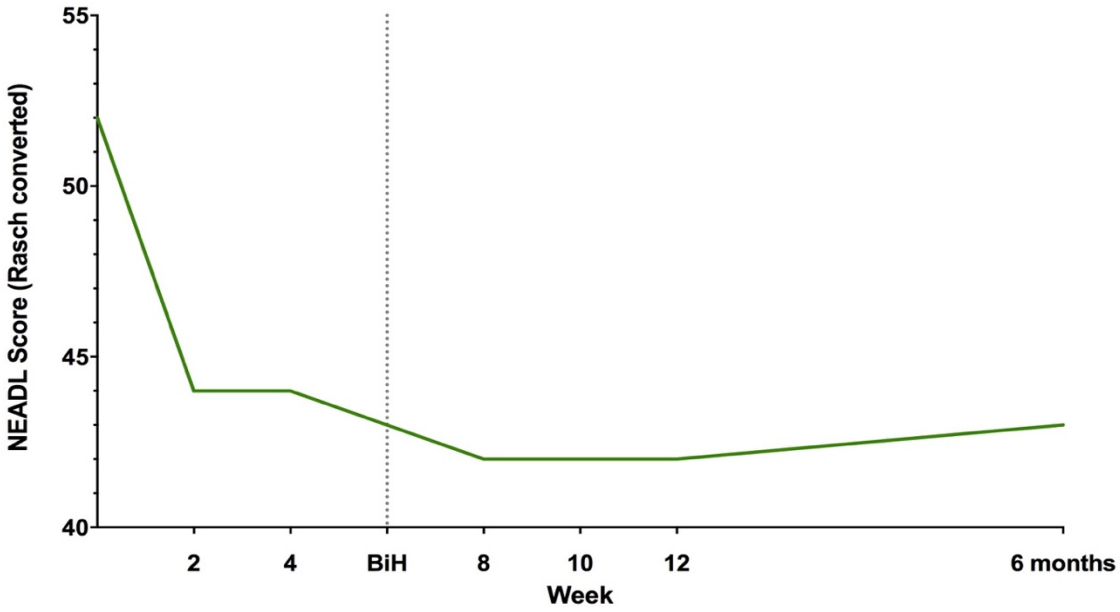


Figure 4-19 Case 5 NEADL (Rasch converted) scores over six months.

The green line represents the NEADL scores over the first six months, showing the initial 12 week fortnightly measures. The dotted line indicates the time BiH was introduced.

4.4.6.3. Brain-in-Hand data.

Colin was using the BiH traffic light system frequently to monitor his anxiety levels and for daily reminders (table 4-13). He pressed a lot of green traffic lights throughout the study (n=710), but most were in the first six months of use (n=540). He pressed fewer amber traffic lights than green overall (n=30); again most were recorded in the first six months (n=23). Colin pressed few red traffic lights in the first six months (n=15) and none in the last six months. The data shows that Colin was using the traffic lights more frequently during the first half of the study. However, there seemed to be an improvement in the final six months as he pressed no red buttons and only two amber buttons.

Table 4-13 Case 5 data over 12 month period exported from the BiH app.

		First 6 months	Last 6 months	Total
Traffic lights (anxiety)	**Green**	540	170	710
	Amber	28	2	30
	Red	15	0	15
Tasks Complete (% total tasks)		1030 (67.4%)	478 (38.1%)	1508 (54.2%)
Tasks Incomplete		499	775	1274
Total tasks		1529	1253	2782
Solutions Used		26	77	103

Colin wanted to use BiH to add more structure to his day, manage anxiety and bedtime routine better. Reminders were added to encourage Colin to use breathing exercises when he felt anxious, to take a moment to relax after his drive to work, and reminders to go to bed at an appropriate time and keep track of the previous night's bedtime. Colin completed a large number of tasks during the study (54.3%). BiH recorded more completed tasks over the first six months (67.4%) compared to the last six months (38.1%). Although, the decline in traffic light use suggests Colin was using BiH less during the final six months. Colin's 12 month assessment was not

returned, which may explain the lack of interest during the latter part of the study. Over 12 months, Colin used a number of solutions (n=103) and interestingly more of these were used in the final six months (n=77).

Colin's traffic light use was relatively consistent over ten months and then stopped around August 2017 (Figure 4-20A). There were a number of red traffic lights pressed early in the study which is shown on the graph between October and the middle of November 2016. There were small spikes in amber traffic light use, but nothing consistent. It is clear from the graph that there is a gradual decline in traffic light use after six months (April 2017). There is an increase in completed tasks at various time points, as shown in Figure 4-20B. Between months five and six, there was a clear increase in completed tasks and decrease in incomplete tasks. At this point, Colin was consistently pressing green traffic lights, which indicates that some reminders were helping him manage his anxiety levels better.

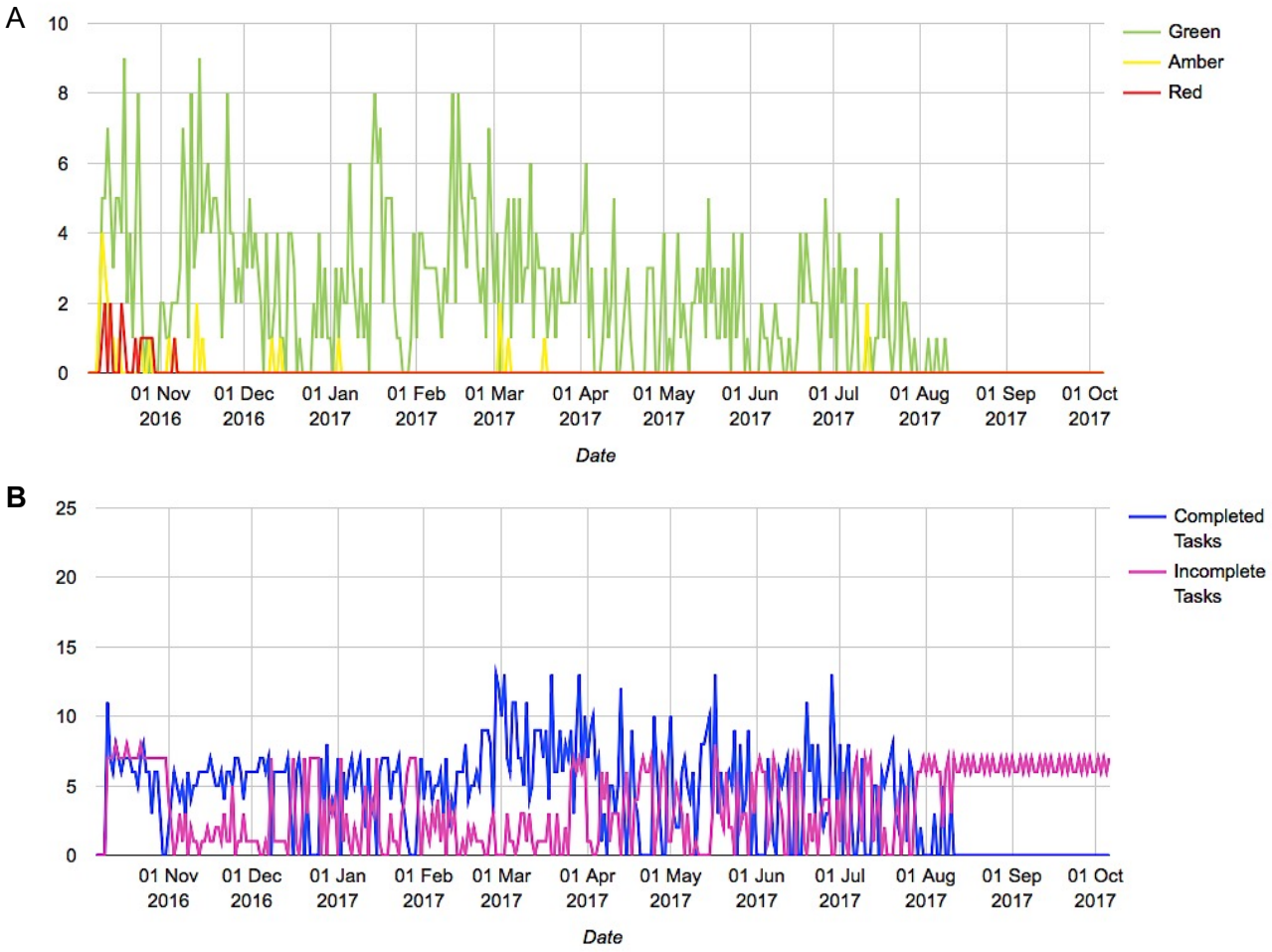


Figure 4-20 Case 5 data exported from the Brain in Hand cloud.

Graph A shows the total number and colour of traffic lights pressed between October 2016 (BiH intervention introduced) and October 2017 (12 months post-intervention).

Graph B shows the number of tasks completed (blue) and not completed (pink) over the 12 month period.

4.4.6.4. Goal attainment.

Three goals were set at baseline with the help of Colin's OT:

1. **Participant stated goal**: Manage fatigue and bedtime routine better. He wanted to start going to bed later.

   SMART goal: Use BiH to remind him to go to bed at the right time each night, this will be increased gradually over the first 12 weeks and maintained. Keep track of when he goes to bed using a solution the following morning, e.g. what time did you go to bed last night? On time, before reminder time, or after reminder time. Colin was aiming to be on time or later than reminder.
2. **Participant stated goal**: Return to work and manage anxiety when at work.

   SMART goal: Return to work and use BiH to monitor his anxiety levels when at work. The traffic lights should be used daily to help him recognise patterns of anxiety and use solutions to manage this. BiH should be used as a supportive tool at work and discussed with employer.
3. **Participant stated goal:** Structure day better and remember to do things.

   SMART goal: Use reminders on BiH for household tasks and provide more structure when he returns to work. Should have completed at least 60% tasks over the 12 month study period.

Colin achieved two of his three goals set at baseline and exceeded expectation in all cases (table 4-14). The attainment of these two goals was measured using the BiH app data. His GAS-Light score increased over the first 6 months.

Table 4-14 Goal attainment for Case 5 over 12 months.

Goal	0-6 months
1	Yes Managed to change the time he was going to sleep and waited for the 'go to bed' reminder to pop each night before he would allow himself to sleep. He was successfully using BiH to remind him to go to bed later each night.
2	Yes Returned to work within six months of receiving BiH. Using BiH at work to monitor anxiety levels and employer happy for him to take time out if he feels anxious. Successfully using BiH as a supportive tool when working, finds it very useful and an 'excuse' to leave if he needs space.
3	Yes Completed 67.4% of all tasks in the first six months.
GAS-Light score (baseline = 36.2)	+31.8

4.4.6.5. Qualitative data.

A face-to-face interview was conducted with Colin at six months post-intervention. He had a positive experience of using BiH and talked about how it had helped him accept his anxiety and improve self-management. He also talked about how the app has helped him at work. The analysis of qualitative data obtained from case 5 identified the main emerging themes as barriers and facilitators linked to motivation, opportunity, capability and technology. Figure 4-21 summarises the findings from Colin's interview.

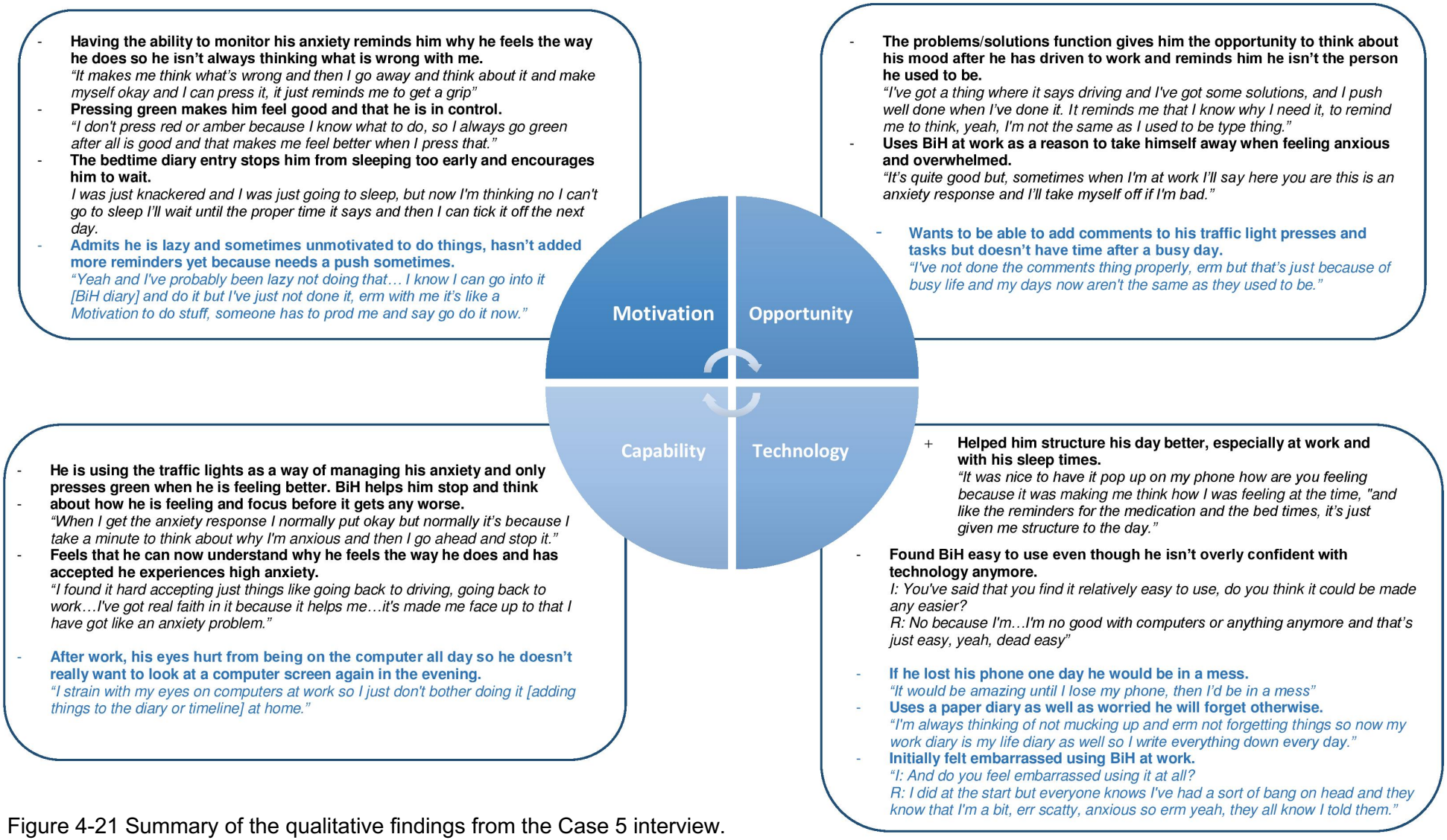


Figure 4-21 Summary of the qualitative findings from the Case 5 interview.

4.4.7. Case 6.

The results from case 6 (James) are presented in this section. He completed all questionnaires and the interview at six months post-intervention.

4.4.7.1. Pen portrait.

James was a 50-year-old male who had a TBI in 2014 (two years post-injury at that time of recruitment). He was a managing director of a company based overseas when he had his TBI and had to return home following injury, meaning he could not return to his previous job. James lived at home with his son and his other son lives nearby. He had a support worker who visited twice each week to help out with various tasks, such as paying bills and general help around the house. This support worker was introduced when James was five weeks post-consent. James was receiving rehabilitation at the time of recruitment, which included occupational therapy, physiotherapy and neuropsychological support. James was a friendly person who enjoyed having long conversations about his life before the injury. He appeared to be struggling with accepting his life post-TBI at baseline, which did not appear to improve during the 12 month study period. He had cognitive impairment and found it difficult to listen to others, frequently forgot to have meals and attend appointments, and talked excessively. James also experienced high fatigue, anxiety and depression. He was not looking for work and was not volunteering. James' main goals were to manage his fatigue better by taking more rests each day and use the traffic lights, and to structure his day better using the BiH diary. He was using a memo board (reusable whiteboard) at the time of recruitment to remember appointments and daily tasks (see appendix 20 for summary).

4.4.7.2. Clinical outcome measures.

The data show little improvement in clinical measures over the 12 month period (table 4-6). BiH appeared to have a positive effect on James' depression levels, as his HADS score decreased after receiving BiH, for four weeks (Figure 4-22). However, the score was still within the probable depression range (≥8). At six months post-intervention, his depression score decreased slightly, then dropped back down to the borderline level at 12 months post-intervention. James' anxiety levels followed a similar pattern and decreased after using BiH for four weeks, then increased after six weeks. His anxiety score remained in the 'probable anxiety' range. At six months post-intervention, James's anxiety score increased, then increased again at 12 months. Following the introduction of BiH, his NEADL score initially decreased (Figure 4-23). However, at six weeks post-intervention, this score increased greatly and exceeded his baseline score. At six months post-intervention, his NEADL decreased again to 19, which was his lowest score. At 12 months, the score increased again to 28, but was still lower than the pre-intervention score.

At six months, there was a slight decrease in fatigue levels (FAS decrease), an increase in participation score (CIQ) and an improvement in cognition (MSNQ decrease) (table 4-6). There was no change in quality of life between baseline and six months, measured by the EQ5D-5L index (0.32). At 12 months, there was a slight decline in cognition from the six-month measure, however there was an overall improvement from baseline (59 to 57). There was an increase in fatigue levels between six and 12 months. There was a decrease in participation. A great decrease in quality of life was observed at 12 months (EQ5D-5L index decrease from 0.32 to -0.016). Overall, there was a slight improvement in MSNQ scores CIQ scores at 12 months post-intervention, suggesting improvement in cognitive function and participation.

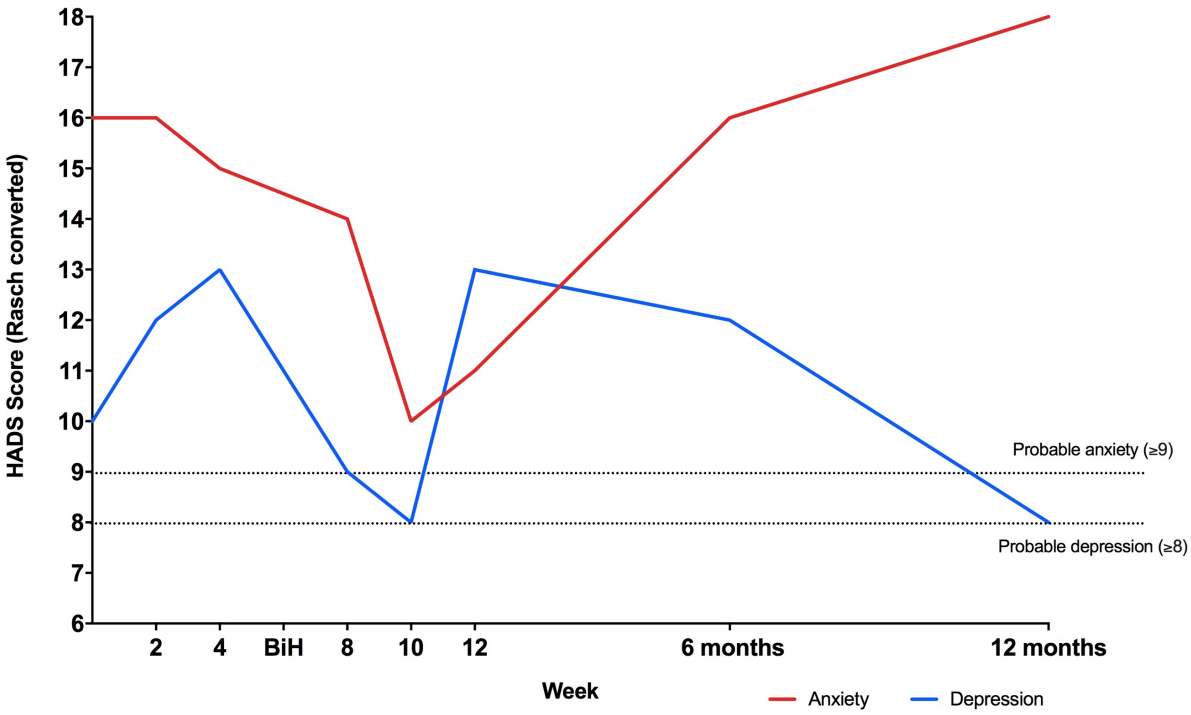


Figure 4-22 Case 6 HADS (Rasch converted) scores over 12 months.

Blue (depression) and red (anxiety) lines represent the HADS scores over the 12 month study period, showing the initial 12 week fortnightly measures. The vertical dotted line indicates the time BiH was introduced. The horizontal dotted lines indicate the clinical cut off for probable depression (Rasch converted HADS depression score greater than or equal to 8) and probable anxiety (Rasch converted HADS anxiety score greater than or equal to 9).

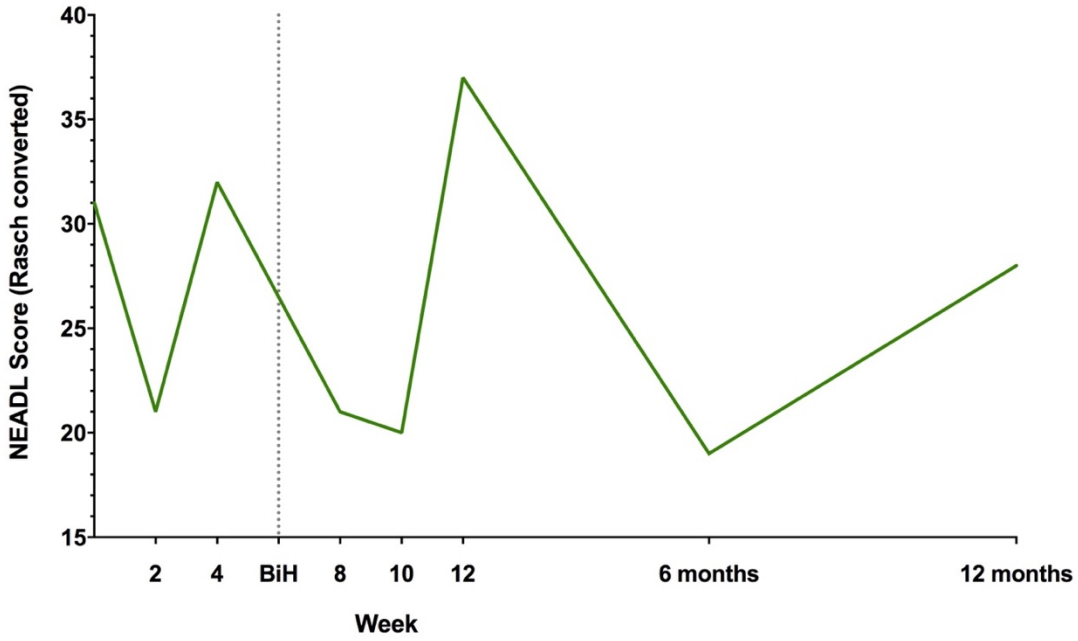


Figure 4-23 Case 6 NEADL (Rasch converted) scores over 12 months.

The green line represents the NEADL scores over the 12 month study period, showing the initial 12 week fortnightly measures. The dotted line indicates the time BiH was introduced.

4.4.7.3. Brain-in-Hand data.

Data collected from the app shows that James was not using the BiH traffic light system very often to monitor his fatigue levels or for daily reminders. Table 4-15 shows that James used the traffic lights in the first six months, however he did not press any traffic lights in the final six months. He pressed more amber buttons in the first six months of the study (n=51) than red (n=8) or green buttons (n=12).

Table 4-15 Case 6 data over 12 month period exported from the BiH app.

		First 6 months	Last 6 months	Total
Traffic lights (fatigue)	**Green**	12	0	12
	Amber	51	0	51
	Red	8	0	8
Tasks Complete (% total tasks)		98 (5.28%)	0 (0%)	98 (2.97%)
Tasks Incomplete		1757	1440	3197
Total tasks		1855	1440	3295
Completed 'Rest' tasks (total rest tasks, % total)		7 (182, 3.85%)	0 (182, 0%)	7 (364, 1.92%)
Solutions Used		0	0	0

James wanted to use BiH to remember to do more tasks, structure to his day better and manage fatigue levels. Reminders were added to encourage James to take planned rests, limit the amount of time he spent on the computer each day and remember to complete more tasks, attend appointments etc. He also planned to use the traffic lights frequently to monitor when he became highly fatigued. James used the traffic lights for the first six months of the study, however he did not use them at all during the final six months. In fact, he did not use the app at all in the final six months, as no tasks were completed during this time period. James only pressed 8 red buttons over the study period, he pressed more green traffic lights (n=12) and

the most amber traffic lights (n=51). All of these traffic light presses were recorded in the first six months of receiving BiH.

James did not complete many of the tasks that were added to his BiH diary. Few were recorded in the first six months, completing only 5.28% of all tasks (98/1855) and none were completed (0/1440) in the final six months of the study. One of the main goals for James' was to manage his fatigue better and take daily rests, therefore a 'rest' task was added to his diary. However, these were poorly completed and only 3.85% (7/182) was completed in the first six months (according to BiH data) and 0% was completed in the final six months. James did not use any solutions during the study period.

His use of the traffic lights is shown in Figure 4-24A, which was relatively sparse over the 12 months, with a peak in usage around the end of January, beginning of February 2017. At this point, James pressed a number of amber traffic lights, with a few spikes in red and green traffic light presses. There was also a small amount of usage at the beginning of the study in November 2016. Figure 4-24B shows an increase in completed tasks at the end of January and beginning of February 2017. At the beginning of November 2016, there was an increase in task completion. For the remainder of the study no completed tasks were recorded. As the lack of traffic light use and periods of incomplete tasks correspond, it suggests James was not using BiH at these points.

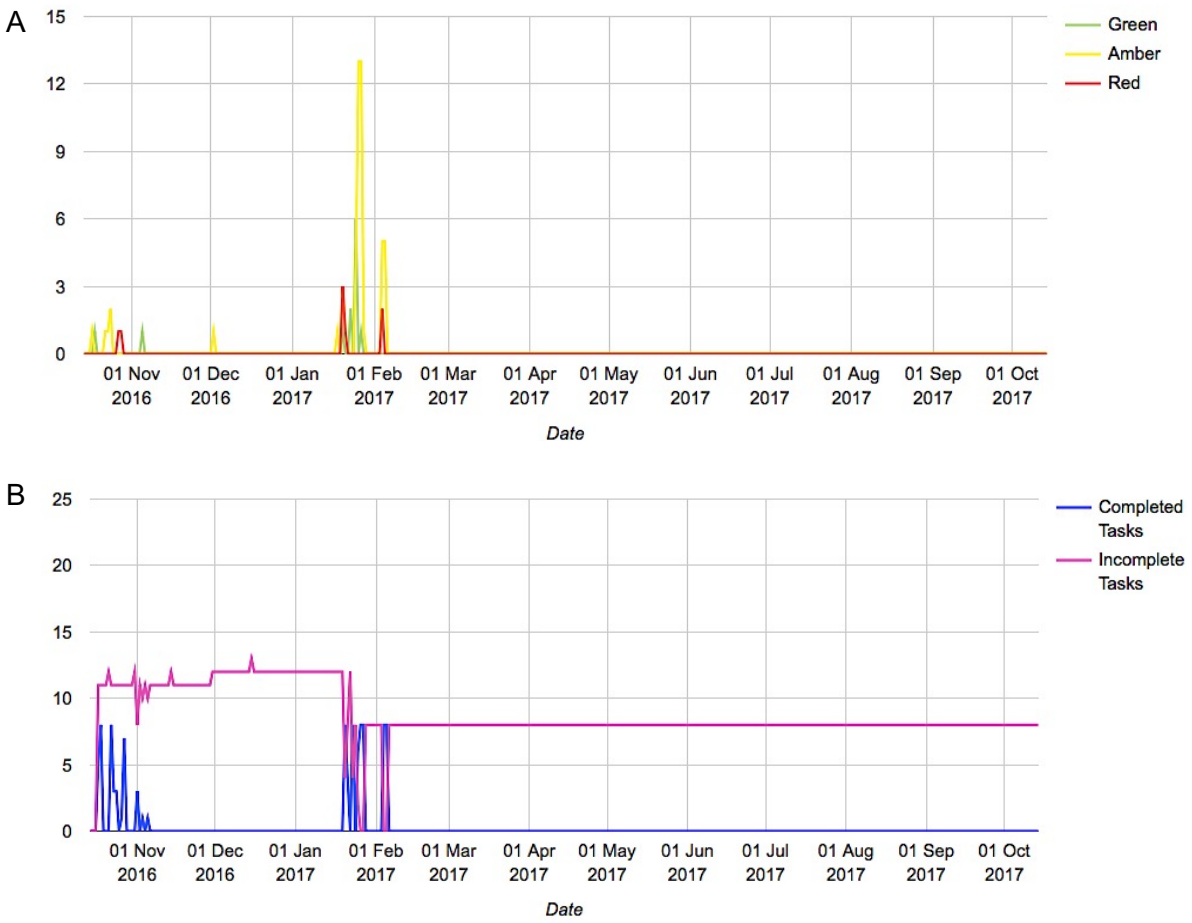


Figure 4-24 Case 6 data exported from the Brain in Hand cloud.

Graph A shows the total number and colour of traffic lights pressed between October 2016 (BiH intervention introduced) and October 2017 (12 months post-intervention).
Graph B shows the number of tasks completed (blue) and not completed (pink) over the 12 month period.

4.4.7.4. Goal attainment.

Two goals were set at baseline with the help of James' OT:

1. **Participant stated goal**: Manage fatigue better.

   SMART goal: Use BiH traffic lights frequently to monitor fatigue levels and follow diary reminders to take rests. His goal was to complete at least 50% rest tasks over the 12 month study period.

2. **Participant stated goal**: Structure day better and rely less on memo board.

   SMART goal: All of James' appointments and reminders were added to the BiH diary at set up. His aim was to rely less on his memo board (whiteboard on kitchen fridge) and use BiH for all reminders and planning. His goal was to complete at least 60% of all tasks on BiH diary.

James did not achieve either of the two goals set at baseline (table 4-16). The attainment of these goals was measured using the BiH app data. His GAS-Light score did not change in the first six months then decreased in the final six months.

Table 4-16 Goal attainment for Case 6 over 12 months.

Goal	0-6 months	6-12 months	Total 12 months
1	No Only completed 3.85% of 'rest' tasks in the first six months. He also stated that he had not been following these reminders when asked.	No Completed none of 'rest' tasks in the final six months. He stated that he had not been using BiH at all.	No He only completed 1.92% of 'rest' tasks over the 12 months and was not using BiH to remind him to rest throughout the day.
2	No Only completed 5.28% of all tasks in the first six months. He had not been using BiH to structure his day better. He had bought a different device with auditory commands and a 'talking' calendar, which he found more useful.	No Completed 0% of all tasks in the final six months. He was no longer using BiH as a reminding tool.	No Only completed 2.97% of all tasks during the study.
GAS-Light score (baseline = 37.7)	+0	-12.3	-12.3

4.4.7.5. Qualitative data.

A face-to-face interview was conducted with James at six months post-intervention. His support worker was present during the interview, however he did not require her support to answer questions. He did not have a positive experience of using BiH and talked about the technological barriers he had faced during the study. He also talked about the need for auditory commands and an alternative device he had found that could do this. The analysis of the qualitative data obtained from case 6 identified the main emerging themes as barriers and facilitators linked to motivation, opportunity, capability and technology. Figure 4-25 summarises the findings from the interview with James.

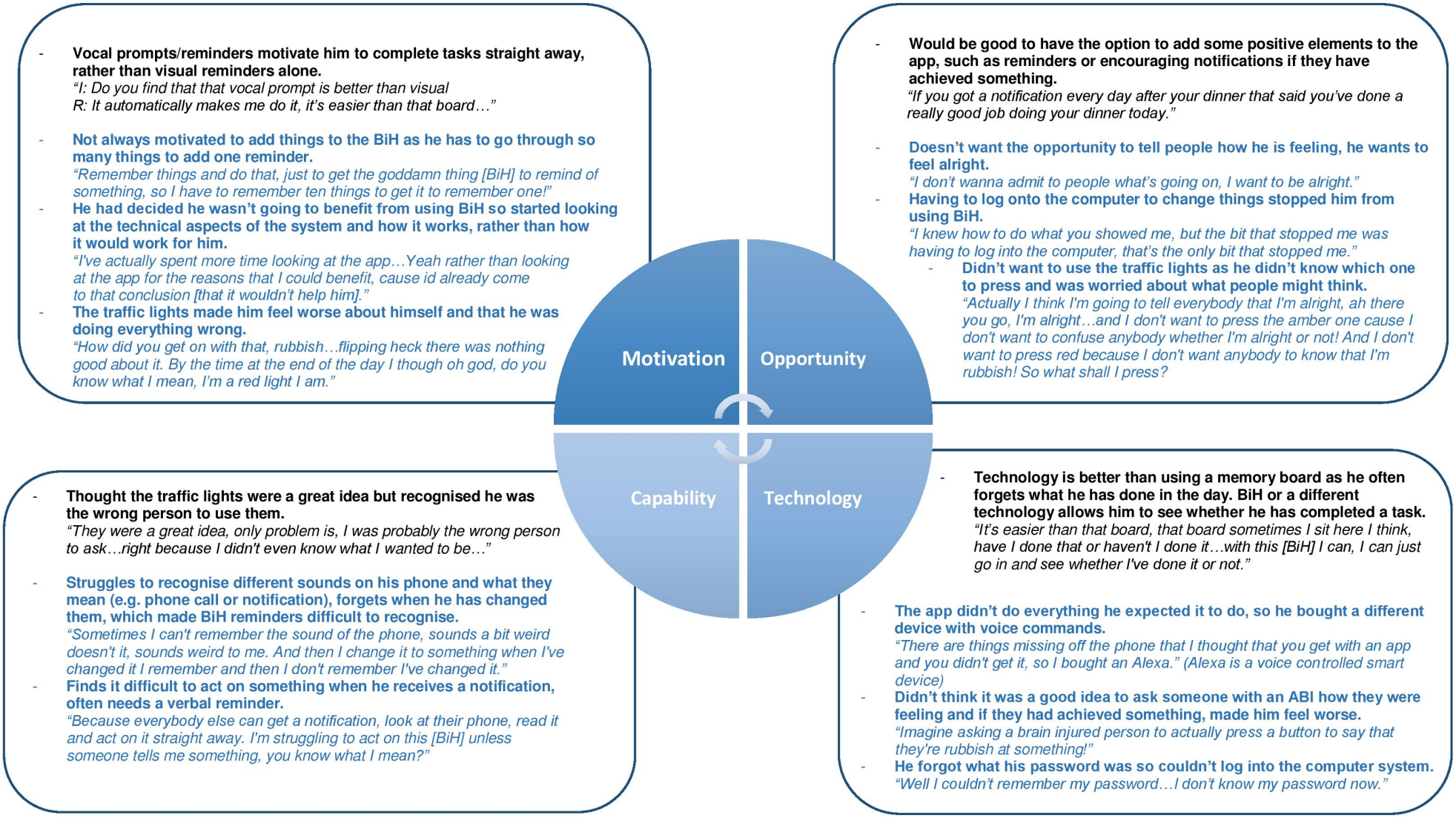


Figure 4-25 Summary of the qualitative findings from the Case 6 interview.

4.4.8. Case 7.

The results from case 7 (Steve) are presented in this section. He did not complete the six and 12 month assessments, but was interviewed at six months post-intervention.

4.4.8.1. Pen portrait.

Steve was a 32-year-old man who had a TBI in 2014 (18 months post-injury at time of recruitment). He was a construction worker when he had his brain injury, which happened while on his job. Steve was not in work at the time of recruitment but was hoping to find some voluntary work over the next 12 months. He lived alone, but had 24-hour care from various support workers who he got on well with, seeing them more as friends rather than HCPs. Steve was receiving rehabilitation at the time of recruitment, which was initially from a community rehabilitation team (occupational therapy, neuropsychological therapy), but this was moved to a private case management company half way through the study, around four months post-intervention. Steve had cognitive impairment. He was often easily distracted, found it hard to listen to people and forgot appointments, however his impairment did not disrupt his life. He did not experience anxiety or depression, with a moderate level of fatigue, but this was linked to his bedtime management. One of Steve's goals was to go to bed at a normal time each night, as he would often lose track of time and fall asleep on the sofa watching films. Steve was a happy, positive individual with a good sense of humour. He liked socialising, playing the guitar and going to pottery classes each week. He was also planning on returning to college. Another one of Steve's goals was to be more independent by remembering tasks and appointments using the BiH diary, rather than relying on his support workers. (See appendix 21 for summary).

4.4.8.2. Clinical outcomes measures.

The quantitative data collected from case 7 at baseline is presented in Table 4-6. As the questionnaires were not returned at six months and Steve subsequently withdrew from the study, no comparison can be made between the different time points.

The intervention appeared to have a minor effect on Steve's anxiety levels. His HADS anxiety score remained the same after receiving BiH, then dropped at six weeks post-intervention) showing a small improvement (Figure 4-26). His depression levels decreased slightly after receiving BiH. Steve's anxiety and depression scores remained within the clinically normal range throughout the study and there was a minor decrease from the baseline scores for both measures.

Following the introduction of BiH, Steve's NEADL score increased from 31 to 37 (at two weeks post-intervention), then continued to increase (Figure 4-27). Although his NEADL score at six weeks post-intervention did not exceed his baseline measure of 47, there was a clear improvement in pre-intervention scores.

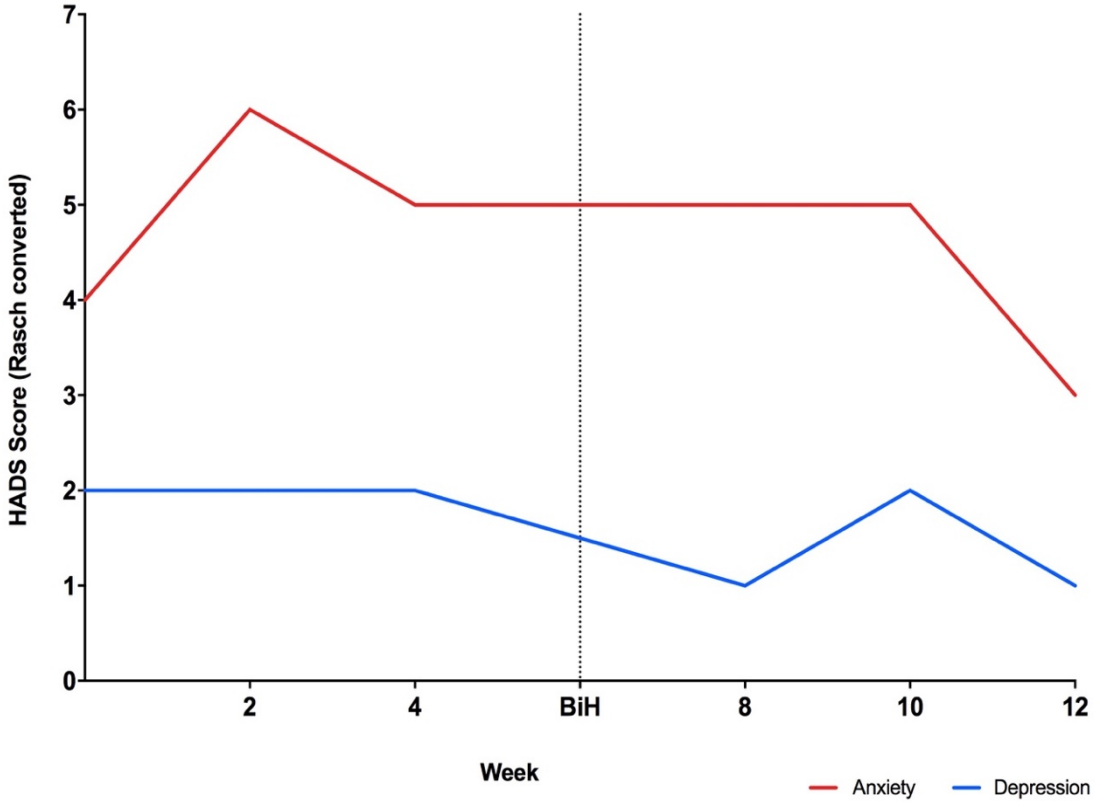


Figure 4-26 Case 7 HADS (Rasch converted) scores over 12 weeks.

Blue (depression) and red (anxiety) lines represent the HADS scores over the initial 12 week fortnightly measures. The dotted line indicates the time BiH was introduced.

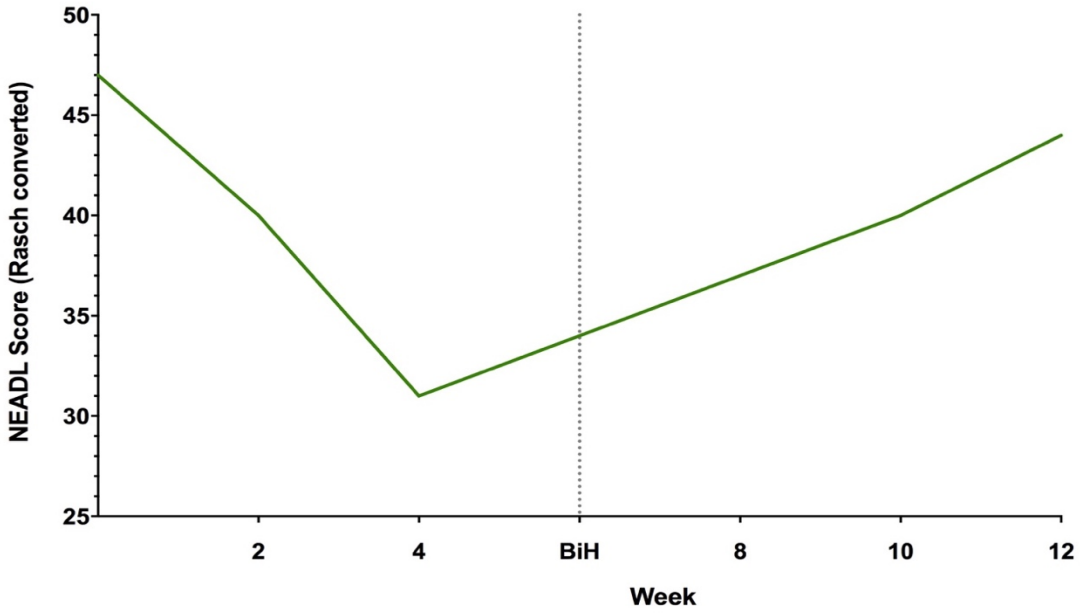


Figure 4-27 Case 7 NEADL (Rasch converted) scores over 12 weeks.

The green line represents the NEADL scores over the initial 12 week fortnightly measures. The dotted line indicates the time BiH was introduced.

4.4.8.3. Brain-in-Hand data

Data collected from the app shows that Steve was not using the BiH traffic light system very often and did not complete many tasks over the six months (table 4-17). As Steve withdrew from the study around six months post-intervention, only data up to this point is shown. He pressed very few red (n=2) and amber (n=1) traffic lights in the six months, however he pressed a lot more green (n=506) traffic lights during this period. This suggests his fatigue levels were being managed better.

Table 4-17 Case 7 data over 6 month period exported from the BiH app.

		First 6 months
Traffic lights (fatigue)	**Green**	506
	Amber	1
	Red	2
Tasks Complete (% total tasks)		576 (60.7%)
Tasks Incomplete		373
Total tasks		949
Completed 'prepare for bed' tasks (total tasks,%)		4 (159, 2.52%)
Solutions Used		237

Steve wanted to use BiH to structure his day better, become more independent and rely less on his carers to remember appointments/plans. He also wanted to manage his sleeping patterns better. Reminders were added to encourage Steve to go to bed at a consistent time each night and make plans each day, therefore taking control of his daily routine. He also planned to use the traffic lights frequently to monitor his fatigue levels. Out of the 949 tasks added to his BiH diary, Steve completed 60.7% of these in six months. However, he only completed 2.52% of his 'prepare for bed' tasks. He used 237 solutions, which were mainly used to decide what evening activity to do and take control of planning.

His use of the traffic lights is shown in Figure 4-28A, which was relatively consistent over the first six months, up until he withdrew from the study. There is a peak in green traffic light presses around the beginning to middle of March 2017. This concurs with the discontinued use of BiH following his six month interview. Figure 4-28B shows a consistent level of completed tasks between November 2016 and beginning of March 2017. At the beginning of May 2017, there was a decrease in task completion. As expected, there were no completed tasks recorded after six months of using BiH as Steve was no longer taking part in the study.

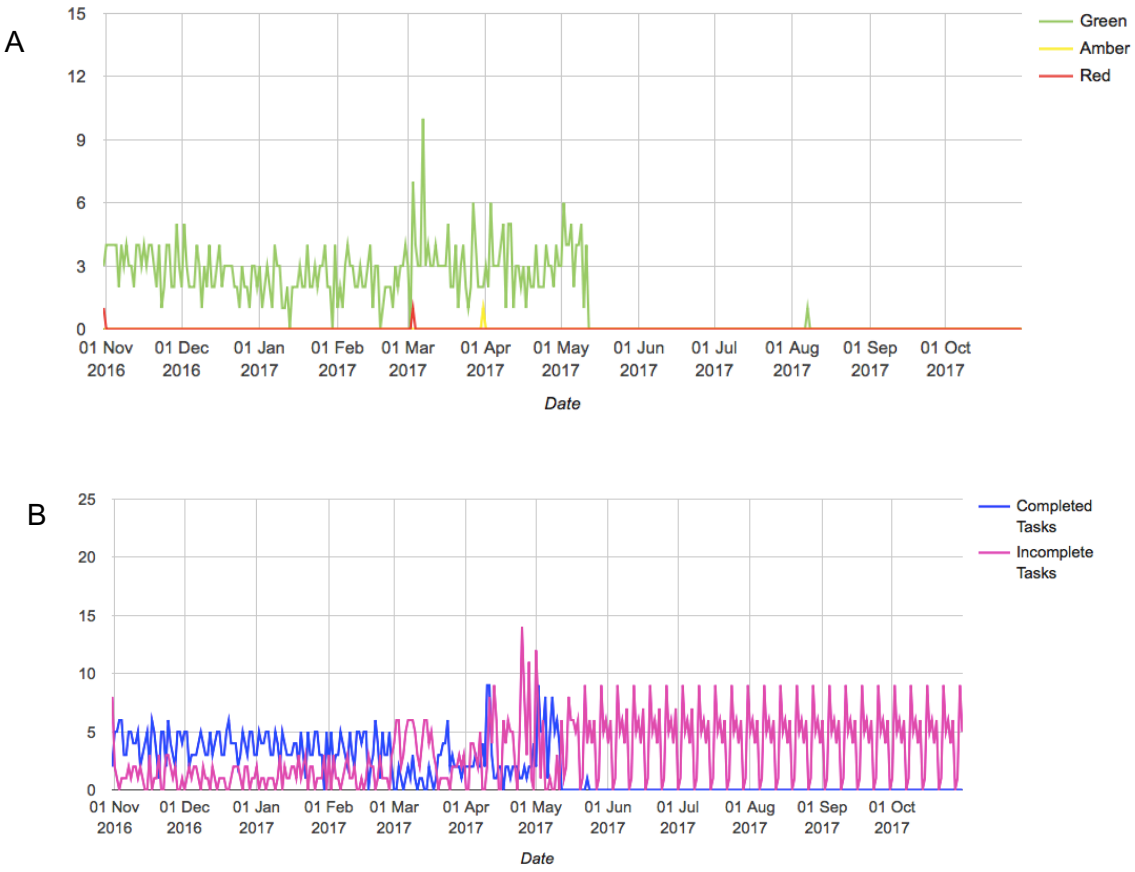


Figure 4-28 Case 7 data exported from the Brain-in-Hand cloud.

Graph A shows the total number and colour of traffic lights pressed between November 2016 (BiH intervention introduced) and November 2017 (12 months post-intervention). This participant withdrew from the study at six months post-intervention, but his account remained active for the 12 month study period.

Graph B shows the number of tasks completed (blue) and not completed (pink) over the six months he was enrolled in the study.

4.4.8.4. Goal attainment.

Two goals were set at baseline with the help of Steve's OT:

1. **Participant stated goal**: Manage bedtime routine better.

   SMART goal: Use BiH traffic lights to remind himself to go to bed at a normal time each night and monitor fatigue levels using the traffic lights. His goal was to complete at least 50% 'prepare for bed' tasks over the study period.

2. **Participant stated goal**: Take control of daily routine and remember appointments.

   SMART goal: Be more independent and rely less on support workers by adding all appointments and important daily tasks to BiH diary. His goal was to complete at least 60% of all tasks on BiH diary.

Steve achieved both goals set at baseline (table 4-18). The attainment of these goals was measured using the BiH app data and confirmed by support workers. His GAS-Light score increased over six months.

Table 4-18 Goal attainment for Case 7 over six months.

Goal	0-6 months
1	Yes Only completed 2.52% of 'prepare for bed' tasks as recorded by the BiH app. However, he stated that he was using the reminders and had started going to bed at a normal time. This was confirmed by his support workers and he was going to bed on time around 4 times per week (over 50%).
2	Yes Steve completed 60.7% of all tasks on his BiH diary, which meets the goal of 60% set at baseline. His support workers confirmed that he had been completing tasks and relying less on them for support during the day.
GAS-Light score (baseline = 38.0)	+20.1

4.4.8.5. Qualitative data.

Although the six month assessment was not returned by Steve, he still took part in a face-to-face interview. He had a relatively positive experience of using BiH, however he talked about some the technological barriers and frustrations he had faced during the study. Unfortunately, due to persistent technical problems, Steve withdrew from the study at six months post-intervention. This was recommended by his case management team who wanted to move forward with his rehabilitation (i.e., focus on new goals and strategies). The analysis of the qualitative data obtained from case 7 identified the main emerging themes as barriers and facilitators linked to motivation, opportunity, support and technology. Figure 4-29 summarises the findings from the interview with Steve.

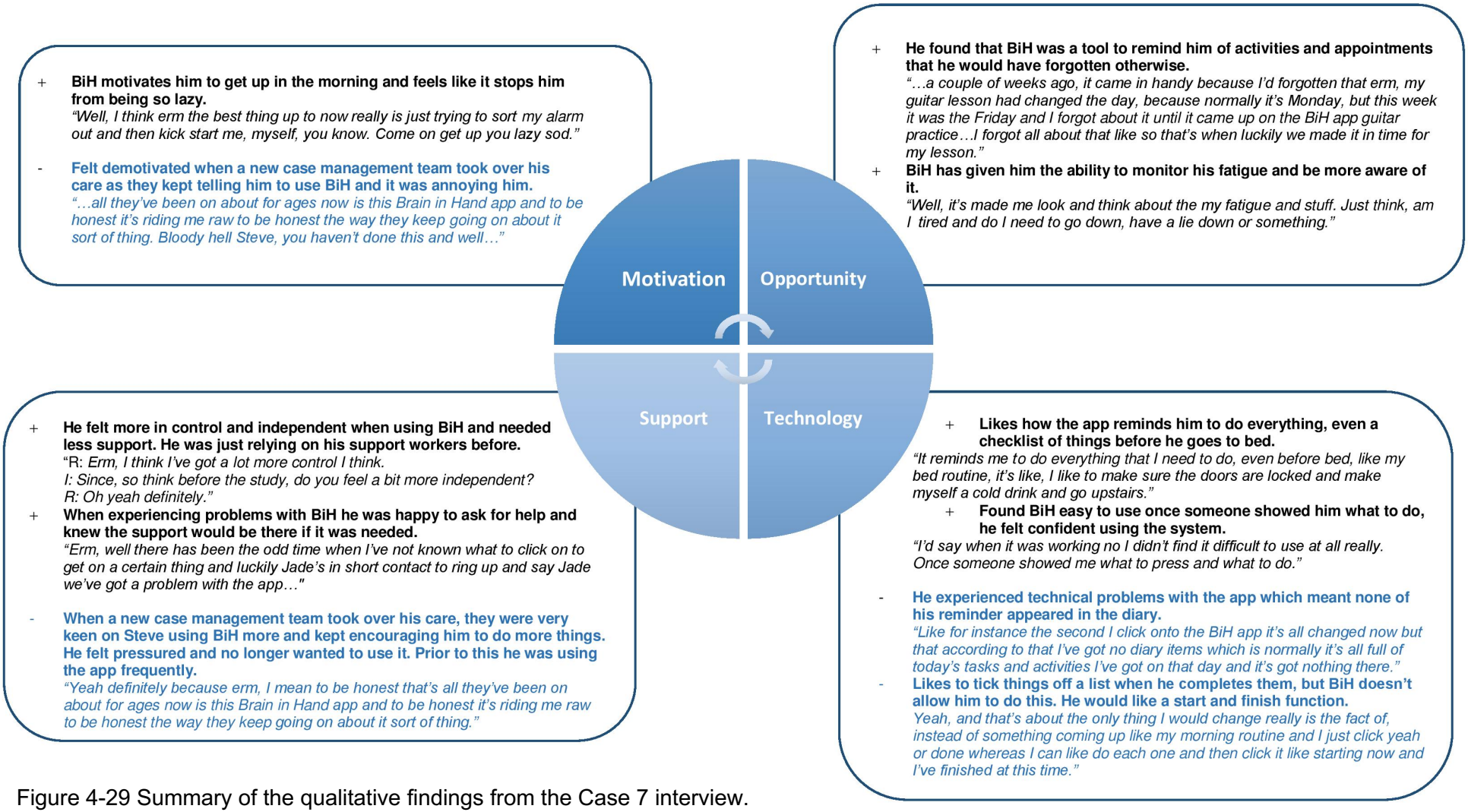


Figure 4-29 Summary of the qualitative findings from the Case 7 interview.

4.4.9. Case 8.

The results from case 8 (Martin) are presented in this section. He did not complete the 12 month assessment, but was interviewed at six months post-intervention.

4.4.9.1. Pen portrait.

Martin was a 58-year-old man who had an ABI in 2015 as a result of a cardiac arrest and subsequent anoxic brain injury (12-18 months post-injury at time of recruitment). Martin lived at home with his wife who was also his carer. He was a successful businessman prior to injury, but was taking sick leave from his job, with the aim to take early retirement. Martin was receiving occupational therapy at the time of recruitment, but would have frequent visits from a case manager and would have appointments with a neuropsychologist when necessary. Martin had dysarthria and cognitive impairment, making communication particularly difficult. He was not very confident at baseline, but improved as the study progressed, relying less on his wife for support when communicating. He often forgot appointments and needed to be reminded to do everyday tasks. He found it difficult to go shopping with a list and often came back with the wrong items, as he did not want to ask for help. He did not experience anxiety or depression, but had a high level of fatigue. One of Martin's goals was to manage fatigue better by having daily rests. Martin was a positive individual and could still see the funny side of things. He was often laughing with his wife about their life and how it had changed, which they felt was the best way to deal with his injury (See appendix 22 for summary).

4.4.9.2. Clinical outcomes measures.

Overall, the data in Table 4-6 show improvement in some clinical measures over six months. BiH appeared to have a positive effect on Martin's depression levels, as his HADS score moved from the borderline range at baseline, to the normal depression range by six months post-intervention (Figure 4-30). His depression score

decreased at four weeks post-intervention and it seemed that BiH was having a positive effect on his mood, however this increased at six weeks post-intervention). At six months, there was a further improvement in his depression levels, presenting a large decrease in HADS score from 8 to 4. Martin's anxiety levels initially dropped following the introduction of BiH and remained the same until four weeks post-intervention. However, this increased to the borderline anxiety level at six weeks post-intervention. Anxiety increase occurred at the same time as an increase in depression score, which coincided with the birth of his grandchild. This was more than likely a stressful time for Martin. At six months post-intervention, his HADS anxiety score decreased again to the clinically normal range. Following the introduction of BiH, Martin's NEADL score decreased at four weeks post-intervention (Figure 4-31). However, at six months, high NEADL score increased greatly from 23 to 36.

The outcome data presented in Table 4-6, shows that Martin improved on some of the outcome measures over six months. At six months, there was an improvement in fatigue levels shown by a decrease in FAS score from 33 to 25. There was also an improvement in functional outcomes as mentioned above, shown by an increase in NEADL score (32 to 36) and a greater quality of life shown by an increase in EQ5D-5L index score (0.649 at baseline to 0.816 at six months). There was no improvement in participation (CIQ score decrease of 14 to 12) and no change in cognition (MSNQ score remained the same at 39). As discussed above, there was an improvement in anxiety and depression scores between baseline and six months post-intervention.

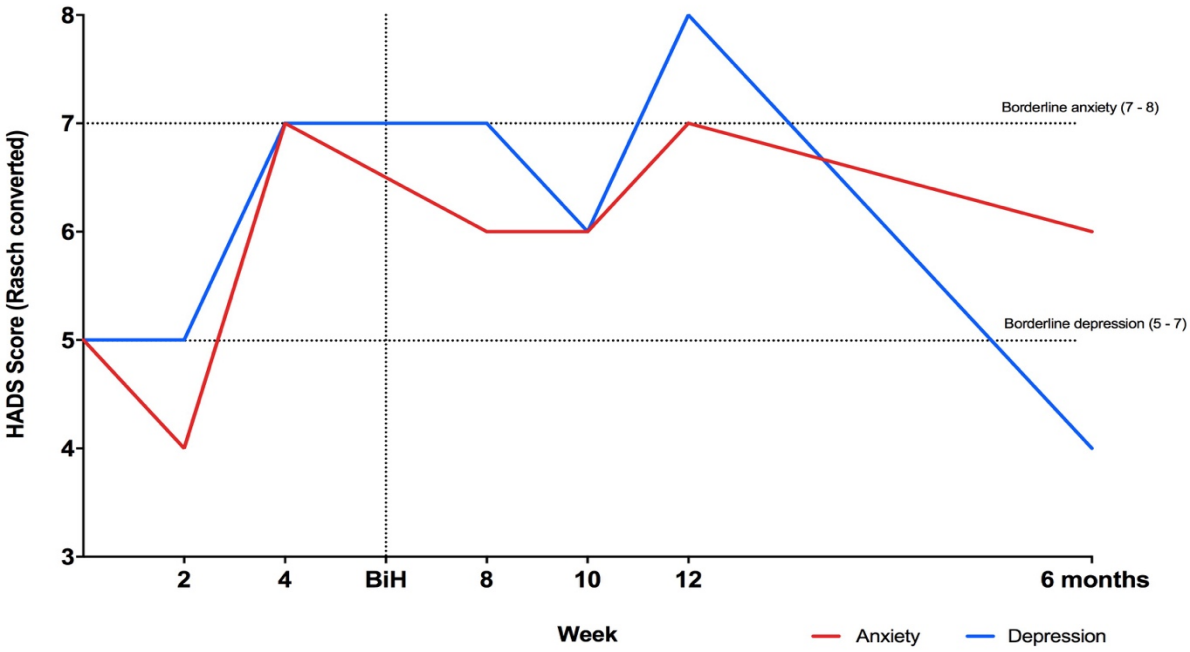


Figure 4-30 Case 8 HADS (Rasch converted) scores over six months.

Blue (depression) and red (anxiety) lines represent the HADS scores over the first six months, showing the initial 12 week fortnightly measures. The vertical dotted line indicates the time BiH was introduced. The horizontal dotted lines indicate the clinical cut off for borderline depression (Rasch converted HADS depression score 5-7) and border anxiety (Rasch converted HADS anxiety score 7-8).

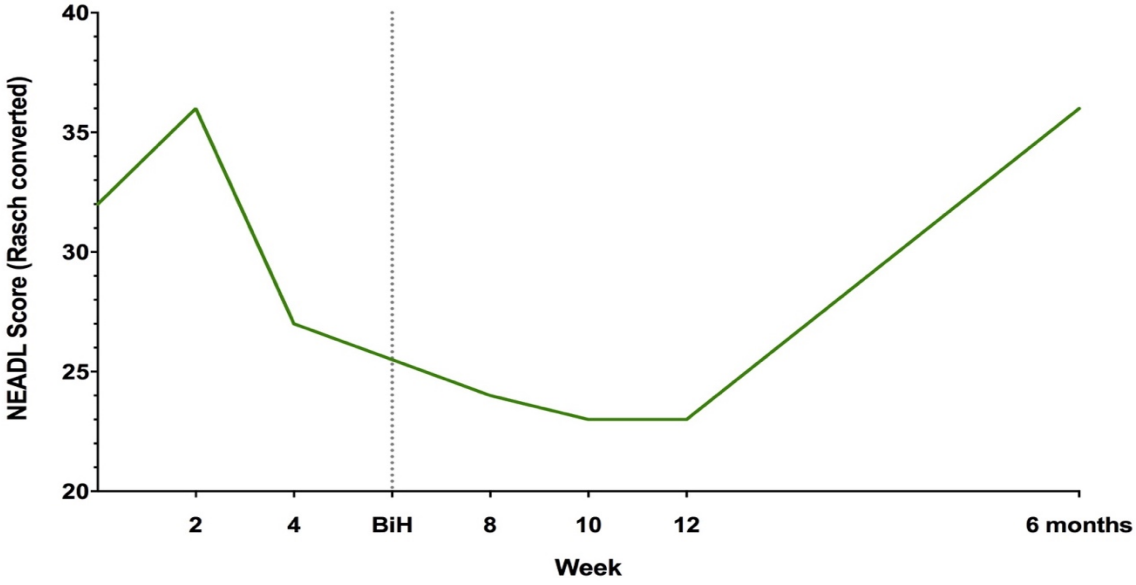


Figure 4-31 Case 8 NEADL (Rasch converted) scores over six months.

The green line represents the NEADL scores over the first six months, showing the initial 12 week fortnightly measures. The dotted line indicates the time BiH was introduced.

4.4.9.3. Brain-in-Hand data.

Data collected from the app shows that Martin was not using the BiH traffic light system relatively consistently over the 12 months, with more use in the first six months (Table 4-19). However, Martin lost his phone for three months and did not having access to BiH, therefore, a number of tasks were recorded as incomplete. Martin pressed few red (n=4) traffic lights and similar amount of amber (n=183) and green (n=228) lights over the 12 months. More of these were within the first six months.

Table 4-19 Case 8 data over 12 month period exported from the BiH app.

		First 6 months	Last 6 months	Total
Traffic lights (fatigue)	**Green**	142	86	228
	Amber	144	39	183
	Red	4	0	4
Tasks Complete (% total tasks)		689 (45.9%)	416 (26.4%)	1105 (35.9%)
Tasks Incomplete		811	1159	1970
Total tasks		1500	1575	3075
Completed 'exercise' tasks (total tasks,%)		57 (187, 30.5%)	38 (185, 20.5%)	95 (372, 25.5%)
Completed 'exercise' tasks (total tasks,%)		73 (182, 40.1%)	80 (225, 35.6%)	153 (407, 37.6%)
Solutions Used		17	7	24

Martin wanted to use BiH to manage his fatigue better, complete therapy exercises consistently and become more independent. Reminders were added to encourage Martin to rest each day and complete his daily exercises. Out of the 3075 tasks added to his BiH diary, Martin completed 45.9% of these in the first six months and 26.4% in the final six months. This lower rate of completion in the final six months

may have been a result of the missing phone. He used 24 solutions during the 12 months.

His use of the traffic lights is shown in Figure 4-32A, which was relatively consistent for the first five months, then again near the end of the study. There is a clear gap in traffic light usage between five and eight months post-intervention. Figure 4-32B shows a consistent level of completed tasks during the first five months. As with the traffic lights, there is a large gap in task completion between May and August 2017. There is a spike in completed tasks at the end of month eight and another spike in month 12, prior to the end of the study. The gap in traffic light and task completion data concurs with his inability to use BiH for a number of months (due to a lost phone). This was only identified when arranging the six month interview.



Figure 4-32 Case 8 data exported from the Brain-in-Hand cloud.

Graph A shows the total number and colour of traffic lights pressed between December 2016 (BiH intervention introduced) and December 2017 (12 months post-intervention).

Graph B shows the number of tasks completed (blue) and not completed (pink) over the six months he was enrolled in the study.

4.4.9.4. Goal attainment.

Two goals were set at baseline with the help of Martin's wife (carer):

1. **Participant stated goal**: Manage fatigue better and have more rests.

   SMART goal: Use BiH traffic lights to remind himself to have a rest during the day, even if he does not feel tired. His goal was to complete at least 60% 'rest' tasks during the study period.
2. **Participant stated goal**: Do therapy exercises more often.

   SMART goal: Martin needs to complete therapy exercises, specifically speech therapy exercises each day. Reminders to do these tasks were added to his BiH diary. His goal was to complete at least 60% of 'exercises' tasks on BiH diary.

Martin did not achieve either of the two goals set at baseline (Table 4-20). The attainment of these goals was measured using the BiH app data and confirmation from his wife. His GAS-Light score increased over the first six months, but did not change in the final six months.

Table 4-20 Goal attainment for Case 8 over 12 months.

Goal	0-6 months	6-12 months	Total 12 months
1	No – partially achieved. Only completed 30.5% of 'rest' tasks in the first six months. During the interview his wife talked about how difficult it is to get Martin to rest, but he was trying. He lost his phone for 3 months, which means he would not have been able to complete half of the tasks on the BiH app. It appears that he partially achieved this goal.	No Only completed 20.5% of 'rest' tasks in the final six months.	No Although he lost his phone for 3 months, he only managed to complete 25.5% of 'rest' tasks during the 12 months. He was a little better at resting than he was at baseline, but did not exceed expectations.
2	No Only completed 40.1% of 'exercise' tasks in the first six months.	No Only completed 35.6% of 'rest' tasks in the final six months.	No Only completed 37.6% of 'rest' tasks in the final six months.
GAS-Light score (baseline = 38.0)	+8.0	+0	+8.0

4.4.9.5. Qualitative data.

A face-to-face interview was conducted with Martin at six months post-intervention. This was conducted alongside his wife (carer) who provided support when Martin was unable to communicate his thoughts correctly. Both Martin and his wife had a relatively positive experience of using BiH and they talked about the problems they had faced during the study. The loss of his phone being the main barrier to use. The analysis of the qualitative data obtained from case 8 identified the main emerging themes as barriers and facilitators linked to motivation, opportunity, support and technology. Figure 4-33 summarises the findings from the interview with Martin and his wife.

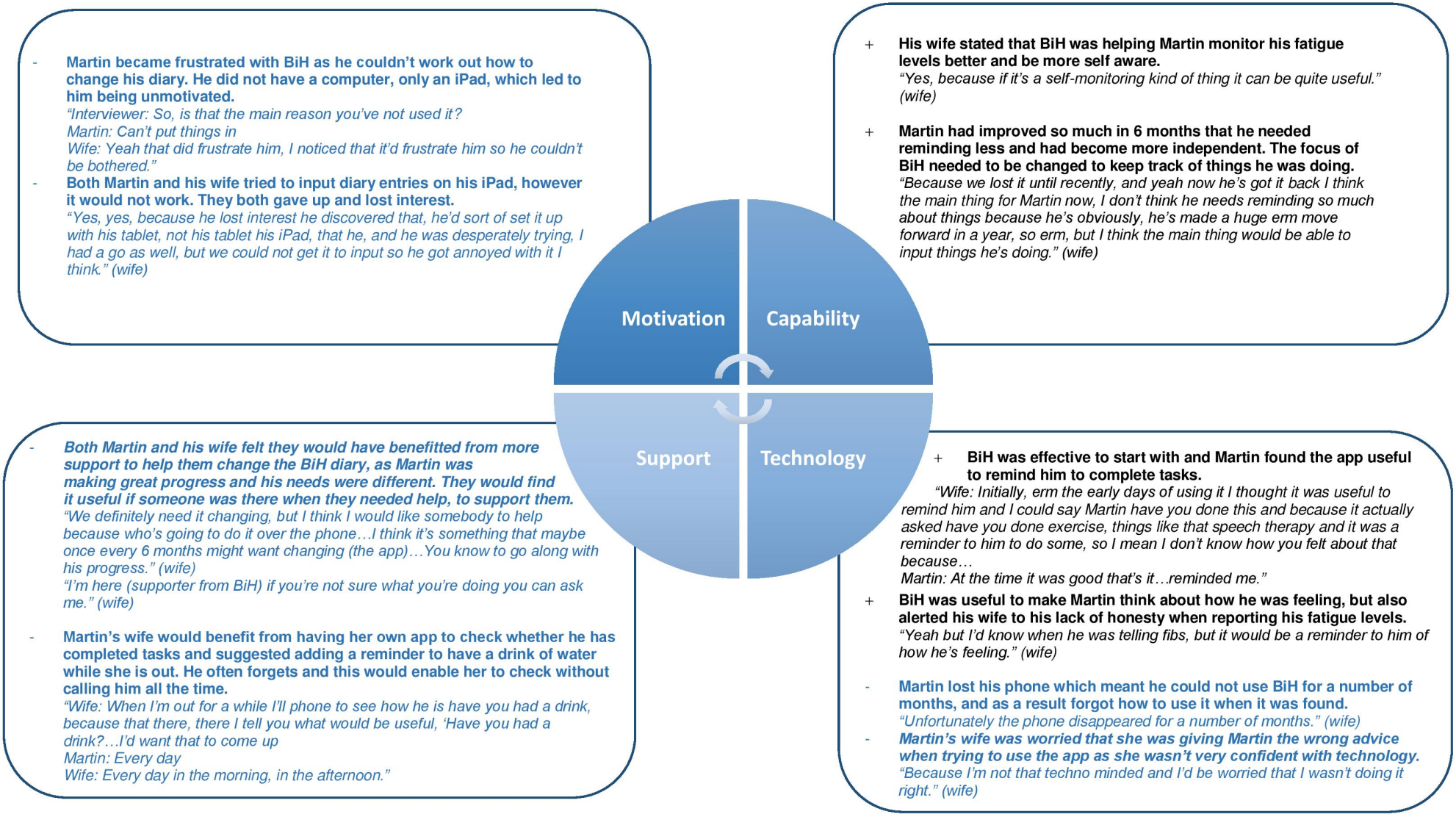


Figure 4-33 Summary of the qualitative findings from the Case 8 (and wife) interview.

4.4.10. Case 9.

The results from case 9 (Danielle) are presented in this section. She completed all questionnaires and was interviewed at six months post-intervention.

4.4.10.1. Pen portrait.

Danielle was a 52-year-old woman who had an ABI in 2015 (12-18 months post-injury at time of recruitment). She had a brain haemorrhage which left her with various impairments (e.g., cognitive difficulties, pain, finds it had to make decisions). Danielle was a store manager when she had her injury. This job was stressful and she was always busy. Danielle was working part-time at a church hall when recruited to the study, but could not return to her previous job due to the level of pressure and responsibility. She was living in her own home with her boyfriend and did not need a carer. Her boyfriend would help with daily tasks when necessary. Danielle was receiving rehabilitation at the time of recruitment and would have frequent appointments with a psychology assistant. She was also seeing a neuropsychologist and OT. She had cognitive impairment and found herself becoming very easily distracted, which disrupted her daily life. She often forgot appointments and needed to be reminded to do certain tasks. Danielle had anxiety and depression, which she was receiving treatment (cognitive behavioural therapy) for at the time of recruitment. She also had high levels of fatigue, which impacted more on her quality of life than the emotional issues she experienced. She used to enjoy going out regularly and misses socialising – it was a lot more difficult at the time of recruitment. However, Danielle was trying to go out every weekend with friends and/or family. Her goals were to better manage fatigue using BiH traffic lights, use the diary and reminders to better structure her day, and minimise anxiety levels by practising breathing exercises (See appendix 23 for summary).

4.4.10.2. Clinical outcome measures.

The data in Table 4-6 shows improvement in all clinical measures over the 12 month period. The introduction of BiH appeared to have an initial positive effect on Danielle's depression levels, as her HADS score decreased at two weeks post-intervention (Figure 4-34). However, this then increased and remained the same up until six weeks post-intervention. At six months, there was an improvement in her depression levels, presenting a decrease in HADS score from the 'probable' depression range to the borderline depression range (decrease from 10 to 6). The score remained the same at 12 months post-intervention. Danielle's anxiety levels initially dropped following the introduction of BiH. At six months post-intervention, her HADS anxiety score decreased further, however this was still within the 'probable' anxiety range. At 12 months post-intervention, her anxiety levels increased again. Following the introduction of BiH, Danielle's NEADL score decreased at two weeks post-intervention, then again to at six weeks (Figure 4-35). At six months, her NEADL score increased, and continued to increase at 12 months. This suggests that Danielle was becoming more functionally independent during the study and completing more ADL.

At 12 months, there was an improvement in fatigue levels shown by a decrease in FAS score from 42 to 37, an improvement in participation shown by an increase in CIQ score from 17 to 19. There was an improvement in quality of life shown by an increase in EQ5D-5L index score (0.714 at baseline to 0.812 at 12 months). There was a large improvement in cognition shown by a MSNQ score decrease from 47 to 30.

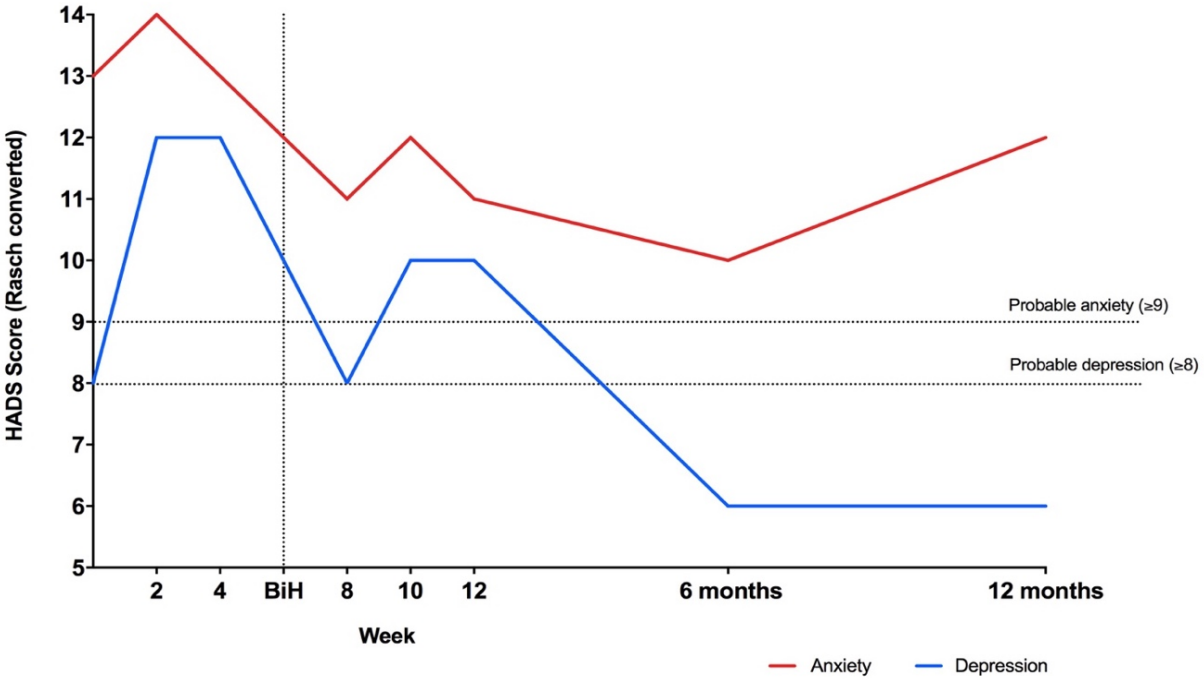


Figure 4-34 Case 9 HADS (Rasch converted) scores over 12 months.

Blue (depression) and red (anxiety) lines represent the HADS scores over the 12 month study period, showing the initial 12 week fortnightly measures. The vertical dotted line indicates the time BiH was introduced. The horizontal dotted lines indicate the clinical cut off for probable depression (Rasch converted HADS depression score greater than or equal to 8) and probable anxiety (Rasch converted HADS anxiety score greater than or equal to 9).

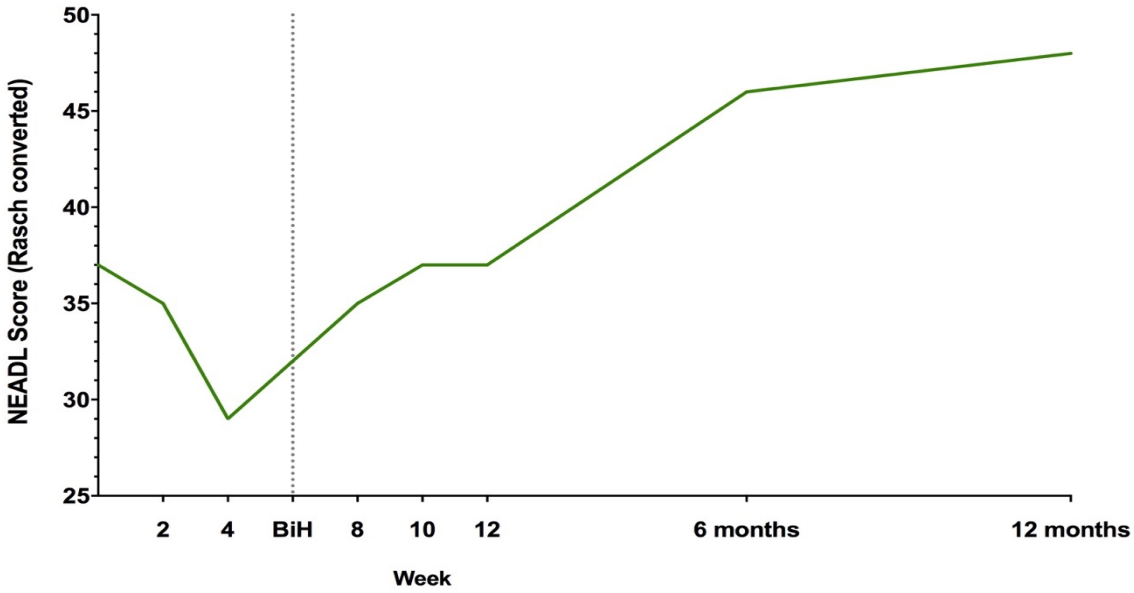


Figure 4-35 Case 9 NEADL (Rasch converted) scores over 12 months.

The green line represents the NEADL scores over the 12 month study period, showing the initial 12 week fortnightly measures. The dotted line indicates the time BiH was introduced.

4.4.10.3. Brain-in-Hand data.

Data collected from the app shows that Danielle was using the traffic light system more in the first six months, but was still monitoring her fatigue in the final six months (Table 4-21). However, Danielle lost her password for a couple of months and this was only picked up when she was interviewed. This will have impacted on the number of traffic lights pressed and tasks completed. In the first six months, Danielle pressed the least number of red traffic lights (n=29), more green lights (n=92) and the most amber lights (n=270). In the final six months, fewer traffic lights were pressed.

Table 4-21 Case 9 data over 12 month period exported from the BiH app.

		First 6 months	Last 6 months	Total
Traffic lights (fatigue)	**Green**	29	22	51
	Amber	270	38	308
	Red	92	23	115
Tasks Complete (% total tasks)		494 (61.2%)	185 (17.3%)	679 (36.3%)
Tasks Incomplete		306	886	1192
Total tasks		800	1071	1871
Completed 'eating' tasks (i.e., breakfast, lunch dinner) (total tasks, %)		300 (479, 62.6%)	114 (639, 17.8%)	414 (1118, 37.0%)
Solutions Used		0	0	0

Danielle wanted to use BiH to better manage her fatigue, remember to eat meals every day and plan her day better. Reminders were added to encourage Danielle to eat breakfast, lunch and dinner. She would click complete when she had eaten, so she could keep track of meals. Danielle completed 61.2% of tasks in the first six months and 17.3% in the final six months. She used no solutions during the 12

months, however stated in her interview that she was not pressing on the solutions when she had used them, therefore would not be captured in the BiH data.

Danielle's use of the traffic lights is shown in Figure 4-36A, which was relatively consistent for the first 4 months. There is a clear gap in traffic light usage between May and July 2017 when she lost her password. After this point, usage increased again but was less consistent, with a spike in red traffic lights near the end of the study (December 2017). Figure 4-36B shows a consistent level of completed tasks for the first 3 months. As with the traffic lights, there is a large gap in task completion between May and July 2017. Following this, there are intermittent period of task completion. The period of incomplete tasks suggest Danielle was not using the app at this point. She was going through a relationship breakup, which may have disrupted her use of BiH.

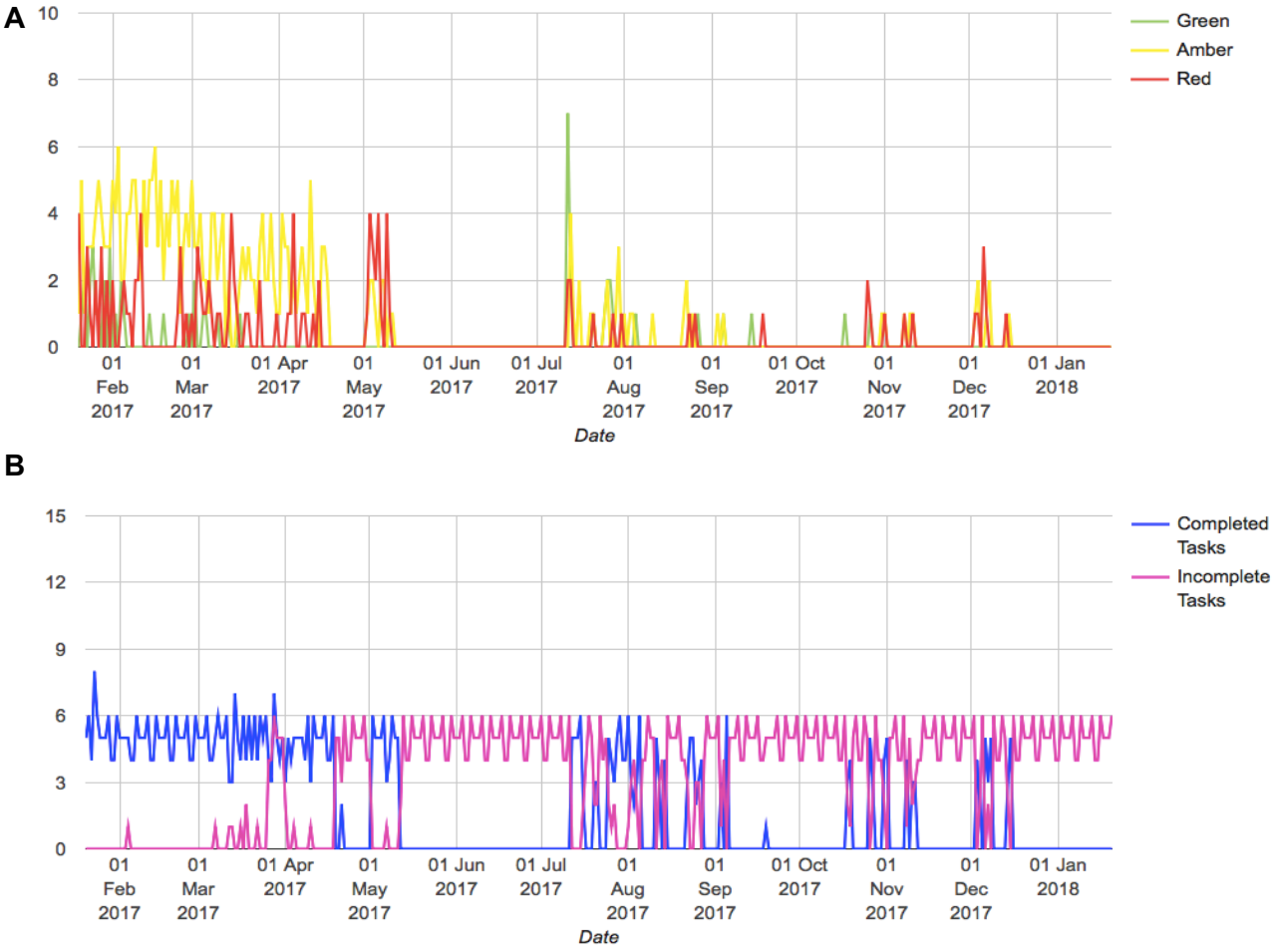


Figure 4-36 Case 9 data exported from the Brain-in-Hand cloud.

Graph A shows the total number and colour of traffic lights pressed between January 2017 (BiH intervention introduced) and January 2018 (12 months post-intervention).

Graph B shows the number of tasks completed (blue) and not completed (pink) over the six months he was enrolled in the study.

4.4.10.4. Goal attainment.

Three goals were set at baseline with the help of her psychologist:

1. **Participant stated goal**: Remember to eat frequently, often forgets to have meals.

   SMART goal: Use the BiH diary to add reminders to eat breakfast, lunch and dinner, plus an extra reminder of 'have you eaten today?' on days after her evenings out with friends. Her goal was to have a meal and then complete the task on BiH, so she could check back during the time and remind herself if she had eaten. The goal was to complete 50% of these 'eating' tasks over the 12 months.
2. **Participant stated goal**: Manage anxiety better using breathing exercises or going for a walk.

   SMART goal: Use BiH to remind her to take a walk down the river when she was feeling anxious. Also, to use breathing exercises when she had high anxiety. These would be added as unplanned solutions on the BiH app so she could access them at any time. The goal was to access these solutions when necessary.
3. **Participant stated goal**: Remember to attend appointments and do daily tasks.

   SMART goal: Use BiH to add reminders for appointment and daily tasks. The goal was to complete at least 60% of all tasks during the study.

Danielle achieved two of the three goals set at baseline (Table 4-22). The attainment of these goals was measured using the BiH app data and discussion with the participant. Her GAS-Light score increased over the 12 months and was the same for the first and final six months.

Table 4-22 Goal attainment for Case 9 over 12 months.

Goal	0-6 months	6-12 months	Total 12 months
1	Yes Completed 62.2% of 'eating' tasks as recorded by the BiH app in the first six months.	No Only completed 17.8% of 'eating' tasks as recorded by the BiH app.	No Only completed 37% of 'eating' tasks as recorded by the BiH app over the 12 months, however when asked, she stated that she was eating more regularly and found BiH useful to remind her.
2	Yes Danielle was using BiH to remind her to take walks each day to help with her anxiety. She was also using the solutions on the app to help with breathing exercises, but was not clicking on the solutions. She didn't need to look at them after a while as she became so familiar with the routine.	Yes She continued to take walks each day and was still practicing her breathing exercises. She didn't really need to use BiH anymore for the exercises as they had become a part of her routine.	Yes Danielle successfully used BiH to help with her anxiety management and used the unplanned solutions for breathing exercises.
3	Yes Completed 61.2% of all tasks as recorded by the BiH app in the first six months.	No Only completed 17.3 % of 'all tasks as recorded by the BiH app.	No Only completed 36.3 % of 'all tasks over the 12 months. She stated that she would often ignore the reminders as the alert sounded the same as a text message. As a result missed some appointments.
GAS-Light score (baseline = 36.4)	+13.6	+13.6	+27.2

4.4.10.5. Qualitative data.

A telephone interview was conducted with Danielle at six months post-intervention. Danielle talked about her positive and negative experiences of using BiH and how it may be improved. She also talked about how she became so used to seeing the problems and solutions that she no longer needed to look at the app. The analysis of the qualitative data obtained from case 9 identified the main emerging themes as barriers and facilitators linked to motivation, opportunity, support and technology. Figure 4-37 summarises the findings from the interview with Danielle.

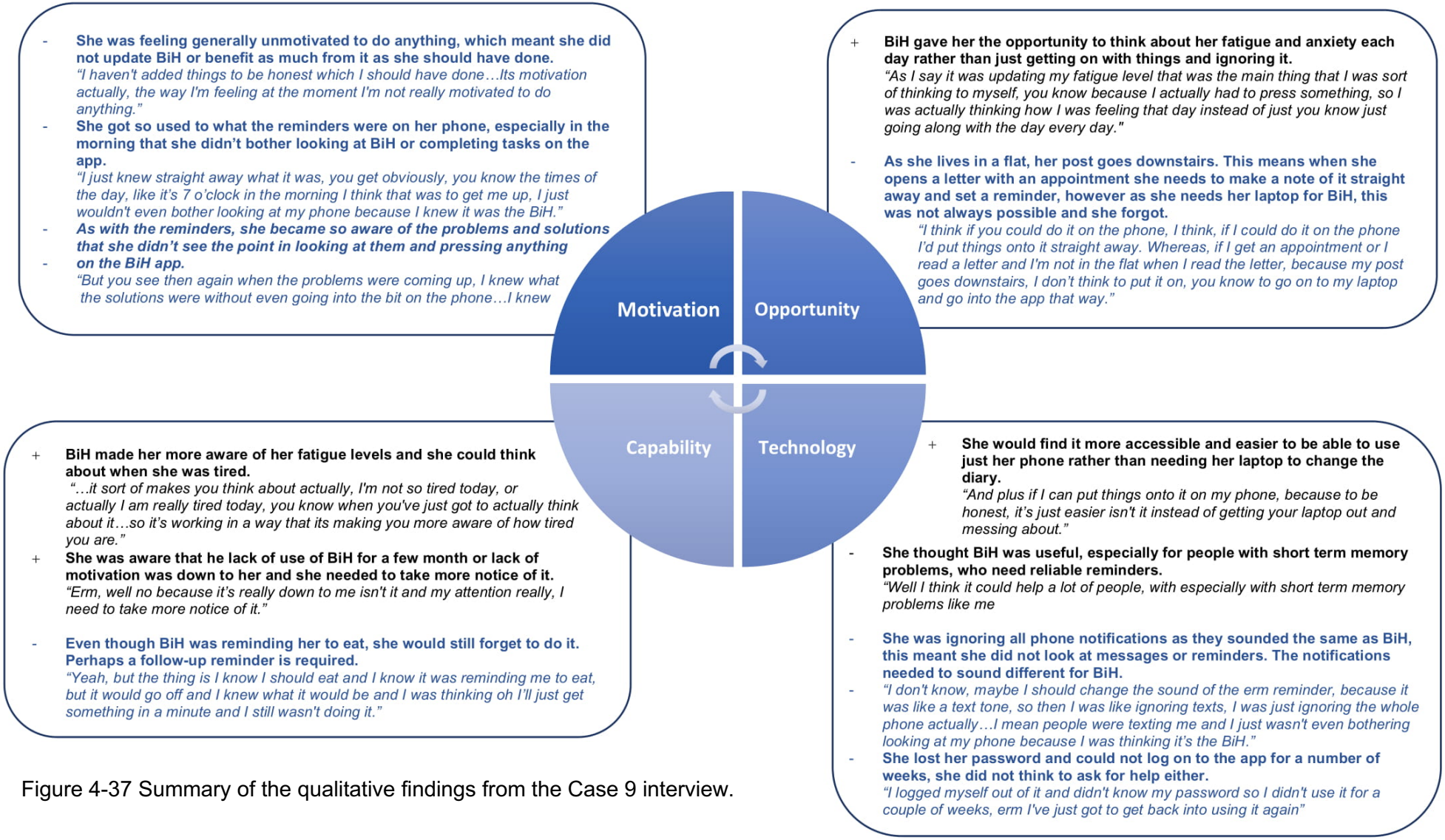


Figure 4-37 Summary of the qualitative findings from the Case 9 interview.

4.4.11. Case 10.

The results from case 10 (Robert) are presented in this section. He completed all questionnaires and was interviewed at six months post-intervention.

4.4.11.1. Pen portrait.

Robert was a 66-year-old man who had a stroke in 2012. He was over 4 years post-injury at the time of recruitment. He was the national manager for a big company at the time of injury and had a busy lifestyle with large pressures. Robert was a friendly, optimistic individual with a good sense of humour, and was determined to regain as much function as possible following his stroke. He lived at home with his wife who also acted as his carer. Robert was receiving rehabilitation at the time of recruitment (physiotherapy, speech and language therapy), and was undergoing various orthopaedic surgeries on his foot. He was not working and had taken early retirement following his stroke, however he did volunteer a couple of times a week at different support groups and liked being involved in research. Robert had aphasia and limited left side movement, making some ADL difficult. He did not have cognitive impairment, but often forgot appointments and needed to be reminded by his wife. He sometimes found it difficult to concentrate when people were speaking. Robert did not experience anxiety or depression and had low levels of fatigue. He did not socialise with many people other than his family, but tried to go out as much as possible with his wife. He enjoyed using technology and used an iPad for speech therapy exercises. His main goals were to take control of his daily routine and become more independent, rather than relying on his wife. Also, to do more tasks without being asked to do them, such as physiotherapy exercises (See appendix 24 for summary).

4.4.11.2. Clinical outcome measures.

Overall, there was no improvement in clinical measures over the 12 month period (Table 4-6). The introduction of BiH appeared to have an initial negative effect on Robert's depression levels, as his HADS score increased at two weeks post-intervention (Figure 4-38). However, this then decreased and remained the same up until six weeks post-intervention. At six months, there was no change in his depression levels. An increase in depression was found at 12 months. Robert's anxiety levels initially increased following the introduction of BiH but decreased slightly at four weeks post-intervention. At six months post-intervention, his HADS anxiety score decreased, then decreased further at 12 months post-intervention. All HADS scores remained in the clinically normal range. Following the introduction of BiH, Robert's NEADL score decreased, then increased to at six weeks post-intervention. At six months, his NEADL score decreased slightly and remained the same for the remainder of the study. However, this may have been due to Robert and his wife going holiday and the inability to complete some of the activities listed on the NEADL measure. Robert also had surgery on his foot during the study, which may have impacted on his ability to complete some ADL.

At six months, there was a worsening in fatigue levels (increase in FAS) and a decrease in participation (lower CIQ score) (Table 4-6). There was a slight decrease in quality of life (EQ5D-5L index score 0.727 at baseline to 0.619 at 12 months) and a decrease in cognitive function shown by a MSNQ score increase from 23 to 38. The change in scores was less remarkable between six and 12 months, suggesting that Robert was underestimating his impairments at baseline.

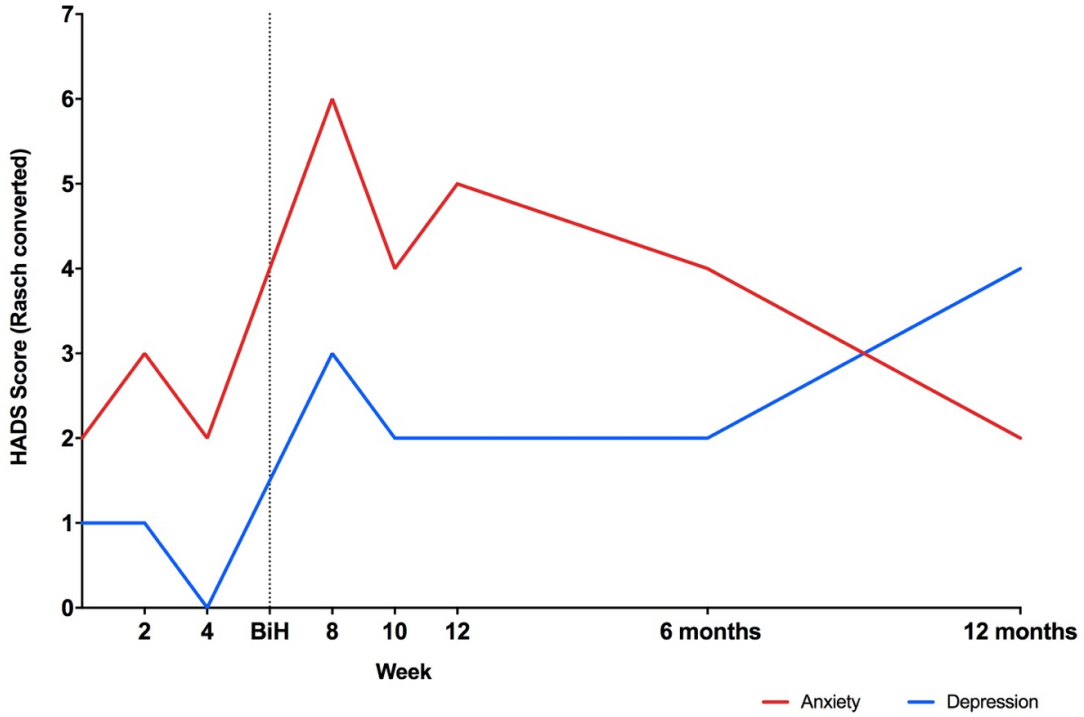


Figure 4-38 Case 10 HADS (Rasch converted) scores over 12 months.

Blue (depression) and red (anxiety) lines represent the HADS scores over the 12 month study period, showing the initial 12 week fortnightly measures. The dotted line indicates the time BiH was introduced.

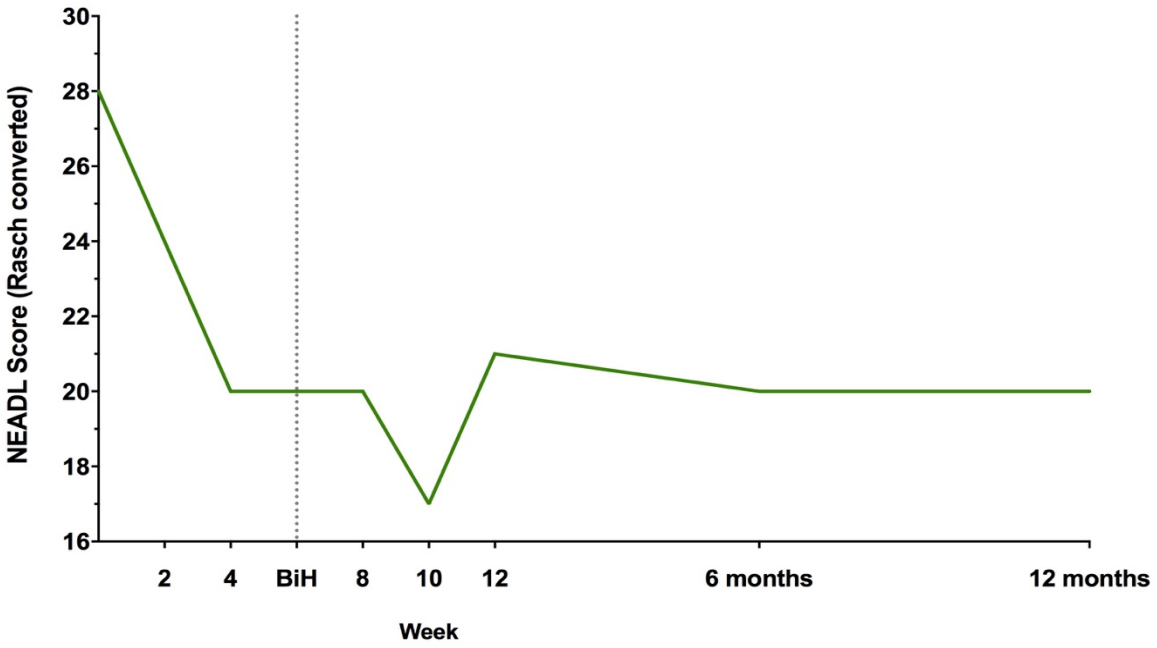


Figure 4-39 Case 10 NEADL (Rasch converted) scores over 12 months.

The green line represents the NEADL scores over the 12 month study period, showing the initial 12 week fortnightly measures. The dotted line indicates the time BiH was introduced.

4.4.11.3. Brain-in-Hand data.

Data collected from the app shows that Robert used BiH consistently over the 12 months. Usage in the first six months was similar to the final six months (Table 4-23). Robert appeared to be using BiH mostly for reminders. He pressed the same number of red (n=1) and amber (n=1) traffic lights over the 12 months and a large amount of green lights (n=1414). This suggests that Robert didn't really need to use the monitoring system for his fatigue levels, or he was not being honest when rating how he felt.

Table 4-23 Case 10 data over 12 month period exported from the BiH app.

		First 6 months	Last 6 months	Total
Traffic lights (fatigue)	**Green**	635	779	1414
	Amber	1	0	1
	Red	0	1	1
Tasks Complete (% total tasks)		558 (55.1%)	555 (61.7%)	1113 (58.2%)
Tasks Incomplete		454	344	798
Total tasks		1012	899	1911
Completed 'Exercise' tasks (total tasks, % total)		210 (429, 49.0%)	298 (525, 56.8%)	508 (954, 53.2%)
Solutions Used		66	0	66

Robert wanted to use BiH to better structure his day and take control of his daily routine. Reminders were added to encourage Robert to complete his physiotherapy and speech therapy exercises. The purpose of BiH was to help Robert be more independent and rely less on his wife. Robert completed 55.1% of tasks in the first six months and 61.7% in the final six months. He completed 53.2% of exercise tasks over the 12 months. Although he completed his exercises consistently during the study period, more were completed in the final six months (56.8%), compared to the first six months (49.0%). He only used solutions (n=66) during the first six months.

Robert's use of the traffic lights is shown in Figure 4-40A, which was relatively consistent during the 12 months. There is a spike in traffic light usage in March 2017, shortly after receiving BiH. All (apart from one red and one amber) traffic light presses were green. Figure 4-40B shows a spike in task completion in the second and third month after receiving BiH. The number of completed tasks decreased after this point and remained relatively consistent until the end of the study. However, the number of incomplete tasks was also consistent over the study period, suggesting that Robert was ignoring a certain group of tasks.

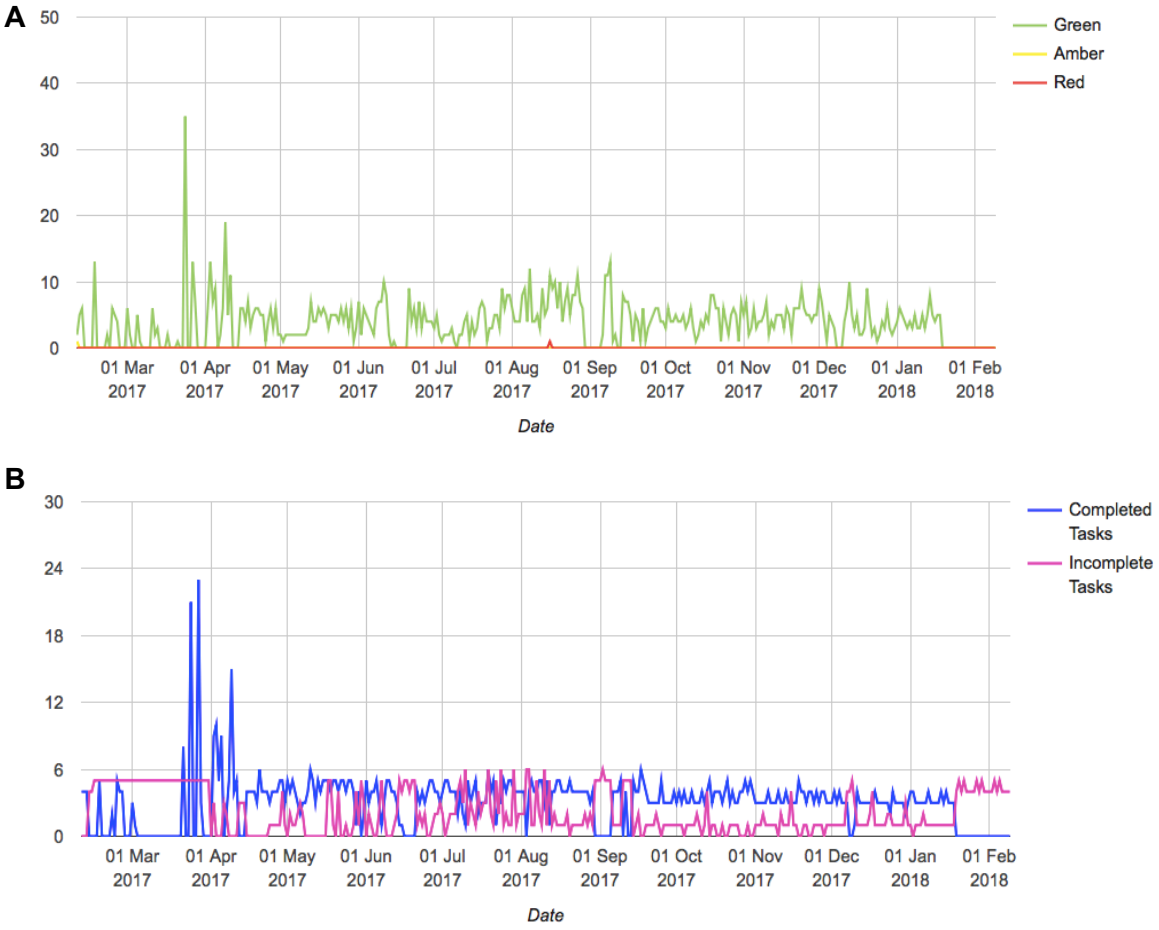


Figure 4-40 Case 10 data exported from the Brain-in-Hand cloud.

Graph A shows the total number and colour of traffic lights pressed between February 2017 (BiH intervention introduced) and February 2018 (12 months post-intervention).

Graph B shows the number of tasks completed (blue) and not completed (pink) over the six months he was enrolled in the study.

4.4.11.4. Goal attainment.

Two goals were set at baseline with the help of Robert's wife:

1. **Participant stated goal**: Be more independent and take control of life so he relies less on his wife.

   SMART goal: To use BiH to structure his day better and use the diary to remember what needs doing during the day. His goal was to feel more independent by the end of the study with the help of BiH. This will be attained if he completes reminders regularly with a goal to complete at least 60% of all tasks.
2. **Participant stated goal**: Carry out daily activities without having to be reminded, such as therapy exercises.

   SMART goal: To use BiH diary to set exercise reminders and complete them without having to be asked. The goal was to complete at least 50% 'exercise' tasks over the 12 months (a lower target was set as they had multiple holidays planned and it is not always easy to do his exercises away from home).

Robert achieved both goals that were set at baseline (Table 4-24). The attainment of these goals was measured using the BiH app data and confirmation from Robert's wife. His GAS-Light score increased in the first six months but increased more in the final six months.

Table 4-24 Goal attainment for Case 10 over 12 months.

Goal	0-6 months	6-12 months	Total 12 months
1	No - partially achieved Completed 55.1% of all tasks as recorded by the BiH app in the first six months. This was almost at the 60% target. They had been on a cruise for a number of weeks and Robert had tried his best to complete tasks (as stated by wife). He had almost achieved his goal.	Yes Completed 61.7% of all tasks in the final six months.	Yes Completed 58.2% of all tasks as recorded by the BiH app over the 12 months. Although BiH did not report the target 60% completed tasks, Robert's wife stated that he was completing his tasks each day and sometimes the app would not let them record a completed task. Taking this into account, it seemed that Robert had achieved his goal.
2	No – partially achieved Completed 49.0% of exercise tasks in the first six months, which was very close to the target of 50%. As with the previous goal, they were on holiday during this time period and Robert did his exercises when possible. He partially achieved this goal at six months.	Yes Completed 56.8% of exercise tasks in the final six months. Robert's wife stated that he had been much more motivated to do exercises and needed less reminding.	Yes Completed 53.2% of exercise tasks during the 12 months. This was a great achievement given the multiple holidays they went on during the study.
GAS-Light score (baseline = 37.6)	+12.4	+24.8	+37.2

4.4.11.5. Qualitative data.

A face-to-face interview was conducted with Robert at six months post-intervention. He was interviewed alongside his wife (carer) who provided support when Robert was unable to understand the question or communicate his thoughts. He has aphasia. Both Robert and his wife had a relatively positive experience of using BiH and discussed how it had helped Robert become more independent. The analysis of the qualitative data obtained from case 10 identified the main emerging themes as barriers and facilitators linked to motivation, capability, opportunity and technology. Figure 4-41 summarises the findings from the interview with Robert and his wife.

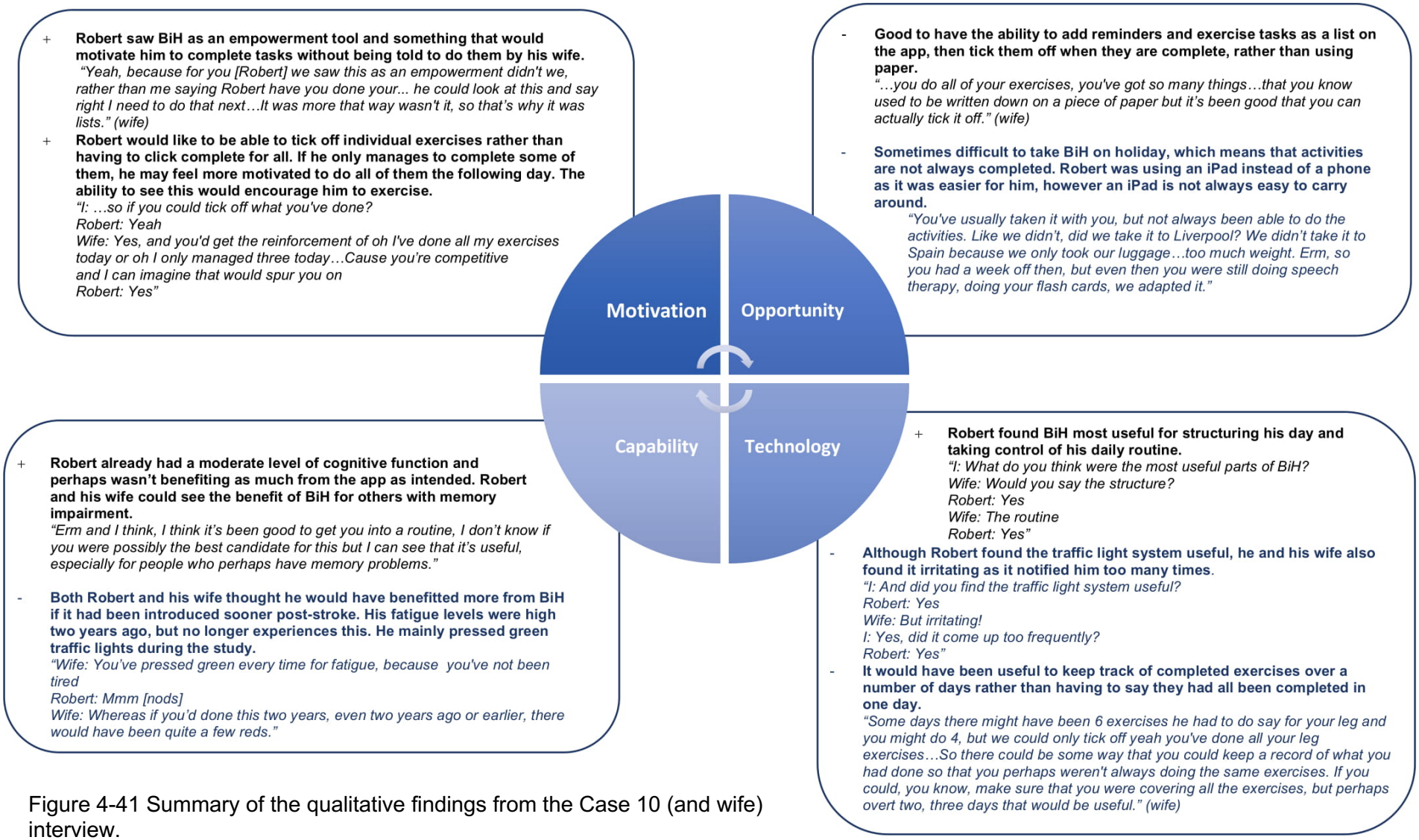


Figure 4-41 Summary of the qualitative findings from the Case 10 (and wife) interview.

4.5. Combined Quantitative and Qualitative Results

4.5.1. Combined quantitative data.

This section presents the combined quantitative data obtained from the outcome measures at baseline, six months and 12 months (Table 4-25). The HADS and NEADL scores have been compared across cases for the first 12 weeks (fortnightly measures) and at six and 12 months. There was no significant difference between the measures at any of the time points (i.e., between baseline and six months, six and 12 months, and baseline and 12 months). The combined data shows a mean decrease in MSNQ scores at six months and 12 months post-intervention, suggesting an improvement in cognition. There was also a mean decrease in NEADL scores at 12 months, suggesting a decline in functional independence.

4.5.1.1. Anxiety.

All participants remained in the same clinical range as their baseline score (HADS anxiety) throughout the study, showing no clear improvement or worsening of anxiety across the cases. Figure 4-42 presents the average HADS anxiety scores pre- and post-intervention, then at six and 12 months post-intervention. There were six participants within the clinically ‘normal’ range (≤6) at baseline and the remaining four were in the ‘probable’ anxiety range (≥9).

Following the introduction of BiH, there was an increase in the average HADS anxiety score (calculated from three measures over six weeks) for four of the participants. The average HADS anxiety score decreased for five participants post-intervention, and for one participant, their anxiety remained the same.

Table 4-25 Summary of quantitative data collected at baseline, 6 and 12 months post-intervention.

		Mean	SD	Min	Max	Mean Change (SD, 95% CI)		
						Baseline-6 months	6-12 months	Baseline-12 months
HADS Anxiety*	**Baseline**	7.50	6.04	0	16	0.38 (SD=1.77, CI -1.10 to 1.85)	-0.33 (SD=1.63, CI -1.38 to 2.05)	0.83 (SD=1.47, CI -0.71 to 2.38)
	6 months	8.25	5.82	1	16			
	12 months	7.83	6.85	1	18			
HADS Depression*	**Baseline**	4.50	3.24	0	10	0.75 (SD=1.91, CI -0.85 to 2.35)	-0.5 (SD=1.98, CI -2.57 to 1.57)	0.17 (SD=2.14, CI -2.08 to 2.41)
	6 months	5.50	3.78	1	12			
	12 months	4.50	2.35	1	8			
NEADL♦	**Baseline**	40.40	10.46	27	53	-0.75 (SD=3.66, CI -3.81 to 2.31)	-0.5 (SD=4.18, CI -3.89 to 4.89)	-0.167 (SD=6.43, CI -6.92 to 6.58)
	6 months	35.38	13.91	19	54			
	12 months	34.67	18.52	14	55			
GAS-Light♦	**Baseline**	37.21	0.76	36.2	38	16.56 (SD=11.15, CI 7.24 to 25.88) *** (p=0.004)	-3.3 (SD=17.67, CI -19.64 to 13.04)	12.77 (SD=16.99, CI -2.94 to 28.49)
	6 months	53.9	11.02	37.7	74.4			
	12 months	50.01	16.68	25.5	71.2			
CIQ♦	**Baseline**	15.50	6.29	8	27	-3.38 (SD=7.23, CI -9.42 to 2.67)	0.5 (SD=5.47, CI -5.34 to 6.24)	3.17 (SD=9.33, CI -12.95 to 6.62)
	6 months	14.63	4.37	10	21			
	12 months	16.17	6.11	6	23			
MSNQ*	**Baseline**	37.30	11.68	22	59	-3.75 (SD=8.50, CI -10.85 to 3.35)	-2 (SD=3.16, CI -1.32 to 5.32)	-2.5 (SD=10.82, CI -13.86 to 8.86)
	6 months	34.13	11.91	18	55			
	12 months	33.50	12.91	22	57			
FAS*	**Baseline**	27.60	10.24	11	42	-1.25 (SD=4.59, CI -5.09 to 2.59)	2 (SD=4.05, CI -2.25 to 6.25)	1.67 (SD=5.28, CI -3.87 to 7.21)
	6 months	27.38	9.09	11	40			
	12 months	29.00	10.22	16	42			
EQ-5D-5L♦	**Baseline**	0.69	0.19	0.32	1	0.055 (SD=0.098, CI -0.027 to 0.14)	-0.11 (SD=0.19, CI -0.31 to 0.09)	-0.057 (SD=0.15, CI -0.22 to 0.10)
	6 months	0.73	0.20	0.46	1			
	12 months	0.64	0.34	-0.016	0.906			

♦ measures where a higher score indicates a positive outcome * measures where a lower score indicates a positive outcome.

HADS: Hospital Anxiety and Depression Scale; NEADL: Nottingham Extended Activities of Daily Living; EQ-5D-5L: EuroQol 5-dimensions 5-levels; CIQ: Community Integration Questionnaire; MSNQ: Multiple Sclerosis Neuropsychological Screening Questionnaire; GAS: Goal Attainment Scaling; FAS: Fatigue Assessment Scale; SD: standard deviation, CI: confidence intervals. ***paired t-test, significant difference in scores ($p<0.05$).

At six months post-intervention, three participants showed an increase in anxiety levels (HADS anxiety score). Interestingly, two of these participants had reported a decrease in anxiety shortly after receiving BiH. Four participants had reduced anxiety levels at six months compared to their HADS anxiety score shortly after receiving BiH. At 12 months post-intervention, three participant had an increase in anxiety score, however the rest decreased or remained the same. Overall, two participants improved at six or 12 months (depending on the final questionnaire returned) compared to their baseline score, and one participant remained the same.

Figure 4-43 shows the variation in scores across the weeks and months throughout the study. Some cases appeared to have quite consistent HADS anxiety scores, with slight fluctuation across the weeks/months. However, the scores for participants within the clinically normal anxiety range (below HADS score 7) tended to fluctuate much more than those in the ‘probable’ anxiety range. This may be due to other rehabilitation problems experienced at the time the measure was taken, or other lifestyle changes which may have had more of an impact on their anxiety levels. Overall, after BiH was introduced, there was no clear spike in anxiety levels, nor any major decrease observed.

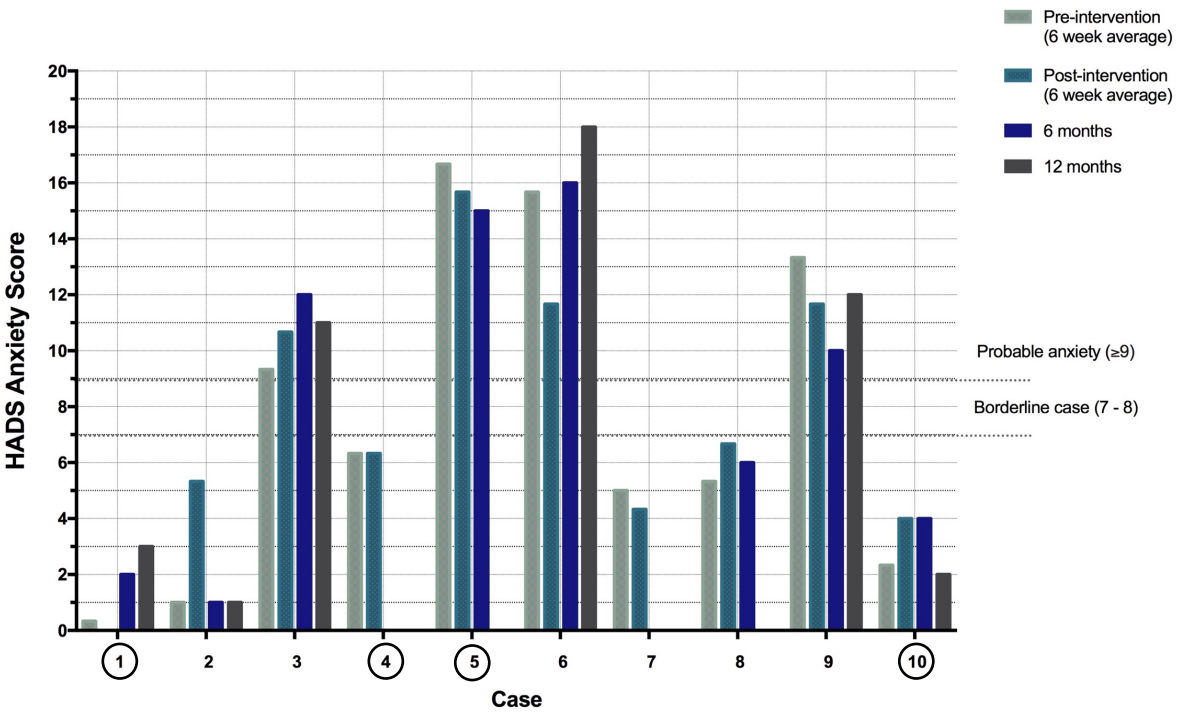


Figure 4-42 Combined HADS anxiety scores (Rasch converted) over the study period showing the (mean) average scores pre- and post-intervention, at 6 months and 12 months.

Circles identify participants that were monitoring anxiety using the traffic light system.

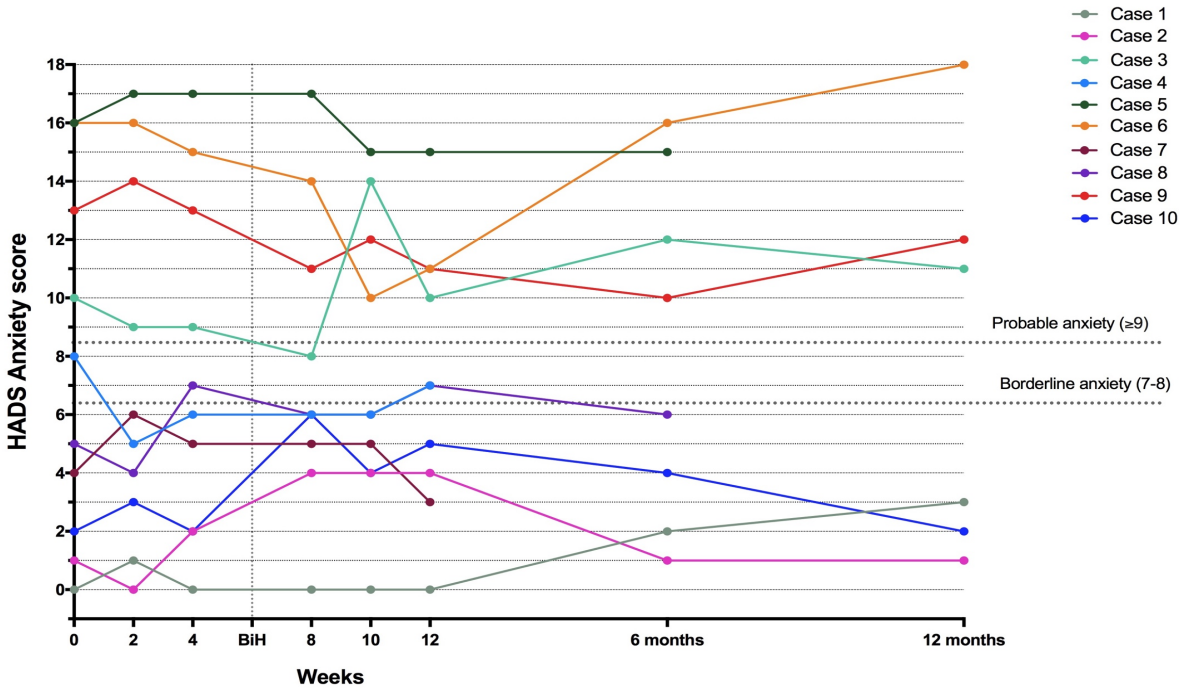


Figure 4-43 Variation in HADS anxiety scores (Rasch converted) for all cases throughout the study period.

4.5.1.2. Depression.

Unlike the anxiety measures, not all participants remained in the same clinical range as their baseline HADS depression score throughout the study. Some showed an improvement and decrease in depression, but others showed an increase in depression (Figure 4-44). There were six participants within the clinically 'normal' range (≤4) at baseline, two were in the 'borderline' range (5 to 7) and the remaining two were in the 'probable' depression range (≥8).

After BiH was introduced at six weeks post-baseline, six of the participants showed an increase in the average HADS depression score (calculated from three measures over six weeks). The average HADS depression score decreased for three participants post-intervention, and for one participant, their depression level remained the same.

At six months post-intervention, three participants recorded an increase in depression levels from the post-intervention measure. As with the anxiety scores, it was interesting to note that two of these participants had reported a decrease in depression (shown by a lower average score) shortly after receiving BiH. Three participants had reduced anxiety levels at six months and one remained the same. At 12 months post-intervention, only one participant showed an increase in depression score, however three decreased and three remained the same. Overall, three participants improved at six or 12 months (depending on the final questionnaire returned) compared to their baseline score and one participant remained the same.

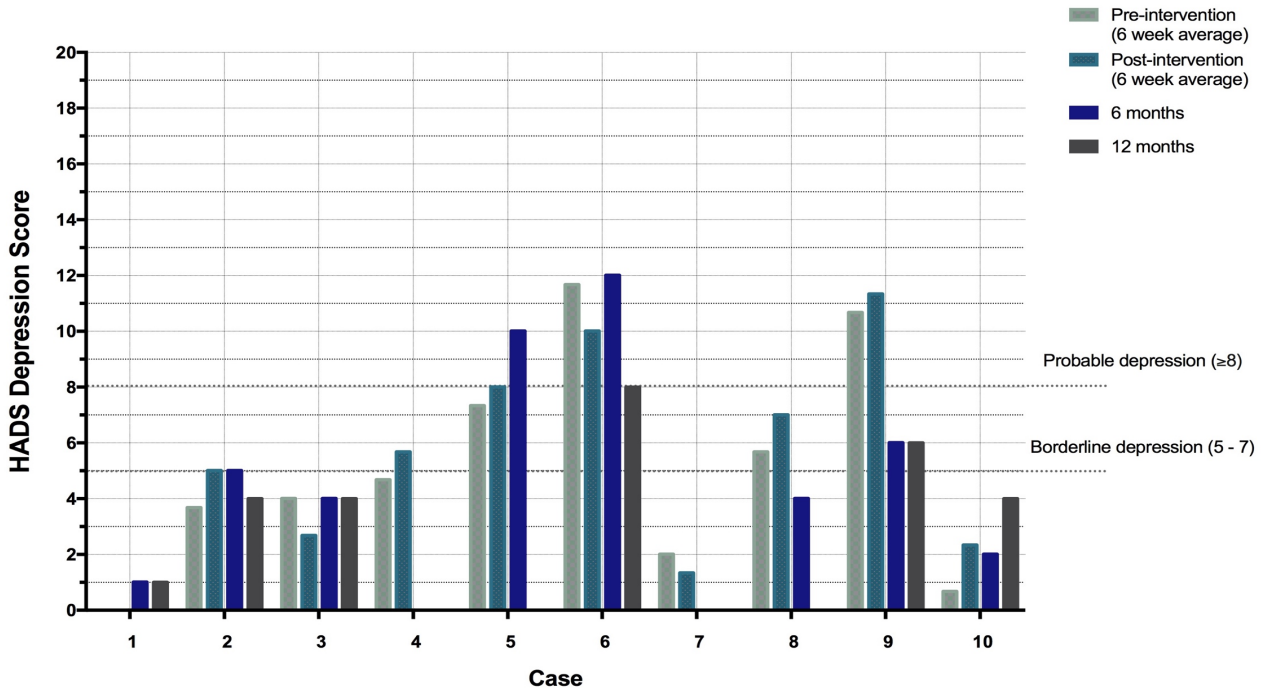


Figure 4-44 Combined HADS depression scores (Rasch converted) over the study period showing the (mean) average scores pre- and post-intervention, at six months and 12 months.

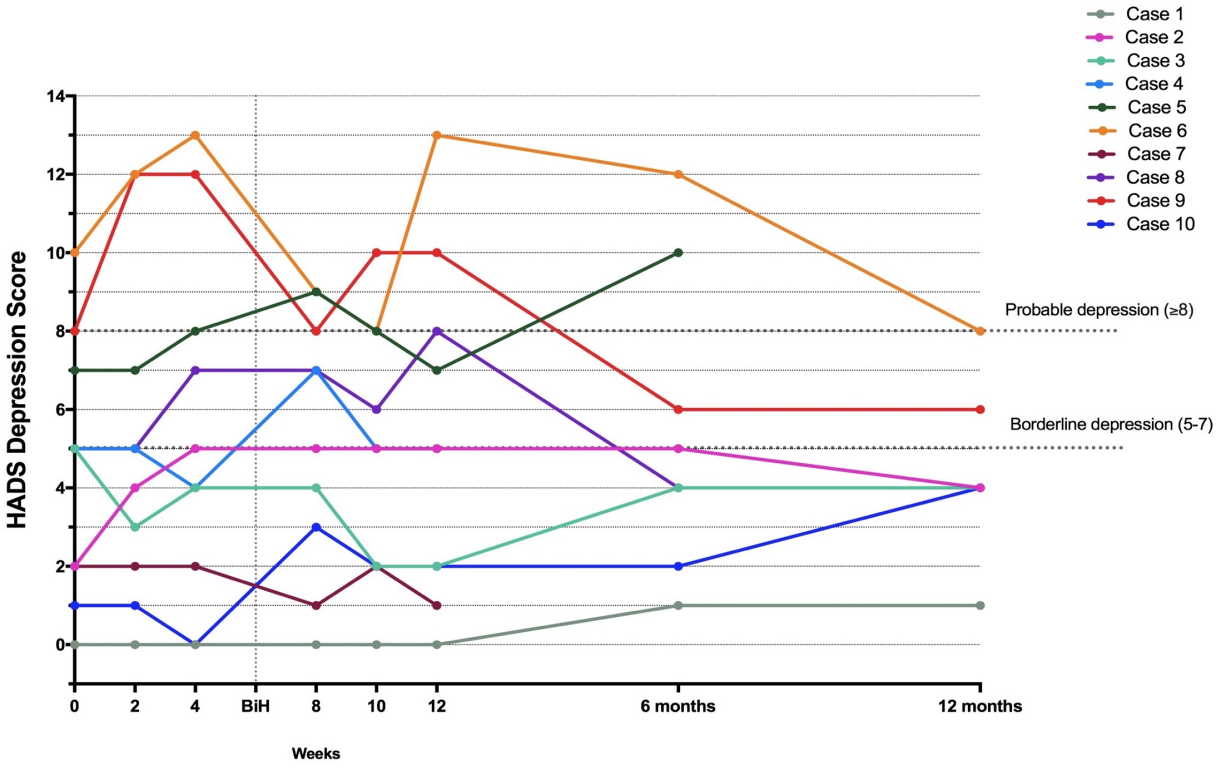


Figure 4-45 Variation in HADS depression scores (Rasch converted) for all cases throughout the study period.

Two participants moved into different clinical ranges of depression during the study. One moved from the ‘borderline’ range into the ‘probable’ depression range at six months post-intervention. Another participant moved into the ‘borderline’ range from the ‘normal’ range shortly after receiving BiH, however they did not complete any further assessments. However, a positive outcome was seen for two of the participants. One moved from the ‘probable’ depression range into the ‘borderline’ depression range at six months post-intervention and this was maintained at 12 months. Another participant moved from the ‘borderline’ range into the ‘normal’ range at six months post-intervention.

Figure 4-45 shows the variation in depression scores across the study period. As with the anxiety scores, some cases appeared to have more stable depression levels during the study, but some appeared to fluctuate throughout. In contrast to the anxiety scores shown in the previous section, it seems that those in the clinically ‘probable’ depression range (HADS score 8 and above) tended to fluctuate much more than those in the ‘normal’ depression range. It appears that participants were initially responding well to BiH and their depression levels were decreasing, but then they increased again. Overall, BiH seems to have a positive effect on HADS depression scores, as most participants within the ‘borderline’ and ‘probable’ ranges reported reduced depression.

4.5.1.3. Functional Outcomes and ADL.

Some participants showed an improvement in function and increased ADL, however some reported less independence and a negative outcome. The level of function varied greatly across the cases at baseline, with four participants scoring above 40 (out of a maximum 54). After BiH was introduced, three participants showed an increase in the average NEADL score and therefore an improvement in ADL. One

participant's score remained the same. However, the average NEADL score decreased for six participants post-intervention, suggesting that they were completing less ADL. This may be linked to increased awareness of function and will be discussed later in this chapter.

At six months post-intervention, six participants showed an increase in their NEADL score from the post-intervention measure (Figure 4-46). Only two participants showed a decrease in ADL at six months. At 12 months post-intervention, four participant showed an increase in NEADL score, however two decreased. Overall, four participants improved in function and ADL at 6 or 12 months post-intervention (depending on the final questionnaire returned) compared to their baseline score. Four participants had a lower NEADL score and therefore a reduction in perceived function at 12 months, compared to baseline.

Figure 4-47 shows the variation in NEADL scores across the study period. There is a great amount of fluctuation in scores over the 12 months and no clear pattern in results. There appears to be a clear drop in scores after baseline, which suggests participants were overestimating their ability and function. Overall, BiH seems to be have a positive effect on function/ADL for most participants, as the NEADL scores generally increased or remained the same post-intervention.

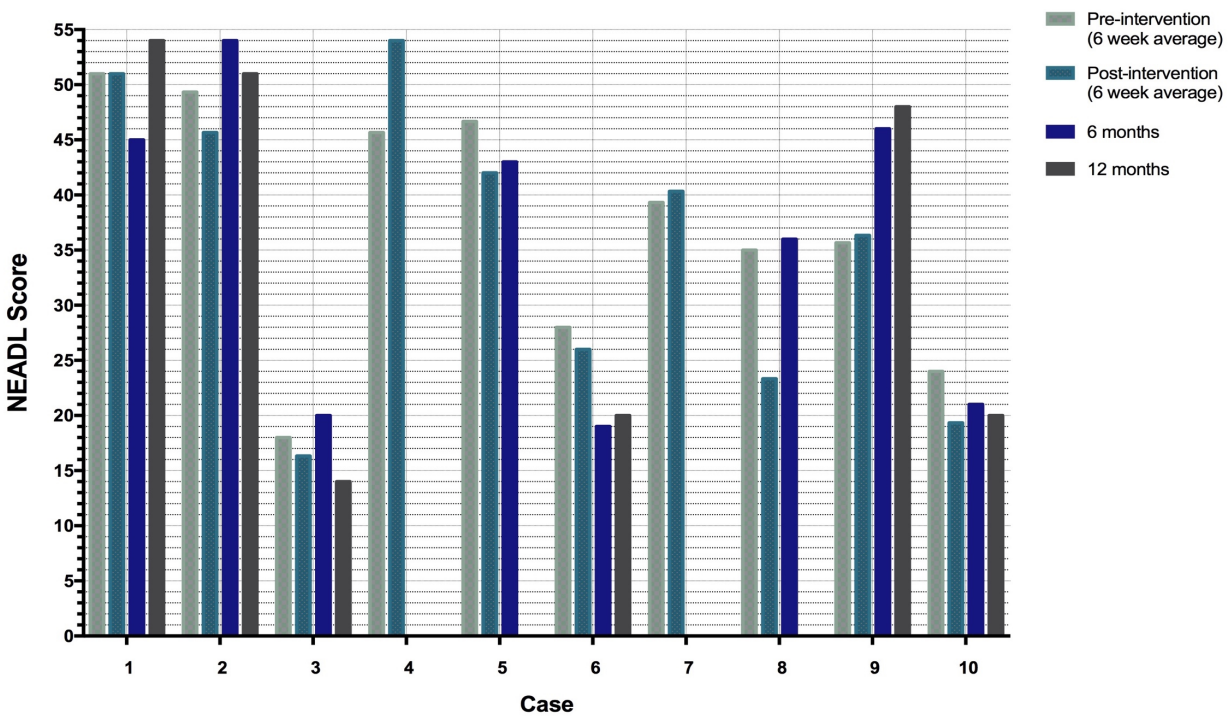


Figure 4-46 Combined NEADL scores (Rasch converted) over the study period showing the (mean) average scores pre- and post-intervention, at six months and 12 months.

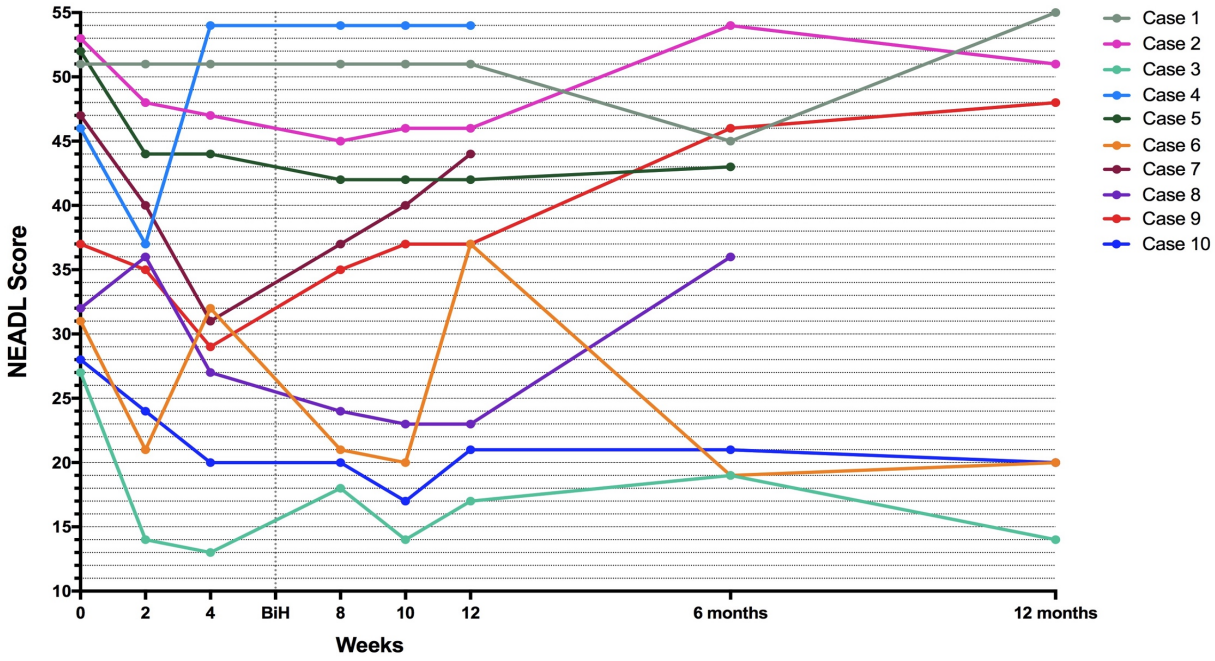


Figure 4-47 Variation in NEADL scores (Rasch converted) for all cases throughout the study period.

4.5.1.4. Fatigue.

Fatigue was reported by multiple participants as their main problem, and something they wanted to monitor and self-manage. Seven of the ten participants used the BiH traffic light system to monitor their fatigue levels. Five of these had a baseline FAS score above the suggested clinical cut-off for post-injury fatigue (Cumming & Mead, 2017). At six months post-intervention, four participants reported a lower level of fatigue shown by a decrease in FAS score (Figure 4-48). Two participants remained the same and two reported higher levels of fatigue (increased FAS score). At 12 months, four participants had a higher level of fatigue shown by an increase in FAS scores. One of these increased and was within into the clinical range of post-injury fatigue. Interestingly, this participant was not using the traffic lights to monitor his fatigue. One participant that was monitoring his levels, improved at 12 months and reported a lower FAS score than baseline. One participant's score did not change from 12 months but improved from baseline.

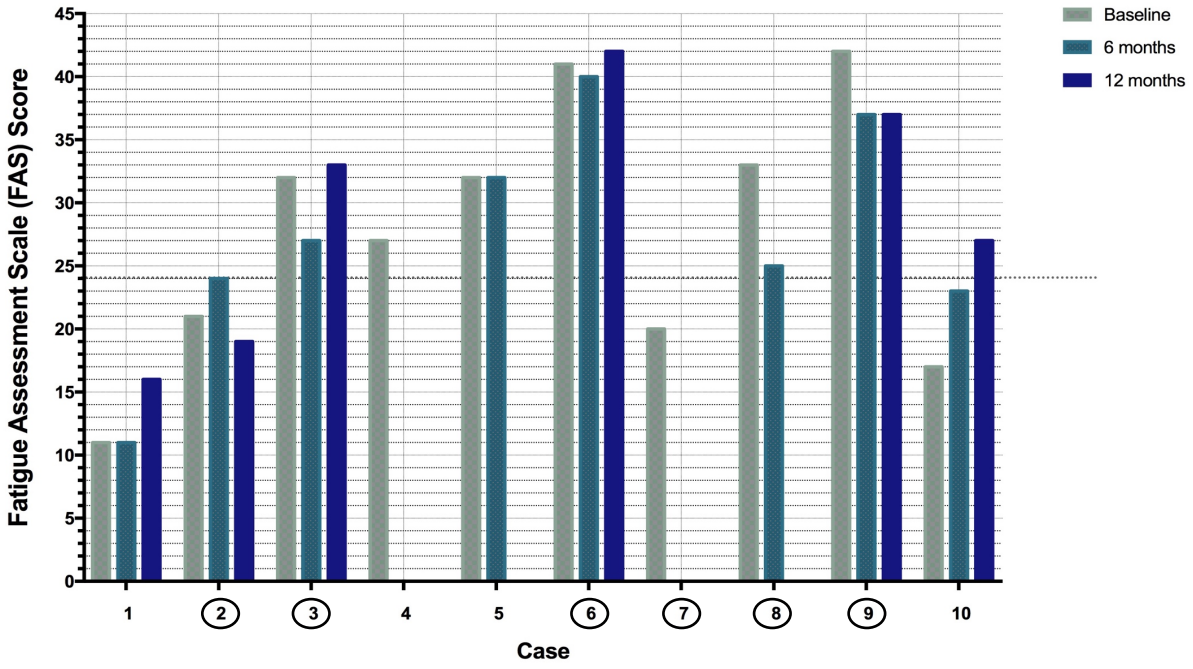


Figure 4-48 Combined fatigue assessment scale (FAS) scores over the study period showing the baseline, 6 month and 12 month post-intervention scores.

Circles identify which participants were monitoring fatigue using the traffic light system. A suggested clinical cut off of fatigue (greater than or equal to 24) is shown by the dotted horizontal line. Minimum score is 10 and maximum score is 50.

4.5.1.5. Goal attainment

Goal attainment was measured using the GAS-Light scale. Eight participants reported a higher GAS score at six months post-intervention. Six participants continued to achieve goals between six and 12 months, however one achieved no goals and their outcome was worse than baseline (i.e., negative GAS score). Figure 4-49 presents the mean GAS-Light scores. A significant increase in GAS was found between baseline (mean=37.21, SD=0.76) and six months post-intervention (mean=53.9, SD=11.02); t(7)=4.20, p=0.004, suggesting that BiH was having a positive effect on goal attainment.

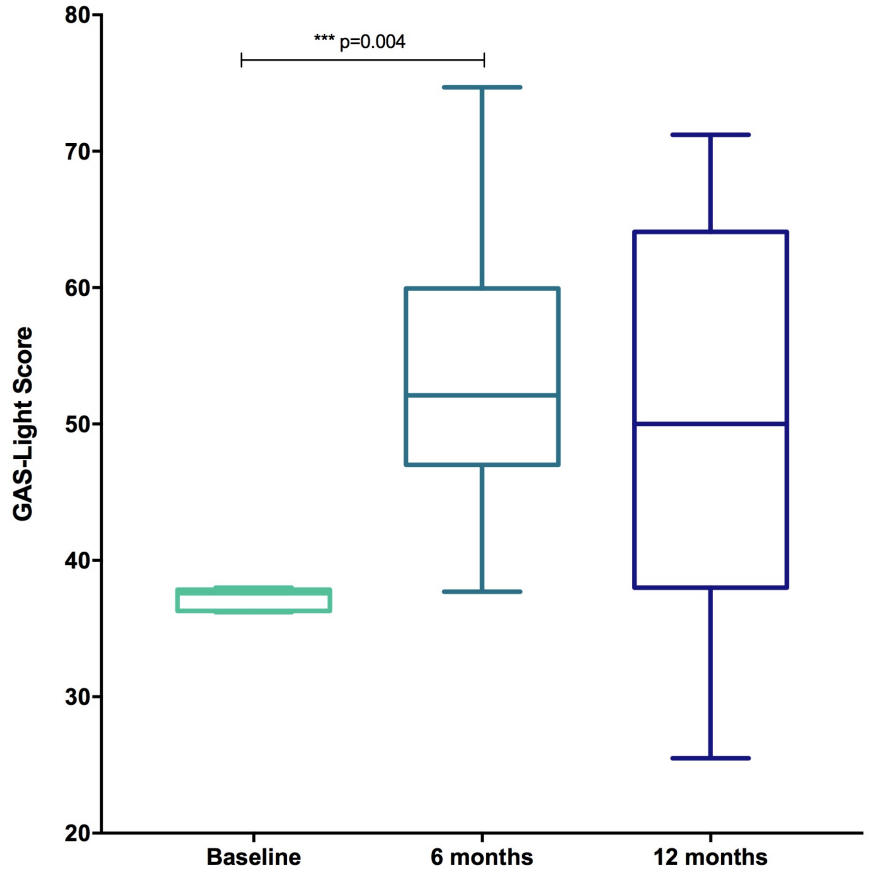


Figure 4-49 Mean GAS-Light scores with interquartile range and range at baseline, six months and 12 months post-intervention.

4.5.1.6. Brain-in-Hand data.

Data exported from the BiH cloud enables comparison across the entire group. Figure 4-50 shows the number of users that were pressing traffic lights and solutions at that point in the study. It also highlights which feature was used most and when app usage started to decline. It is clear from the graph that participants used the traffic light system much more than the solutions function of BiH. Only one to three users at any one time were using the solution function. The traffic light usage increased as more people received BiH and by February 2017, all participants were using the app. At this point, nine of the ten participants were actively pressing the traffic lights and used it most days. By the end of May 2017, traffic light use started to decline and by June, the number of users had decreased by 50% (only four of ten). However, at this point, one participant withdrew from the study, one had lost their password so could not log in to the app, and one had lost their phone. This would explain the decrease in use, then a subsequent spike in August once these issues had been resolved. From September onwards, people started to reach their final 12 month assessments and were no longer taking part in the study. This explains the gradual decline in traffic light use. The use of solutions remained consistently low throughout the study and stopped in September 2017.

The number of completed tasks gradually increased as more people received BiH. By February 2017, all participants had received BiH and the number of completed tasks exceeded the number of incomplete tasks (Figure 4-50A). By the end of May 2017, the trend started to change and more incomplete tasks were being recorded that completed tasks, as shown by the blue line in Figure 4-50B. At this point, most of the six-month interviews had taken place and I was no longer contacting participants, as I had done in the first half of the study (to arrange appointments and interviews). This reduced support may have had an impact on the way participants were using BiH. As the study progressed, from June 2017 onwards, the number of

incomplete tasks continued to increase and the number of completed tasks decreased. This decline was somewhat expected, as participants reached their final assessment and were no longer in the study, however, this decline appeared much sooner.

As the use of traffic lights declined, the number of completed tasks also declined, suggesting that participants were no longer using BiH as frequently as they had done before. This may be due to a reduction in support provided to participants, or a lack of motivation following the six-month interview. This will be discussed in more detail later in the chapter and synthesised with the qualitative findings to ascertain why this decrease in use occurred.

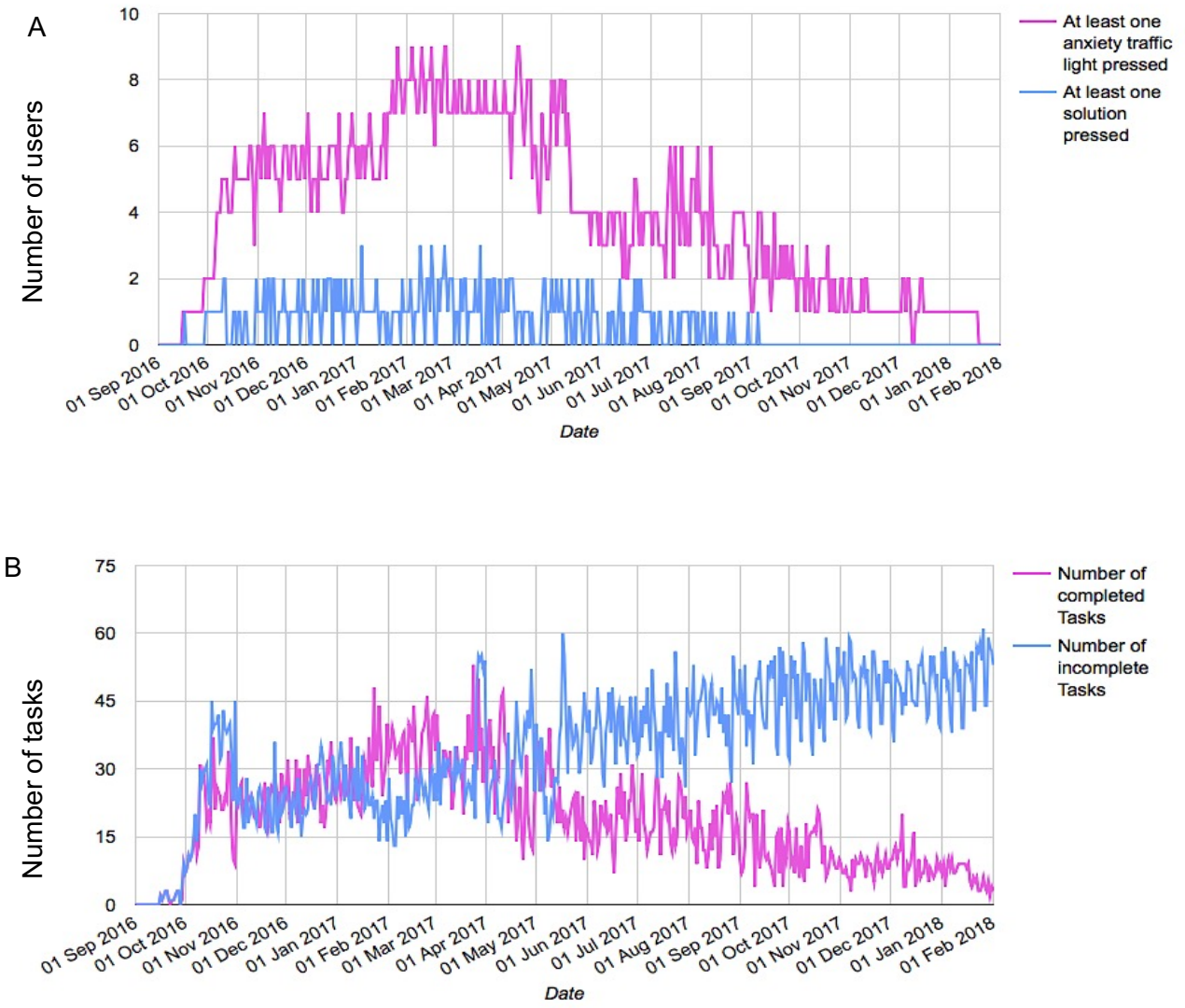


Figure 4-50 Data exported from the BiH app and combined for all cases over the study period.

Data presented from September 2016 (first case received intervention) to February 2018 (final case end of study).
Graph A: total number of users at a certain period of time that pressed at least one traffic light (monitoring fatigue or anxiety) shown in pink and those pressing at least one solution shown in blue; Graph B: total number of users at a certain time period that completed tasks on their BiH app shown in pink and total number of users that did not complete tasks shown in blue.

4.5.2. Combined qualitative data.

Qualitative data was coded and a framework developed (based on the ICF and BCW) once all interviews had been analysed (framework shown in Appendix 12). Following the individual interview analysis presented earlier in this chapter, data was combined for all participants using the framework. This highlighted the most frequently used codes across the whole data set. All transcripts were re-read to ensure the key themes were reflected by all interviews. Some were read by an independent researcher (AW), who agreed with my findings. The themes were presented at a study steering group of mixed professionals (clinical and academic) and service users, who agreed with my interpretation. I concluded that the main emerging themes were:

1. Insight
2. Support and training of people with ABI and HCPs
3. Motivation of people with ABI
4. Technology

The four themes sat within an overarching theme of context. The ICF and BCW were used to inform the coding of interviews and were integral to the analysis of data. A summary of the ICF is shown below in Figure 4-51 to aid the understanding of qualitative findings. The main areas of interest to me when coding the interviews are highlighted by the green shaded boxes; environmental and personal factors.

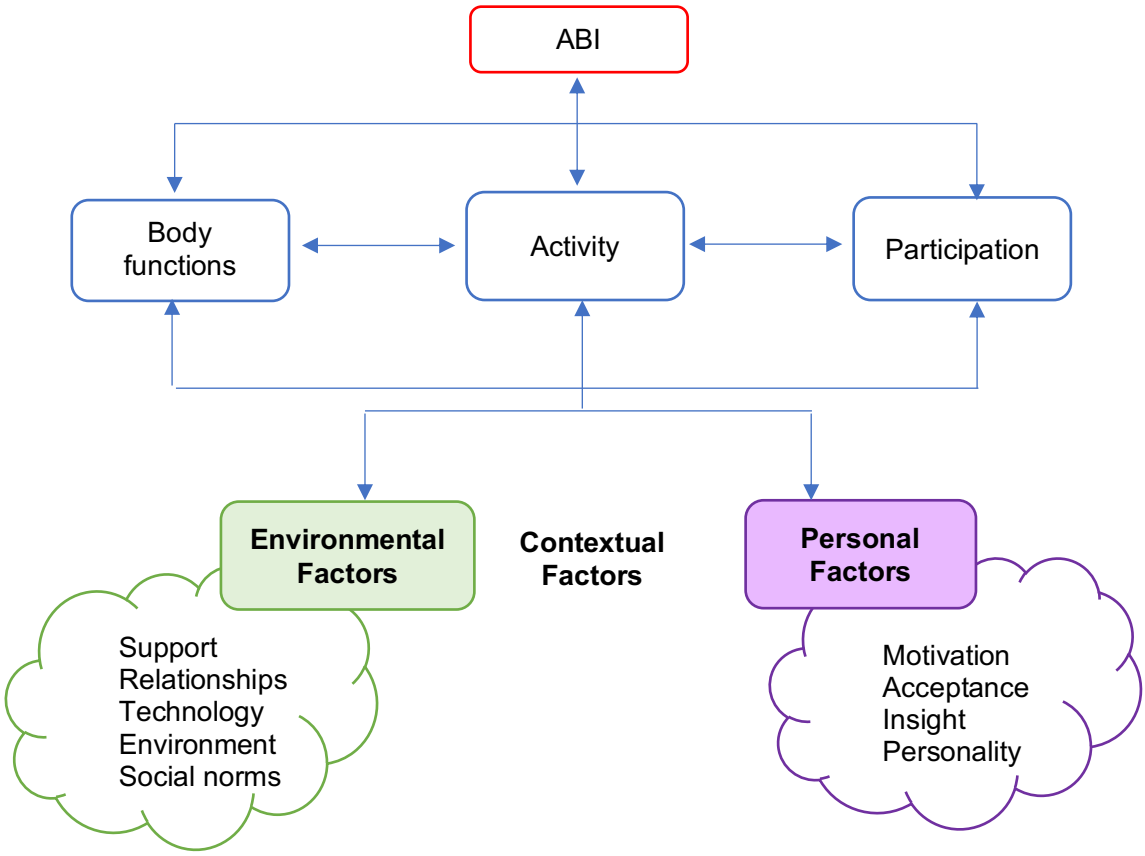


Figure 4-51 Representation of the ICF and coding used to identify barriers and facilitators in qualitative analysis.

The key themes used to code the environmental and personal factors are shown in the green bubbles. These were important to identify key barriers and facilitators within these domains.

4.5.2.1. Main interview themes.

4.5.2.1.1. *Context.*

Context was an overarching theme of all interviews and appeared to play a key role in the use and effectiveness of BiH. Contextual factors include environmental and personal factors as shown in Figure 4-51. It is clear that the contextual factors need to be considered and correct for the ABI user, if BiH is to work in this population. This idea is reflected by the other main themes.

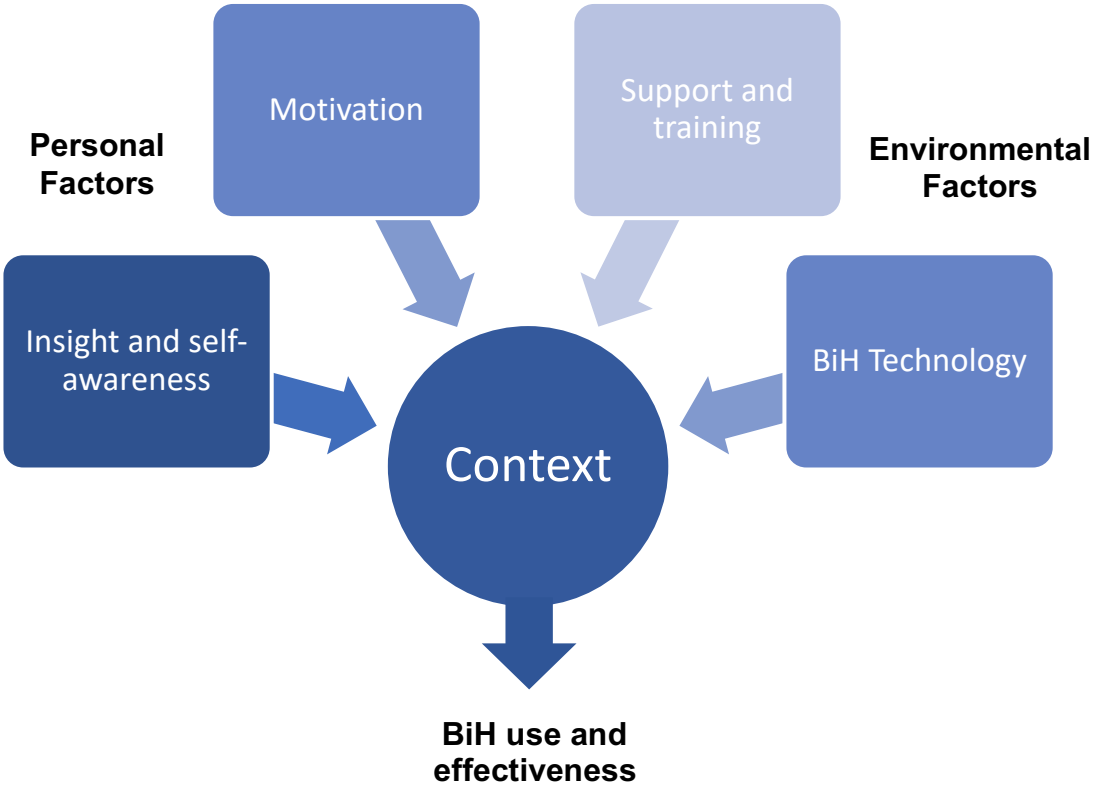


Figure 4-52 Context as an overarching theme and pivotal point for the use and effectiveness of BiH.

Figure 4-52 presents the relationship between context, and the use and effectiveness of BiH. Personal and environmental factors contribute to the context, and in this case, have an influence on the intervention. Environmental factors that were of most importance to ABI participants were support, training and technology. The participants also mentioned various personal factors in their interviews, mainly discussing motivation to use BiH and achieve goals. It was apparent that some individuals had not fully accepted their ABI and did not have a level of self-awareness at that point. This may have been a barrier to intervention use. One HCP suggested fact that if an individual does not have most of these factors in place at the time of intervention, then BiH would not be effective:

> *I work in this area because it's always challenging and we're a bit like the patients, we think that the next thing might be the magic wand that helps us really move them forward, and actually you still come down to the fact that someone's got to have the insight they've got to have the motivation, they've got to have erm, the skills to take themselves forward and no matter how much you want them to go forward, unless you've got the environment right for them, they can't. (Participant 11, female, occupational therapist)*

This highlights the importance of context from a therapy perspective and the need for multiple factors to be considered prior to the implementation of interventions like BiH. This therapist makes the point that no matter how much support an individual has, there are many other personal and environmental elements that can act as barriers. The idea of context and its importance was reflected by all interviews, either focusing on the environmental barriers/facilitators to BiH (such as having access to a computer), but also the personal factors that impact on BiH effectiveness (such as motivation to use the app). The following sections explore the themes within this overarching theme of context.

4.5.2.1.2. *Insight and self-awareness.*

Insight emerged as a key theme running through the interviews. Analysis highlighted the need for people with ABI to possess a level of self-awareness in order for BiH to be useful to the individual. A lack of self-awareness can be defined as, '*the inability to recognise deficits resulting from one's injury*' (FitzGerald, Carton, O'Keeffe, Coen, & Dockree, 2012). Individuals who have some insight and self-awareness are often more able to self-monitor and self-correct behaviour. Participants that recognised their limitations tended to have realistic expectations of BiH and how it could help them. They were also more aware of when they needed to change behaviours (e.g. taking more rests in the day to manage fatigue). Unrealistic goals and lack of motivation are often a result of impaired self-awareness or lack of insight (Robertson & Schmitter-Edgecombe, 2015).

One participant who was lacking some insight, but had the potential to achieve goals, found BiH particularly useful for developing his self-awareness. After using BiH for six months, he became more aware of his anxiety and recognised that he needed to manage this better:

> *Yeah, it's made me face up to that, I have got like an anxiety problem because it's not linked to any kind of depression or anything like that… yeah and this [BiH] reminds me all day that I need to be mindful. (Participant 5, male, TBI)*

Initially, the participant did not feel that BiH was helping him, but as he used the traffic lights more to monitor his anxiety levels, he realised he needed to find a solution to manage this. By using BiH, the individual appeared to gain greater insight into when he became anxious and developed ways to control these feelings.

Conversely, one therapist mentioned that even when individuals have a level of insight, they might not have enough self-awareness to know when to press a red, green or amber traffic light. Some ABI users might struggle to recognise symptoms of fatigue or anxiety, which makes it difficult to monitor when these 'red' episodes (i.e., highly fatigued/anxious) appear most frequently. The therapist mentioned that one barrier to BiH effectiveness and correct use might be that users sometimes don't recognise their symptoms, or might not be completely honest about them:

> *I think for our patients, I think they're trying desperately not to press that for 'I'm struggling', we wanted them to press it for fatigue, but again you've still got an insight issue for am I fatigued or do I want to press this button. Erm they're trying to prove to themselves that they can cope, they don't want to press the button. (Participant 11, female, occupational therapist)*

Some individuals might find it hard being honest with themselves and accepting that they have a problem. One participant realised during the interview that he was not being honest with himself about his fatigue levels. He wanted to let himself believe that his improved health and wellbeing was not due to daily rests, which were set up on his BiH diary. He realised than he was feeling low again because he was not

following the rests and managing fatigue. At this point he had developed a level of self-awareness and recognised where he needed to change:

> *I got on a little bit of a high and I ignored the rest one [reminders] when I was on the high and I've slumped back down again now…I let myself believe that it wasn't [the rest], that I was better and I've stopped following it and things have got worse. (Participant 2, male, ABI)*

Another participant became more aware of the level of support she needed and by six months, she was feeling more independent after using BiH:

> *I: If you never saw your OT again, do you think you could cope with just having the Brain-in-Hand app?*
>
> *R: I think if you asked me that like early on, I wouldn't have been able to cope at all without the OT as well, but I think maybe now that I'm more able, shall we say, and independent I think that I could probably just get on with using just the app. (Participant 3, female, TBI)*

She was not aware of her limitations when she first started using BiH, however she had become more self-aware over the six months and knew that she initially needed support. It was positive to find that BiH had supported independent living and helped her move forward.

4.5.2.1.3. *Support and training.*

Support and training of ABI participants and HCPs emerged as another key theme. Interviews revealed that ongoing support and training would be beneficial for BiH users. Most participants felt that frequent contact (every 1-2 months) from a BiH trainer would help them address any issues they were experiencing with the app. One participant mentioned that greater support would have encouraged him to use BiH more and prompted him to report technical problems:

> *I: Do you think you would have benefitted from maybe, someone from the company providing you with ongoing support?*
>
> *R: That would have probably prompted me to use Brain-in-Hand more, erm having that support, that level of support, even if they were to phone and say look I'm fine thanks. Erm, but it would have given me the opportunity to iron out any niggles. (Participant 2, male, ABI)*

This participant went on to say that support is important because when you have an ABI, you might not always remember what the problem was that you were experiencing:

> I *think the problem with having a brain injury is you can have a problem and you can forget it the next minute. (Participant 2, male, ABI)*

This highlights the need for frequent contact to ensure the app is working correctly for the individual and may prompt them to remember what is wrong. Linking back to the previous theme, some individuals may not have the insight to ask for help when BiH was working. This was apparent for a number of participants after interviewing them and many did not ask for help when they needed it. One participant forgot her password and as a result could not use BiH for several weeks. This was only picked up during the interview when asked why she was not using the app recently:

> *Apart from when I logged myself out of it and didn't know my password so I didn't use it for a couple of weeks. (Participant 9, female, ABI)*

This was significant barrier to use and could have happened to any user. Technical support needs to be improved to avoid these issues.

The BiH monitoring system may be useful for healthcare services, especially social care, allowing HCPs to remotely observe changes in behaviour and receive alerts. However, healthcare services may not have time to provide necessary support:

> *Time is a huge factor for us...I don't think we put enough time in…in an ideal world we would have put much more time into it.*
> *(Participant 12, female, occupational therapist)*

Not having enough time to spend with the person with ABI and ensure BiH is working correctly for them could have an impact on how individuals use the app. The same therapist mentioned that it is not only a time restriction for them within healthcare, but her patient no longer had frequent appointments. This made it difficult for her to notice when he was not getting the most out of BiH:

> *I suppose if he'd been coming in more frequently, it would have been more of a conversation point and I would have picked up then that he wasn't using it and then we could have perhaps we could have taken it, you know, I could have been in touch more and said what can we do.*
> *(Participant 12, female occupational therapist)*

Support from family members may not always be appropriate and could have an effect on BiH use. One participant spoke about the problems associated with having his wife as his mentor. She would receive alerts when a red traffic light was pressed, which initially was useful as he could let her know when he was struggling with high fatigue. However, he then started to worry about how she would feel about this and he didn't want his wife to know how bad his fatigue was. As a result he was less honest when pressing the traffic lights and therefore not benefitting from the self-monitoring component of the app:

> *I don't want to let Kim know that I am struggling, but Kim doesn't really see that I am struggling erm and as she's my wife more than anything else I don't want to let her think I am struggling too much because she will probably dump me…so there is a fear of upsetting… maybe it should be somebody else other than Kim so I get support from another angle without Kim needing to be worried. (Participant 2, male, ABI)*

This was a key point that emerged from the interviews, as it has implications for the long-term implementation of BiH. It is important to select an appropriate mentor or supporter for people using BiH, which might not always be a family member. By choosing the correct source of support, the user may feel more comfortable about pressing the traffic lights and be more honest. The correct mentor may vary depending on the individual, as some people would prefer to be open with those around them.

The presence of good support and therefore appropriate goal setting improved the benefits of BiH for participants. However, it is not always possible to provide enough support in a healthcare environment, particularly within the NHS due to time restrictions. I alluded to this earlier in the section, but it seems that one of the main

benefits of BiH for therapists may not be feasible in an NHS healthcare setting. As the frequency of therapy sessions is limited, sometimes they will not have the time to review their BiH diary:

> *I think if it's a person, quite a lot of our patients we'd be seeing weekly or fortnightly for quite a long period, whereas with [my patient] it's not worked like that. Erm, so I think with that sort of person I would definitely be on it more often just checking what they're doing and as you say, using as a conversation point for when they come in and seeing how they are getting on and just talking about the triggers and just trying to support them a bit probably. (Participant 12, female, occupational therapist)*

4.5.2.1.4. *Motivation.*

Many participants admitted to lacking motivation and some recognised that this was affecting their use of BiH. Unsurprisingly, reduced motivation had an impact on the effectiveness of the app and goal attainment. Some individuals were motivated to maintain BiH use, as they were achieving goals and could see the benefits. One participant spoke about how the app had helped him remember important tasks. However, hadn't realised how much it had benefited his daily life until he reflected on the past six months of use:

> *It has always helped me remember my meds and it has always gone off in my pocket and I've had a look, so it has pretty much helped, erm a lot I would say. I would have said not a lot, but I do think it has helped a lot in hindsight. (Participant 2, male, ABI)*

It was identified throughout the interviews that participants were often unaware of how BiH was benefiting them until they were asked about it. This links back to the earlier theme of insight. If individuals lack insight, they may not see how useful BiH is and therefore be less motivated to use it. One participant had used the solutions on the app so many times that she no longer needed to look at them. This led to reduced motivation as she knew what was coming and didn't bother to select anything on the app:

> *But you see then again when the problems were coming up, I knew what the solutions were without even going into the bit on the phone. I knew what they*

> *were so I didn't bother pressing anything. I think with me it just all boils down to the fact that I know what's coming I know what time it's coming. (Participant 9, female, ABI)*

Sometimes a lack of motivation led to laziness and people not being bothered to change their diary. One participant spoke about his diary changing during school holidays, but there was no easy way to suspend tasks for that period of time. He suggested being able to postpone tasks on the app so that when weeks change, he wouldn't have to ignore things that were irrelevant. Often this resulted in a lack of motivation to change things and it seemed easier to just ignore tasks or click 'complete' on the app so they would disappear:

> *I started to dismiss it when it was buzzing to tell me to do cycling club and it was holidays, erm and cycling club got suspended completely over the winter and I was just, it, I'm going to use a word here, I was too lazy to go in and change it myself. (Participant 2, male, ABI)*

Another participant spoke about how a lack of motivation and laziness meant she had not added anything to her diary:

> *I haven't added things to be honest which I should have done…Its motivation actually, the way I'm feeling at the moment I'm not really motivated to do anything. (Participant 9, female, ABI)*

The wife of one participant (supported during interview as he has dysarthria) stated that her husband had lost interest in using BiH because he knew she would fill in the traffic lights for him and complete tasks in the app if he had already done them. This was not ideal for the participant or his wife, as the app should have been facilitating his independence. However, it ended up adding more pressure to his wife's day. His wife recognised this and took a step back, encouraging him to take control of BiH. This links back to the importance of appropriate support and whether his wife was the one taking control, therefore, not allowing him to use BiH independently:

> *He lost interest and he just left it to me because he knew I was doing it, so I've now, in these last couple of months, I've been trying to step back a bit more and getting him to do more things. Because I just did everything didn't I? [participant 9 nods] So he knows he's got to start doing things. (Wife of Participant 9, male, ABI)*

Some participants liked having the app as it felt like a friend and something they could use to monitor how they were feeling:

> *Well at the start it was a bit of a friend really, erm and yeah it was nice to have it pop up on my phone how are you feeling because it was making me think how I was feeling at the time. (Participant 5, male, TBI)*

He went on to say how pressing a green traffic light made him feel better. This motivated him to keep using the traffic light system:

> *That's why I don't press red or amber because I know what to do so I always go green after all is good and that makes me feel better when I press that. (Participant 5, male, TBI)*

4.5.2.1.5. *Technology.*

As expected, technology was a common theme running through all of the interviews, highlighting some of the barriers that compromised the use and effectiveness of BiH during the study. The ability to edit things on the app was important to most participants, with one user stating that he thinks BiH is useful but hasn't been able to use it in the way he wanted:

> *You know like I say I'm sure it is a really good piece of kit and I have used it to a certain level… I've not been able to use it because you can't update things on your phone I've not been able to use it like my own. (Participant 1, male, TBI)*

This was highlighted by a number of participants as it made changing the diary more difficult, especially if they wanted to add appointments quickly. One participant spoke about how she doesn't add things to her BiH diary when she receives letters as she is doesn't think to go onto her laptop:

> *Well you have to go onto the laptop don't you, you can't do it on the phone…I think, if I could do it on the phone I'd put things onto it straight away. Whereas, if I get an appointment or I read a letter and I'm not in the flat when I read the letter, because my post goes downstairs, I don't think to put it on, you know to go on to my laptop and go into the app that way. (Participant 9, female, ABI)*

Some wanted BiH to have an auditory function so that they could have verbal

reminders throughout the day. One participant struggled to act on instructions when he received them on his phone. His support worker had noticed that the phone reminders didn't work for this person and he needed direct instructions:

> *But if it's like a reminder that's not, it's not a direct instruction, it doesn't seem to have the same effect, like James said he'll think 'oh, I'll do that in 10 minutes' and then he's forgotten, erm which brings me onto my next bit that it needs to follow that up. (Participant 13, female, support worker)*

She also discussed the need for follow-up reminders on the app to check that users had actually completed a task. Other participants discussed the need for tasks to have a start and finish, especially if a something was not an activity that could be completed immediately. One participant spoke about reminders for rests. He often forgot to have a rest as there was no follow-up reminder, which would have been useful when he was distracted by other activities:

> *That's the other thing as well, when you, when it says rest, you complete it, but you, you're pressing rest you've completed your rest before you have your rest. So then if something comes up and stops you from having the rest when you've had your reminder to have your rest, say like a phone call comes through or a client phones you up, then you've failed to have your rest.*
> *(Participant 2, male, ABI)*

Participants suggested adding a postpone task function to the BiH app so that they could delay a task and not forget to complete it. Also, having the ability to follow-up after a task has been completed is important so that users do not forget to do something that they have already clicked 'complete' for. This has implications for the data stored in the BiH cloud and whether users are actually doing the tasks or whether they are forgetting shortly after receiving the notification.

The majority of users found the traffic light monitoring system to be the most useful part of BiH, with a few people preferring the reminder function. All participants found BiH easy to use and could see the benefit of it, even if it wasn't for themselves. Those that weren't over confident with technology also found BiH simple and easy to access:

> *I'm no good with computers or anything anymore and that's just easy, yeah, dead easy. (Participant 5, male, TBI)*

It seemed that all participants were happy using the app and did not necessarily need more training to use the system, but needed more human support, as discussed earlier in this chapter. Although BiH was well received by participants and the majority were motivated to continue use, one key barrier remained:

> *It would be amazing until I lose my phone, then I'd be in a mess. (Participant 5, male, TBI)*

This is an issue for all types of technology and something that unfortunately cannot be avoided. However, the long-term aim of BiH is to encourage users to be more independent and learn new strategies, with the hope that they will not rely on the system. This user was relying on BiH to help with his anxiety and manage daily life so if he was to lose his phone, he would find it hard to cope. Conversely, one user felt that he had become more independent and taken control of his life as a result of using BiH. This shows that although you may begin to rely on BiH for monitoring or reminders, there is the hope that the system will empower people:

> *And I think you've taken ownership of what you have to do…I know we've talked about it but you've said that you felt in control of that, I can do this now I don't need anybody else, I'm independent…I think it's the empowerment, it's that you're not being told to do something, that now it is part of your routine and so your more in control of it, even though some parts of that you do need me just to check. (Wife and carer of Participant 10, male, stroke with aphasia)*

This highlights the importance of BiH to encourage people to self-manage and self-monitor, and ultimately be more independent. Other participants alluded to this idea of empowerment and how they felt more comfortable now with less input from their therapist or carer, while before they could not imagine not having their support.

Finally, various improvements were suggested by participants, which would facilitate the use and effectiveness of BiH in the ABI population. Barriers are always expected

when using technology as often things cannot be prevented, however some issues can be overcome. One user lost their password and another lost their phone for a number of weeks. However, these problems were not mentioned until the interviews, when asked why they had recently stopped using BiH. This links back to the theme of insight and the inability of some participants to use their initiative and ask for help. However, lack of ongoing support or knowing who to contact may have prevented participants from asking for help. Nevertheless, once the users were aware of what they had done and realised how much BiH was helping them prior to losing their password or phone, they seemed more motivated to use it again:

> *Yeah that is positive I mean it's, I mean apart from when I logged myself out of it and didn't know my password so I didn't use it for a couple of weeks, erm I've just got to get back into using it again, but definitely that it sort of makes you think about actually, I'm not so tired today, or actually I am really tired today, you know when you've just got to actually think about it.*
> *(Participant 9, female, ABI)*

4.5.3. Synthesis of data.

4.5.3.1. Convergence coding matrix.

A convergence coding matrix was used to synthesise and integrate the quantitative and qualitative data across all cases. This allowed me to identify whether the key themes from the qualitative findings agreed with the quantitative findings, and vice versa. These themes were searched for agreement and disagreement between the two methods. I used the following coding strategy (O'Cathain A, 2014):

- *Convergence* – this was used if both findings completely agreed.
- *Complementarity* – this was used if findings offered complementary information about the same theme or barrier/facilitator.
- *Disagreement* – this was used if one finding contradicted the other.
- *Silence* – this was used if only one set of findings linked to the theme.

Data was synthesised and is presented in Table 4-26, indicating the level of agreement between data sets. The data generally complemented each other but did not completely agree on all themes. The outcome data collected was quite specific and did not cover some of the information picked up in the interviews with participants (e.g. motivation and insight). However, the mixed methods data obtained from the case studies agreed on some of the findings. Some themes were drawn from the qualitative data alone, with no link to quantitative data, such as contextual factors. The data only disagreed on one theme (anxiety) as the outcome measures showed no improvement, however some participants reported the benefit of BiH for anxiety management. This synthesis has enabled me to interpret and discuss the findings in more detail by adding perspective to the quantitative data and exploring the meaning of the qualitative data when compared with the outcome measures.

Table 4-26 Convergence coding matrix integrating the quantitative and qualitative case study results.

Theme/key finding	Quantitative findings	Qualitative findings	Convergence coding
Anxiety	There were no obvious changes in the anxiety scores (HADS questionnaire) for any of the participants, suggesting that BiH was not having any effect on this outcome.	Out of those participants monitoring anxiety, one of them reported a clear improvement in his anxious demeanour after using BiH for six months. He was using the traffic lights to monitor his anxiety levels and managing them better, especially when at work. He was also using the problems and solutions to cope when he was feel anxious. This suggests that BiH was having a positive effect on his anxiety levels.	Disagreement – the qualitative findings suggest that BiH was helping one of the participants with high anxiety, however this was not observed in the quantitative data.
Cognition	There was no significant improvement in cognitive function, however the combined data showed a mean decrease in MSNQ at six months and again at 12 months. This suggests BiH was having a positive effect on cognitive function.	Participants stated that BiH had helped them remember to take the medication or complete rehabilitation exercises, and it was really useful to have frequent prompts. One participant was using BiH to remind her to eat during the day, which was useful for the first couple of months. However, she would often tick complete task then forget to make some food.	Complementarity - the findings both suggest that BiH was useful to remind participants to complete important tasks.
Contextual factors	There were no specific measures indicating the importance of context in terms of environmental and personal factors.	Interview findings revealed contextual factors as an overarching theme. All participants suggested at least one barrier/facilitator linking to environmental and personal factors. Context was mentioned by HCPs as something that has to be right for an intervention to work. Context was pivotal to the use and effectiveness of BiH.	Silence – only the qualitative data identified contextual factors as an important finding.
Fatigue	Some participants recorded an improvement in fatigue (FAS score) at six months post-intervention, others improved at 12 months post-intervention. However, some participants that were monitoring fatigue with the traffic lights did not report a decrease in fatigue, and some experienced more.	Fatigue was mentioned by some participants who stated that BiH was helping them self-monitor using the traffic light system.	Complementarity
Functional outcomes/ independence	Six participants improved on their NEADL score at six months post-intervention and four improved at 12 months post-intervention. This suggests that BiH was facilitating self-management.	Some participants stated that they felt more independent and empowered after using BiH. Others felt that it had helped them self-manage and rely less on others to remind them to complete tasks.	Complementarity

Goal attainment	BiH appeared to have a positive effect on goal attainment for the majority of participants. Seven of the eight participants achieved at least one BiH related goal at 6 or 12 months post-intervention, two of these achieved 3 of their goals. There was also a significant increase in overall goal attainment (p=0.004) between baseline and 6 months post-intervention.	Participants stated that BiH had helped them work towards specific goals.	Complementarity
Insight	There was a clear drop in NEADL scores from baseline to 2 weeks post-baseline for 8 of the 10 participants. This suggests a lack of insight regarding their abilities with everyday tasks and how much support they needed. As the study progressed, it became clear that those who lacked insight did not use BiH as much, as they could not see a use for it.	Lack of insight was a key barrier to BiH use and effectiveness. Participants that had a level of insight prior to receiving BiH, or developed it as a result of using the intervention, stated that they had benefitted more.	Complementarity - data sets do not completely agree but share complementary information about the participants lacking insight.
Motivation	There were no specific measures of motivation.	Motivation was a key theme identified by nearly all participants. Those that had motivation to use BiH benefitted more from it and achieved more goals. Some that were not motivated recognised this and planned to use it more in the final six months.	Silence – only the qualitative data identified motivation as a key findings.
Ongoing support	As support was withdrawn, the number of completed tasks decreased and incomplete tasks increased as shown in Figure 4-49B. This happened shortly after the 6 month interviews.	Mentioned by most participants that ongoing support would have been useful to encourage them to continue using BiH and help them update their diary, even though they found it easy to use.	Complementarity and Convergence
Self-monitoring	Traffic light usage for all participants over the study period was consistent, suggesting that people were using it for self-monitoring. Out of the 6 participants monitoring fatigue, 4 of them had reported a decreased FAS score at six months post-intervention. One participant initially increased in FAS score at six months, but then decreased below baseline score at 12 months post-intervention. Out of the 4 participants monitoring anxiety, 2 improved (decreased HADS anxiety score) at 12 months. One of these used the traffic lights consistently to monitor his anxiety levels.	Participants found the traffic light system useful for monitoring fatigue or anxiety levels. Those that were using the traffic lights frequently stated that it had made them more aware of their problems. Some participants felt BiH was useful for self-monitoring.	Complementarity

4.6. Discussion

4.6.1. Summary of findings.

The data obtained from each case study provided valuable information about the perspectives and experiences of using BiH and identified potential improvements of the technology. All participants used BiH in a different way, with some focussing on the reminding function and ability to add problems/solutions to their diary. Others preferred the traffic light system and found it helped with anxiety or fatigue management. Overall, BiH helped participants achieve goals and it facilitated self-management in some cases. All participants could see the benefit of BiH, even if it wasn't appropriate for them. Over half (56%) of those still taking part in the study at six months stated they were motivated to continue using BiH. Some of the reasons for wanting to use or losing interest in the app will be explored in the qualitative summary.

4.6.2. Quantitative findings.

4.6.2.1. Effect of BiH on outcomes.

One of the aims of the case studies was to determine if using BiH was associated with improved functional outcomes, quality of life, cognition, mood and participation in society. Individual participants improved on some outcome measures, which may be a result of using BiH, but could also be attributed to other factors or rehabilitation progress. Overall, seven participants improved on at least one outcome. Although there was no significant change in combined data, there was a mean improvement in cognition (MSNQ) and participation (CIQ).

The findings suggest that BiH had a positive impact on cognitive function. At baseline, eight of the ten participants were above the suggested threshold for cognitive impairment, meaning the sample had a lower level of cognition prior to

using BiH. Some of the participants improved at six and 12 months post-intervention, and two of these were frequently using BiH for reminders (one completed 85% medication reminders in the first six months and completed ~60% reminders to eat in the first six months). There is a recognised benefit of reminding devices for people with ABI and various sources corroborate the impact of frequent prompts on cognitive function (Charters et al., 2015; Dowds et al., 2011b; Jamieson et al., 2014; Lannin et al., 2014). This study has shown promising results for the use of BiH to improve cognition.

There was also a decrease in mean NEADL scores and only three participants reported an improvement in these scores. For the remaining participants, there was a worsening in their functional independence over the study period and an obvious drop from baseline to six months post-intervention. The implementation of BiH may have made participants more aware of their impairments, leading to lower NEADL scores, or they may have overestimated their abilities at baseline. The former point can however be seen as a positive outcome for BiH, as it is important for individuals to be self-aware and have a realistic view of their abilities and potential progress. BiH could be used to facilitate self-perception and independent monitoring via the traffic light system in the ABI population.

It could be assumed that a lack of insight led to an overestimation of functional abilities in the context of everyday living. There was a drop in NEADL scores observed in the second assessment, completed two weeks after the baseline measure. As some participants scored higher on the NEADL at baseline, then dropped to a much lower score prior to receiving BiH, it appears their outcome worsened when comparing at six months post-intervention. Due to the heterogeneous nature of ABI, it can often be difficult to capture reliable measures of function, making it hard to draw definite conclusions about the effect of BiH.

Although the decrease in NEADL scores suggests a worsening in functional abilities in the context of ADL, it may be linked to increased awareness of their impairments. Participants were able to recognise their level functional independence better by the end of the study, possibly as a result of using BiH. The app might have highlighted areas of impairment, such as poor memory, need for support or high anxiety.

Anxiety and depression scores fluctuated throughout the study period for most participants, however they all remained within the same clinical range (i.e., HADS cut-off) as their baseline score. Although there was no decrease in mean anxiety or depression scores, some participants reported an improvement in their mood after using BiH. However, this was not picked up by the HADS questionnaire. I anticipated some improvement in the scores over the 12 months, however the impact of other life events may have affected the outcomes. One participant was returning to university and another returned to work during the study. Although these were positive steps in terms of rehabilitation and independence, they were also anxious periods in their lives. Other studies have reported an increase in anxiety following a return to work in the stroke and TBI population (Phillips et al., 2018; Radford et al., 2018). Unexpected changes in a person's daily life can have an impact on outcome measures and it highlights the need for qualitative methods alongside quantitative, to facilitate the collection of contextual information.

Fatigue is a common long-term effect of ABI and can have a significant impact on quality of life. It is important that individuals are aware of when they are feeling tired and when they need to take rests. However, ABI survivors sometimes ignore their fatigue, which leads to poor pacing of activities. This can affect other aspects of life, such as relationships, anxiety and cognitive function. There was no significant change in fatigue levels during the study period, however there was a worsening in the individual FAS scores. At baseline, six participants were above the threshold for

clinical fatigue (FAS) and four monitored this using the BiH traffic lights. Interestingly, only one participant reported improved fatigue levels after using the app for six months. BiH provided a way for individuals to self-monitor and manage their tiredness, and use reminders to encourage frequent rests. The increase in fatigue levels after using BiH suggests that it was not helping, but it may have made them more aware of their impairments. Participants would have benefitted from more training/support to identify what high fatigue meant for them. As the traffic lights can be tailored to the individual, more training needs to be allocated to defining the labels for each traffic light (e.g. red – I feel exhausted and really need to lie down). Fatigue can be different for each person and the way they recognise this needs to be clarified. By personalising the traffic lights, BiH will be more effective at monitoring fatigue, anxiety or other effects following the ABI.

4.6.2.2. Effect of BiH on goal attainment.

Goal setting is important for individuals following ABI and forms an integral part of clinical rehabilitation (Playford, Siegert, Levack, & Freeman, 2009; Wade, 2009). People often feel more determined when working towards personally valued goals. The results from the case studies show that nearly all participants achieved at least one goal, or were close to reaching one. Goal attainment can be affected by various factors in an individual's life, sometimes making them difficult to achieve. Factors may include lack of motivation or opportunity, setbacks associated with injury (e.g. physical difficulties, high fatigue), holidays, work or unplanned family changes (e.g. relationship breakdown, illness). This highlights the importance of setting realistic goals and considering potential barriers to attainment.

The majority of goals in this study were linked to BiH and the data collected from the app determined whether they had been achieved. This included the number of tasks completed and number of solutions used. Those participants that did not reach their

goals were often close to the required percentage for attainment. For example, one person completed 54.2% of all tasks and 60% was their aim, and another completed 49% exercise task and 50% was their aim. By using the BiH data, the attainment of goals was measurable and reliable, however it made the scoring very rigid. As this was a mixed methods study, discussion with participants helped to determine if goals had been achieved when disagreement with the BiH data arose. Other participants had perhaps set unrealistic goals, leading to poor attainment. Goals were guided by therapists (where possible) prior to discussing with individuals, however the anticipated percentage of task completion was usually the choice of the participant. As a result, those that wanted to achieve 60% exercise tasks during the study period only managed to complete 30%. This meant the goal attainment was worse than expected. The findings highlight the need for a therapist or HCP with strong goal setting experience to guide this process and determine a coherent set of criteria for attainment.

There was a significant increase in goal attainment between baseline and six months, suggesting that BiH was having a positive effect on the goal attainment and perhaps encouraged participants to work towards specific goals. However, goal attainment was not as high in the final six months compared to the first six months, which suggests that users may have lost motivation. Participants might have been more engaged if goals were revised throughout.

People with ABI often lack insight, which leads to poor goal setting and unachievable aims (Plant et al., 2016). Ultimately this will impact on their motivation and confidence. Some studies implementing smart technologies have shown that interventions like BiH do facilitate goal attainment. However, when compared to usual care/control (e.g. paper based methods), there is no difference in goal attainment between smart technology and usual care. Sometimes, those that use

pen and paper methods achieve more goals (De Joode et al., 2013; Gracey et al., 2017; Hart & Vaccaro, 2017; Plow & Golding, 2017). This suggest that goal attainment is not linked to the interventions as such, but more to the process of identifying and implementing goals. Researchers indicate that some barriers to goal setting are: a difference in patient and HCP perspectives (i.e., lack of insight in their impairments), lack of skills in goal setting, person with ABI lacking knowledge about goal setting, rehabilitation processes and the individual's potential for recovery (Conneeley, 2004; Leach, Cornwell, Fleming, & Haines, 2010; Plant et al., 2016; Scobbie, McLean, Dixon, Duncan, & Wyke, 2013). These sources corroborate with the case study findings, suggesting that participants did not achieve some goals due to common barriers (such as unrealistic aims, disagreement with HCPs and inexperienced goal setter). These factors should be considered when implementing BiH, and training ABI users and therapists.

4.6.3. Qualitative findings.

The semi-structured interviews were useful to identify key barriers and facilitators to the use and effectiveness of BiH. The qualitative analysis enabled me to add context to some of the quantitative findings and determine if goals had been achieved when the BiH data suggested they had not. By speaking to participants and questioning their use of the intervention, I could obtain information about other problems they had experienced during the study period. In some cases, this may have impacted on their use of BiH and its effectiveness. By looking at the outcome measures and app data alone, these important contextual factors would have been missed.

4.6.3.1. The effect of contextual factors on BiH

Contextual factors are pivotal to the success of BiH, and can be divided into personal and environmental factors (as seen in the ICF). These factors can influence one another and impact on the overall success of the intervention. Ultimately,

context and its interacting components have to be correct for technologies like BiH to work. Researchers have developed one of the first known frameworks to provide guidance for assessing context and implementation of complex interventions (Pfadenhauer et al., 2017). This highlights the importance of understanding these factors and the part they play in the successful translation of evidence based research to clinical practice. Various sources corroborate the need to identify key contextual factors and their impact on the effectiveness of an intervention (May et al., 2007; McCormack et al., 2002; Squires et al., 2015).

The key themes identified by the qualitative analysis have been combined to demonstrate the underlying mechanisms linking these factors. Figure 4-53 summarises the relationships between the key themes. By creating a 'theoretical model' and illustrating the mechanisms of action between environmental and personal factors, I was able to enhance my understanding of the different components of BiH and their impact on use/effectiveness. This theory could be applied to similar complex interventions. The BCW describes the interaction of all components needed to initiate behaviour change and has been useful when evaluating the technology. A similar model could be applied to the BiH components. I will discuss the importance of 'context' alongside 'content' of BiH later in this chapter. The model presented in Figure 4-53 illustrates how context impacts on multiple factors.

The key emerging themes (within the overarching theme of context) were motivation, support, insight and technology. Some participants had a lack of self-awareness and insight, meaning they had the inability to recognise deficits resulting from their ABI (FitzGerald et al., 2012). This was evident in some quantitative measures resulting in the overestimation of abilities. It poses a potential barrier for individuals using BiH and appeared to impact on its effectiveness. Participants that had a level of self-

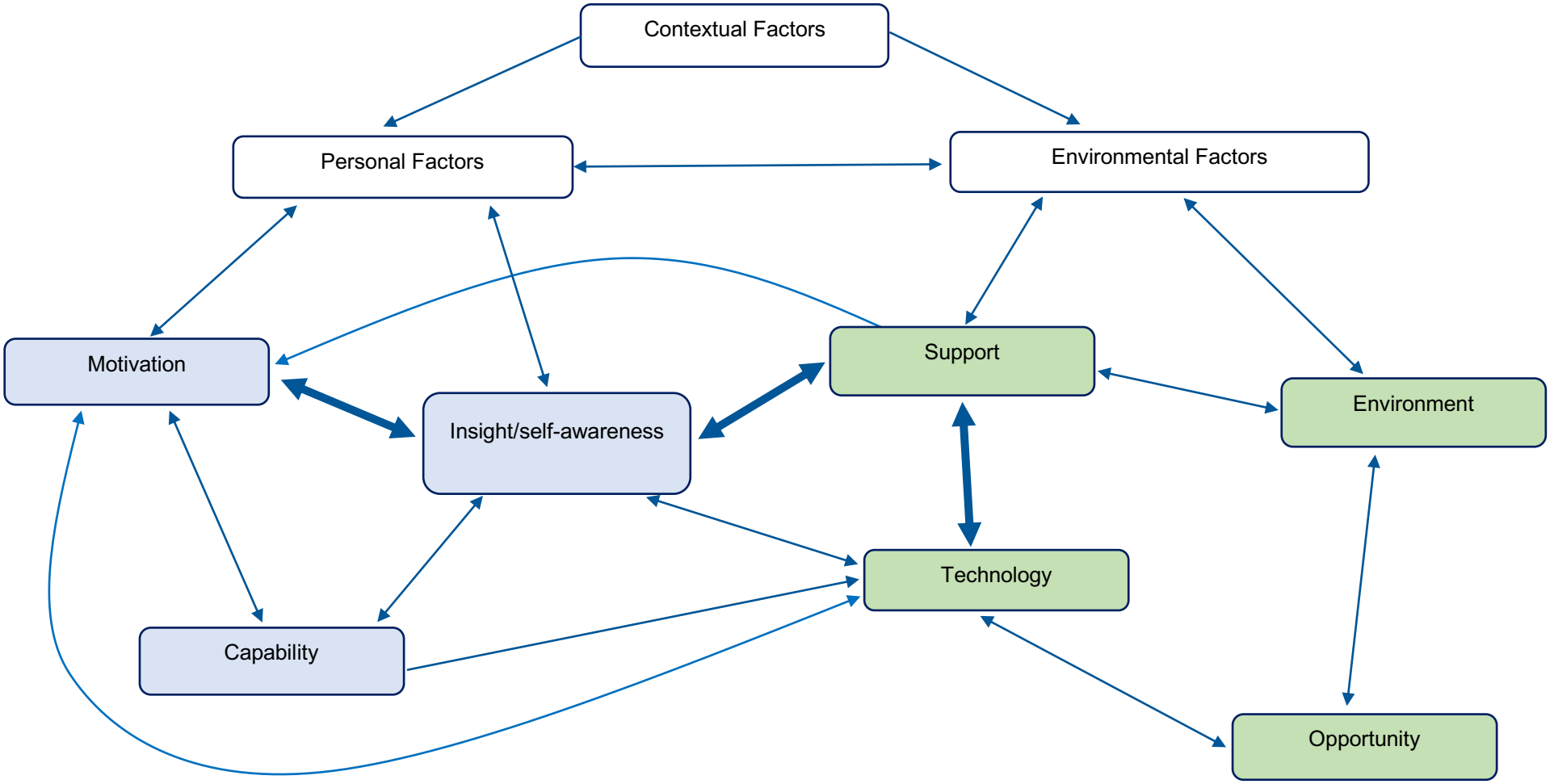


Figure 4-53 Theoretical model of the interaction between the contextual factors associated with the use and effectiveness of BiH.

The arrows indicate the direction of effect from one component to another (i.e., inappropriate support can have a negative impact on the insight of ABI users leading to unrealistic goals. This can lead onto decreased motivation to use the technology). Bold arrows highlight the key areas of impact. Barriers and enablers within these interactions are important.

awareness prior to receiving BiH were able to self-monitor using the traffic light system, and subsequently self-correct behaviour. This also links to their ability to identify attainable goals. Individuals with impaired insight often set themselves unrealistic goals following ABI (Robertson & Schmitter-Edgecombe, 2015). Barriers and facilitators associated with insight and self-awareness also have an impact on motivation and capability. There is a strong link between insight and motivation, as those that cannot see a use for BiH were less motivated to use it. In turn, this lack of motivation impacts on multiple other factors.

Environmental factors play an important role in the use and effectiveness of BiH. Ongoing support and training was identified as a key facilitator. Although participants received a two-hour training session, they felt that ongoing, regular support (e.g. once a month) was necessary to encourage BiH use, but also understand more about the system as a whole. Some participants might not have seen a personal use for it, possibly as a result of reduced insight, but also a lack of support to identify these issues. As with a lack of insight, some participants did not ask for help when they needed it (e.g. forgetting their password). The inability for individuals to use their initiative poses a challenge for technology interventions like BiH. Frequent contact from a technology supporter would reduce this barrier.

Therapists and HCPs require more training around the implementation of BiH, its potential barriers and how it could fit into their current rehabilitation processes. The training of participants is usually well reported in research, however the training of professionals or those delivering the intervention is inconsistently described. By allocating more time to train those using BiH or similar technologies with their patients, the more likely the intervention will be a success. It appeared that some ABI users did not understand how BiH would benefit them, which created a large barrier to its use and effectiveness. However, the therapists may not have fully

understood how BiH could benefit them in their clinical role, by facilitating remote monitoring and goal attainment. This may have limited its effectiveness. As support can have an impact on multiple factors (Figure 4-53), such as the use of the technology, the insight of people with ABI, their motivation to use BiH and the environment, it is important that the support provided is appropriate and sufficient. The incorrect support/training can create a barrier for other interacting components, potentially leading to reduced motivation and ineffective use of BiH.

Technology barriers are common among interventions like BiH and have been reported by multiple sources. The most important finding of this study, with regards to technology, is the impact these barriers can have on other factors and what this means for the overall effectiveness of the intervention. The frequent limitations experienced with technologies are the device not working, cost, persistent technical problems, lack of technical knowledge, losing the device, unable to access the app or system etc. Technology interventions are evolving rapidly and it is important that all barriers are reported by researchers, highlighting the issues experienced with the device and its content, but also the contextual factors, such as the environment and support.

The theoretical model of interacting components provides a way of identifying the key areas of focus for future research and clinical use of BiH. Barriers and facilitators that impact on support, insight/self-awareness, motivation and technology require more attention. These factors were highlighted as the most important during the interviews and have the potential to improve BiH use and effectiveness.

4.6.4. Synthesis of findings.

Using the convergence coding matrix facilitated the synthesis of findings and enriched my analysis. Although the data did not completely agree, it offered

complementary information about the key themes. As there was no clear change in quantitative measures and a lack of goal attainment for some participants, it appeared that BiH had been ineffective. By introducing the qualitative findings and converging the data sets, I was able to add contextual information to the questionnaires. This facilitated understanding of why some participant outcomes worsened and in most cases, this was not linked to BiH. It also emphasised the key barriers, both environmental and personal, that need to be addressed prior to implementation.

4.6.4.1. Importance of context and content.

Technologies like BiH can be divided into two components (Figure 4-54). The findings of this thesis suggest that technology has two parts: the 'Big T' (context) and the 'small t' (content). Researchers should consider both of these when designing and evaluating interventions. The 'small t' refers to how the technology actually works (i.e., nuts and bolts). It includes the smartphone app and online portal for BiH. This element can be thought of as the intervention 'content' and the object/device that individuals will use. Without addressing barriers associated with this part of the technology, it would not be as effective and sometimes not work at all. Barriers include losing the smartphone, the app not working correctly, losing login details and having no access to a computer to edit the BiH app.

The second element of technology is the 'Big T', or the system as a whole. As with the content of the intervention, the context is equally important and if barriers associated with this are not addressed, the technology will be less effective or not used. The 'Big T' refers to many interacting components that can either hinder or facilitate successful implementation. The key contextual factors that influence BiH use/effectiveness have been explored in this thesis (Figure 4-52). Context not only

refers to the environment, but also the personal factors such as motivation, insight and capability.

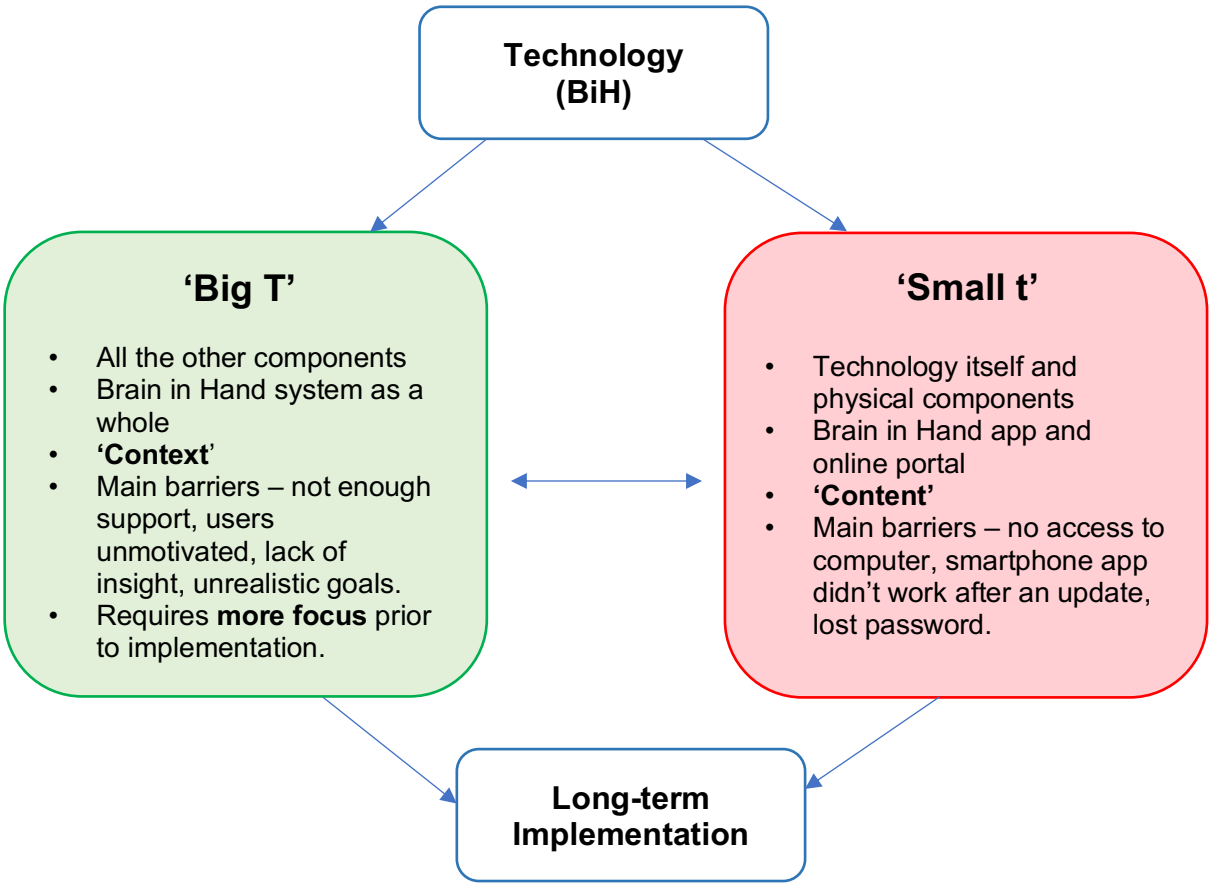


Figure 4-54 Representation of the two elements necessary for the long-term implementation of technologies like BiH.

The idea of context and content has been corroborated by other researchers, highlighting their importance in implementation (Palinkas et al., 2011; Roberts et al., 2017; Vignoli, Nielsen, Guglielmi, Tabanelli, & Violante, 2017). However, there is limited evidence supporting the interaction between the 'Big T' and the 'small t', with many studies focussing on the environmental context (i.e., setting) rather than the intervention as a whole (i.e., environmental and personal factors).

Context is pivotal to the success of BiH and similar technologies. When implementing complex interventions like BiH, the environmental and personal factors need to be considered. Various barriers and facilitators are associated with these factors and should be addressed alongside the technology itself.

4.6.5. Strengths and limitations.

One of the main strengths of the study was the n-of-1 design. This use of this methodology enabled me to explore the data obtained from each case in more depth. By using this design, I could determine whether the intervention was having any effect on individual outcomes, rather than comparison as a group of participants. I was also able to compare the results within each individual case (within-subject) but also between cases (between-subjects). This added another element to my analysis and as a result my findings are more robust and detailed. Although some participants withdrew, which may have been due to the length of the study and a lack of ongoing support, I feel the 12-month study duration was a strength rather than a limitation. It allowed me to see what might happen in clinical practice if BiH use is unsupported and goals are not reviewed. This may have not been captured with a shorter study duration.

Another strength of the study was the mixed methods design, as it provided a comprehensive description of the effectiveness of BiH and the key factors that could impact on the long-term implementation of BiH. By using quantitative and qualitative methods, I could explore the barriers and facilitators contributing to the use and effectiveness of a complex intervention. The combination of quantitative and qualitative methods provided me with a rich insight into the experiences and perspectives of those with ABI using BiH. Also, the integration of the mixed methods added another strength by using a convergence coding matrix to determine whether findings agreed with each other and where divergence occurred. This provided a

further element of comprehension across findings and highlights the challenges faced when evaluating technologies like BiH. It also emphasises the need for mixed methods when designing implementation research and examine the content and context of complex interventions (Palinkas et al., 2011).

A final strength was using theoretical models to inform my topic guides and qualitative analysis, but also the reporting of case studies. By using the ICF to aid the reporting of the case studies and guide interview coding, I have identified core, transferable information about BiH and factors affecting its implementation. This universal framework enables researchers and clinicians to explore my findings in a common language, which can be applied to other complex interventions. The BCW was used to identify key barriers and facilitators that impact on the components necessary to bring about behaviour change – capability, opportunity and motivation. By using these components to guide qualitative analysis and coding, I have been able to provide a clear exploration into the behavioural/contextual factors affecting the use of BiH and its effectiveness in the ABI population. The BCW has also been used successfully by other researchers to guide intervention development. Alongside the ICF, both frameworks have provided a useful theoretical basis for further development of BiH and an insight into the contextual factors that require more focus prior to a larger study.

Although there were many strengths to this study, there were also limitations:

- Some of the outcome measures used might not have been sensitive enough to detect relevant changes. They were useful to show overall patterns of change, such as reduced levels of anxiety and fatigue, or improvements in ADL. However, no clear conclusions could be derived about whether BiH was effective at improving any of the outcome measures. Also, some of the measures used were inappropriate for certain participants that were functionally able and did not

experience anxiety or depression. Although the measures were selected based on the design of the study (n-of-1) and consideration of previously used measures in similar studies, they did not appear to capture the improvements identified by the qualitative data.

- The short training period provided to participants in line with the usual practice for BiH (autistic users receive two hours training) may not have been suitable for the ABI population. As cognitive impairment and communication difficulties are often experienced following brain injury and stroke, it took some participants longer to grasp the concept of BiH. They all found the device easy to use and competently navigated the app, however some did not understand the context of BiH within their rehabilitation, as opposed to its content (i.e., how to use the app and system). This links back to the idea of insight and ability to see a personal need for the device. A limitation of the study design was that more training time could not be allocated to specific individuals that needed support. In a future study, participants may benefit more from shorter and more frequent sessions over the first four weeks, to reinforce learning and facilitate their understanding of its context in everyday life (i.e., how can it help them achieve goals, why do they need to use it, why is the potential of BiH for them long term).
- There was a drop in NEADL scores shortly after baseline, suggesting that participants were not reliably scoring their functional abilities in ADL. BiH might have raised awareness and made participants recognise their limitations, thus resulting in a worse NEADL score. As with other types of therapy, there can be a worsening in outcomes before an improvement. This meant that analysis comparing the initial 12 week data, then six and 12 month (post-intervention) data with baseline scores, may not have reflected the true change in outcome measures. A longer baseline period may have been required to establish a stable result. This is why a pre-intervention average has been used in the combined quantitative analysis.

- Goal setting was conducted by a researcher within limited clinical experience, which may have impacted on the attainment of goals in the case studies. Although GAS was guided by the participants' therapists, where applicable, or a relative/carer, the final setting of goals was between the participant and researcher. This might have impacted on the criteria for attainment, with some participants having unrealistic expectations of themselves. In a future study or in clinical practice, the aims/goals of BiH should be overseen by someone with substantial clinical experience in goal setting.
- The quantitative analysis of the study could have been improved by determining the effect of BiH vs. reliable change, rather than comparing mean change in scores and movement between clinical boundaries. The Leeds Reliable Change Index could have been used to calculate benchmarks and determine whether change in the questionnaire score was significant and reliable. However, as there was no obvious change in any of the measures, it may not have added any value to the findings.

4.7. Summary

The case studies identified key barriers and facilitators associated with BiH and its potential success in practice. By using mixed methods, I was able to determine if the app had any effect on functional outcomes, cognition, goal attainment, fatigue and mood, but also understand more about the interaction of intervention components. BiH appeared to have no clear effect on the majority of outcome measures, but participants reported an improvement in anxiety and fatigue levels as a result of using the technology. While some participants improved, others appeared to deteriorate. There was a significant improvement in goal attainment after using BiH for six months. The findings suggest that BiH is more helpful for individuals with specific characteristics, such as those that have a level of insight and are aware of their impairments (even if they aren't aware of the extent of them), and individuals

with cognitive impairment and need BiH to support planning and decision making. The participants that reported an improvement in cognitive function (decreased MSNQ score) set memory and planning related goals at baseline. This suggests that BiH might be most useful for reminding and structuring daily routine. Various barriers were identified that need to be addressed prior to implementation. The main issues were linked to: 1) a lack of support and training, or inappropriate support, 2) participants not feeling motivated to use BiH, 3) lack of insight and self-awareness to set realistic goals and identify a personal need for BiH, and 4) persistent technical problems and common technical issues that meant participants could not use the app. It is important that both the content (small t) and context (big T) of interventions like BiH are consistently reported by researchers, so that technology can progress and common barriers avoided. Both of these elements are pivotal to the success of BiH, however the contextual factors require more focus during the early stages of implementation research.

Chapter 5 Feasibility of Health Economics Evaluation

5.1. Chapter Overview

This chapter will discuss the findings of a feasibility health economics evaluation of the use of BiH in the ABI population, including the resource use of participants before injury, pre-intervention and post-intervention. The costs of the intervention (BiH) are presented (including the cost of providing the equipment and the service to users), identifying the key cost drivers in this population. The feasibility of collecting resource use data has been explored and a framework for a larger trial to evaluate cost-effectiveness of BiH has been created. The findings from this evaluation alongside the case study findings have informed the design of a future feasibility trial.

5.2. Introduction

Health economic evaluation involves the analysis of costs and effects of alternative interventions within a given population, to determine which has the greatest benefit in terms of cost and gain (i.e., improvement in quality of life) (Drummond, Weatherly, & Ferguson, 2008; Drummond, Drummond, & McGuire, 2001; Shiell, Donaldson, Mitton, & Currie, 2002). The aim of economic evaluation in healthcare is to present data and conclusions to support decision making when prioritising interventions based on the greatest benefit per unit of cost. Evaluation helps to identify the best course of action, based on the evidence available.

Within the context of rehabilitation interventions, it is important to ensure aims and methods of future trials are consistent with UK decision making bodies such as the National Institute for Health and Care Excellence (NICE). In 2014, NICE published a

set of guidelines for intervention development, suggesting that the incorporation of economic evidence within the context of public health interventions is essential (NICE, 2014a). To determine whether an intervention is effective, studies need to identify if it actually works (i.e., does it improve outcomes) and whether it is worth the cost. NICE recommends that these types of evaluations should adopt a consistent approach to ensure the appropriate outcomes and costs are reported.

Specialist rehabilitation following ABI is reported as a highly cost-effective intervention, as it provides an offset by savings in costs of community care (Barber et al., 2018; Oddy & da Silva Ramos, 2013; Turner-Stokes, 2004, 2007; Turner-Stokes, Williams, Bill, Bassett, & Sephton, 2016). A multicentre cohort analysis found that the mean total cost of a rehabilitation programme was £39,381 and mean savings in community care costs was £496 per week. The time taken to offset the initial costs took an average of 17.9 months (Turner-Stokes et al., 2016). There is evidence to show rehabilitation interventions following ABI can improve outcomes, quality of life and decrease medical costs by decreasing length of hospital stay (Barnes & Radermacher, 2003; Edwards, Thompson, Losseff, & Playford, 2002; Kwakkel, Wagenaar, Twisk, Lankhorst, & Koetsier, 1999; Langhorne, Williams, Gilchrist, & Howie, 1993; Turner-Stokes, 2008). Health economics evaluations show that specialist rehabilitation interventions can reduce the costs of disability and health/social care (Turner-Stokes, 2007; Turner-Stokes et al., 2006; Worthington, Matthews, Melia, & Oddy, 2006). Researchers have demonstrated societal cost benefits from a community reintegration intervention following brain injury (van Heugten et al., 2011), another study found that continuous rehabilitation is more effective and less expensive that interrupted rehabilitation (i.e., broken chain of treatment) (Andelic et al., 2014). A different study reported an average cost benefit of £1.13 million per person with brain injury following neuro-behavioural rehabilitation within one year post-injury (Oddy & da Silva Ramos, 2013). Although there is a

wealth of evidence to suggest these types of interventions are clinically effective and cost-effective, there is a current lack of provision for rehabilitation services and a growing number of people not receiving the support they need.

There is currently limited evidence for the cost-effectiveness of technology interventions and no known economic evaluation to date of personal smart technologies like BiH. There is a need to address this gap in research, however, key questions need to be considered at this early stage to ensure an economic evaluation is feasible and is designed appropriately (i.e., which perspective should be taken, which measures of health and non-health benefits should be used). Therefore, this feasibility of health economics evaluation was conducted to determine whether accurate and comprehensive data could be collected on relevant resource use in the ABI population. This evaluation focuses on testing the feasibility of collecting resource use and cost data only, not health-related quality of life data. It was also designed to identify key cost drivers and inform a framework for a future economic evaluation. A cost analysis estimating the rates of intervention provision and the key cost drivers has been be carried out.

5.2.1. Aims.

The overall aim of this study was to determine the feasibility of collecting relevant resource use data in the ABI population and consider key cost drivers associated with BiH.

The objectives of the economic evaluation were:

- To assess the feasibility of collecting resource use data and costs from the ABI population.
- To evaluate the feasibility of attributing costs to resource use using national published data and local unit costs.

- To provide a preliminary assessment of the costs associated with implementing BiH.
- To provide suggestions of a suitable economic evaluation framework for a future feasibility RCT.

5.3. Methods

5.3.1. Participants.

Participants with ABI (n=10) that were taking part in the case studies (chapter 4) and received BiH for 12 months, were asked to complete a service use questionnaire (SUQ) at baseline, six and 12 months post-intervention.

5.3.2. Data collection.

5.3.2.1. Service use questionnaire.

The SUQ was used to identify the health and social care services that individual uses/receives through the NHS. This included contact with consultants, occupational therapists, physiotherapists, support workers, psychologists, GPs, nurses, case managers, speech and language therapists, psychologists and other HCPs. The questionnaire asked for information regarding work status, state benefits, compensation claims and medication use, to obtain an estimation of social and health service use. The SUQ was used in this study to determine the potential impact BiH intervention may have on health and social care costs and identify the main cost drivers.

Resource use data were collected from participants taking part in the case studies by self-reported questionnaires (off the shelf and bespoke questionnaires). These were completed at baseline, then at six and 12 months post-intervention. Resources included contact with healthcare providers (community and hospital), social services and any other services that had been used in the past three months. Participants

were asked to detail the amount of time in contact with these services and frequency of visits. At various assessment points (baseline, six and 12 months), participants were asked to report resource use over the previous three months.

The feasibility of collecting comprehensive data was determined by the usefulness of data reported (i.e., were conclusions drawn) and whether it provided the necessary information to meet the study objectives. The amount of missing data was recorded to determine how well the questionnaire was completed by each participant (i.e., its accuracy). Also, difficulties associated with completing the questionnaire were recorded. This was noted if data appeared contradictory and in instances when too many options were selected. If participants reported confusion with specific questions and required help, this was also recorded. This information was used to determine the feasibility of collecting resource use data in the ABI population.

5.3.3. Resource use and costing.

Resource use and costs were evaluated from a health and social care perspective. Participants were asked to record how many inpatient/outpatient appointments they had attended and identify the professionals they had seen over the past three months. This also included social care appointments and visits. Where possible, the services used by each participant were costed using published sources (references shown in Table 5-1).

Participants were also asked to report any medication they were currently taking, what the dose was and how long they had been taking this. This was costed using the BNF (Joint Formulary Committee, 2018). The frequency and cost of all services and medication were calculated for each participant at baseline, six months post-intervention and 12 months post-intervention. Where participants reported no

change in medication at follow-up, it was assumed that medication was unchanged. In the case of missing data, a recommended dose was applied.

Table 5-1 Unit costs for health and social care

Resource Item	Setting	Unit Cost per hour [including qualification]	Source	Comments
Clinical Psychologist (Band 8a-b)	Community	£62-74 Mean = £68	PSSRU unit costs 2017[a]	No specific data about unit cost for this role - estimated from NHS bands.
Consultant clinical Psychologist (Band 8c-d)	Community	£87-106 Mean = £96.50		No specific data about unit cost for this role - estimated from NHS bands.
Case manager (Band 7)	Community	£45		No specific data about case manager unit cost - estimated from NHS bands.
Physiotherapist (Band 5)	Community	£34 [£38]	PSSRU unit costs 2015[b]	
SALT (Band 5)	Community	£34 [£38]		
OT (Band 6)	Community	£42 [£45]	PSSRU unit costs 2017[a]	
Practice nurse (Band 5)	GP	£36 [£42]		
Advanced nurse practitioner (Band 7)	Community	£53		No specific data about unit cost for this role - estimated from NHS bands.
CBT (average duration 55 minutes)	Community		PSSRU unit costs 2016[c]	£97 per CBT session
Support worker (adult services)	Community	£40 [£57]		£55 [£79] per hour of client-related work
GP (per patient contact lasting 9.22 minutes)	GP	£205 [£242]	PSSRU unit costs 2017[a]	Per patient contact lasting 9.22 minutes £32 [£38 with qualifications]. Including direct care staff costs and carbon emissions (5 $KgCO2e)^2$(carbon costs less than £1).
Consultant: surgical	Hospital	£107		Unit cost per working hour.
Consultant: medical	Hospital	£106		Unit cost per working hour.
Orthotist (band 5)	Hospital	£34 [£38]		No specific data about unit cost for this role - estimated from NHS bands.
Medication	GP		BNF	Cost of prescribed drug if known (British National Formulary: BNF).

[a] Personal Social Services Research Unit (PSSRU) Unit costs of health and social care 2017 (Curtis & Burns, 2017)
[b] PSSRU Unit costs of health and social care 2015 (Curtis & Burns, 2015)
[c] PSSRU Unit costs of health and social care 2016 (Curtis & Burns, 2016)

The costs of the BiH intervention were obtained directly from the company providing the system (Brain in Hand Ltd.). This included the cost of annual licenses and additional training costs. As the company did not provide all of the training during the study, separate costs have been calculated for a research assistant (or in this thesis, myself as a PhD student) to deliver the training to ABI participants and therapists. Resource item unit costs and sources are shown in Table 5-2. An overall cost of the intervention for the ten case studies participants will be calculated.

Table 5-2 Unit costs of the BiH intervention.

	Resource Item	Description	Cost (£)	Unit cost (£)	Source
Intervention specific costs	**Standard individual BiH license**	Cost to receive BiH license for 12 months without the traffic light response. Includes training and set-up.	648	54/month	Brain in Hand Ltd.
	BiH license with traffic light responder	Cost to receive BiH license for 12 months with a traffic light responder (currently using a charity to provide this in the autistic population, see chapter 1). Includes training and set-up.	995	82.92/month	Brain in Hand Ltd.
	Group BiH license	Cost of a group license for BiH for 12 months without the traffic light responder as this would normally be supplied by the organisation purchasing the licenses.	540 (excl. VAT)	45/month	Brain in Hand Ltd.
	Training and set-up of BiH app for all users	Training session for users. Typically 4 hours of training split over 2 sessions (2 hours each). This cost is included in the overall license cost.	336	84/hour	Brain in Hand Ltd.
	Red button supporter	Cost to add a traffic light responder for 12 months alongside the standard BiH license.	347	28.92/month	Brain in Hand Ltd.
	Additional support sessions	Any additional training sessions required for users. This is not included in the overall license cost.	84	84/hour	Brain in Hand Ltd.
	Training of therapists	Typically the therapist would be trained alongside the individual users, however in-depth bespoke training can be provided over one day .	400	50/hour	Brain in Hand Ltd.
Other costs	**Research assistant (PhD student) to deliver training**	Training and set-up sessions provided to all participants and therapists. The sessions lasted 2 hours.	34	17/hour	University of Nottingham
	Additional support provided by research assistant (PhD student)	Any additional training sessions or support needed.	17	17/hour	University of Nottingham

5.3.4. Accuracy of self-reporting.

To check the accuracy of participant questionnaire responses, information regarding appointments and contact with services was verified by treating therapist(s) where possible. If participants did not have a therapist (or did not have frequent contact with one), their significant other, carer or support worker was consulted, to verify if the number of appointments, time of appointment and medication was correct. I was unable to contact GPs to verify appointments with them or hospital admission, as ethics approval for the case studies did not permit this activity.

5.4. Results

The feasibility of collecting the economic data will be discussed, including the practical aspects of this and difficulties experienced with completing SUQs. The amount of missing data will be presented, along with the costs of the intervention (BiH) and the results of the economic evaluation of resource use from a health and social care perspective.

5.4.1. Feasibility of collecting economic data.

5.4.1.1. Missing data.

The SUQ was completed in full (100% questions answered) by all participants (n=10) at baseline. At six months post-intervention one participant had withdrawn from the study and two participants did not return their postal questionnaires. Therefore, service use data was only collected from seven participants. However, the ones that were returned did not have any missing data. The only problem was the reporting of HCP appointments for one participant, as they used the names of the person they saw rather than their role. However, as I knew the members of the ABI team, I was able to assign the correct cost for that appointment/service use. This is a potential issue when completing the SUQ, as some individuals might not

know the specific job title for clinicians they are seeing. If I had been unaware of any names, I would have contacted the participant or ABI team to clarify. At 12 months post-intervention, one participant had withdrawn from the study and some participants (n=3) did not return their SUQs, therefore there was only service use data obtained from six participants. Again, all questionnaires were completed in full.

5.4.1.2. Practical considerations.

Most participants were supported by a therapist, family member, carer, or by myself when completing the SUQs. At baseline, all participants were supported by myself and any queries regarding confusing questions were either explained to them in greater detail, or a therapist/family member was consulted to establish the correct answer. The majority of these questions were linked to medication (e.g. dose and frequency) or number/duration of appointments with HCPs. At six and 12 months post-intervention, participants were not always supported by someone when completing the SUQ, however this did not seem to affect the completeness of data. This may not have been the case if participants had not previously completed the SUQ with support. To ensure accuracy and completeness of the questionnaire, there should be someone available to provide support and explain questions to those with ABI. Otherwise, questions could be simplified or presented differently to facilitate understanding.

5.4.2. Feasibility of attributing costs.

The costing of resource use was straightforward and easy to attribute published unit costs to the majority of services. The Personal Social Services Research Unit (PSSRU) documents were used to locate the unit costs for all resource items, apart from medication (costed using the BNF as detailed in the methods). Some roles were not specifically outlined in the PSSRU documents as with some other job titles (e.g. GP, support worker), so the unit cost for the NHS band was used instead. This

was the case for some of the community based rehabilitation roles, such as case manager, speech and language therapist, orthotist and clinical psychologist. The PSSRU 2017 document specifies where these roles sit within the NHS bands, which made the attribution of costs easier. Using the online version of the BNF to determine medication costs was straight forward and simple to navigate, making the attribution of costs simple. Overall, the costing of health and social care resource use would be feasible in a larger trial, as the unit costs for most services have already been determined. Updated versions of the PSSRU would however need to be checked and other databases (e.g., NHS reference costs) would be explored to provide a comprehensive coverage of costs.

5.4.3. Pre-injury economic status of participants.

Only one participant (10%) reported having the lowest household income prior to injury (<£10,000 per annum) and one participant was a student so did not have an annual income on the day before injury. Three participants (30%) had an annual income of £10-19,999, three participants (30%) had a higher household income of £20-29,999 and two (20%) had the highest income of £50,000 or more.

5.4.4. Baseline resource use.

Resource use at baseline was determined by the mean number of appointments per participant. Table 5-3 presents the baseline resource use for all participants. From the health and social care perspective, participants had a total of 160 hours of therapy over the three months prior to baseline. A mean of 16 hours of therapy was recorded over the three months, with an overall average of 5.33 hours per month. The total health and social care appointments were 304.67 hours at baseline, which equates to 101.56 hours per month. The most frequent appointments were with a social worker totalling 127 hours over three months. The second most frequent, and

the highest recorded therapy appointments were with OTs, equating to 60 hours (mean=6, SD=11.18).

Table 5-3 Resource use and costs at baseline from the health and social care perspective.

Health and social care costs or appointments	Total (hours)	Mean* (hours per participant)	SD	Total cost	Mean cost** (per participant)
Case manager	7	0.70	1.16	£315	£31.50
OT	60	6.00	11.18	£2700	£270
Physiotherapist	49	4.9	8.33	£1,862	£186.20
SALT	21	2.1	4.01	£798	£79.80
Neuropsychologist	16	1.6	2.91	£1,544	£154.40
CBT	7	0.7	1.89	£679	£67.90
Psychologist	0	0	0	£0	£0
Consultant: surgical	1	0.10	0.32	£107	£10.70
Consultant: medical	0.75	0.075	0.24	£79.50	£7.95
GP (9.22 minutes per patient)	2.92	0.292	3.87	£706.64	£70.66
Support worker	127	12.7	37.73	£7,239	£723.90
Practice nurse	3	0.3	0.67	£546	£54.60
Advanced nurse practitioner	9	0.9	2.85	£477	£47.70
Orthotist	0	0	0	£0	£0
Medication	-	-	-	£518.66	£51.87
Total therapy	160	16	22.49	£7,898	£789.80
Total health and social care	304.67	30.47	37.38	£17,572	£1,757.18

The total health and social care cost at baseline was £17,572, which equates to a mean of £1,757.18 (SD=£188.10) per person over three months and £585.73 per month, per person. The resource item that accumulated the highest cost was visits from a support worker, equating to £7,239 and a mean cost of £723.90 per participant. This costed, on average, £241.30 per participant, per month. The total cost of medication at baseline was £518.66, which worked out as a mean of £51.87 per person over three months and £17.29 per month. The total cost of therapy was

£7,898 for all participants, which on average was £789.80 per participant (SD=£95.10). The mean cost of therapy per participant per month was £263.27.

5.4.5. Resource use post-intervention.

The resource use data recorded at baseline was collected again at six and 12 months post-intervention, to determine if there was any change in service use since receiving BiH. This section will summarise the data obtained at these follow-up time points and identifies potential cost drivers. As the number of participants reduced over the 12 months study period, the mean values have been calculated (per participant) to maintain a level of consistency in the analysis and comparison across time points.

5.4.5.1. Resource use at six months post-intervention.

Information about health and social care appointments was collected at six months post-intervention and compared with the baseline data. A summary of the data collected is shown in Table 5-4. The total number of health and social care appointments was 292 hours at six months, which worked out as an average of 36.5 hours (SD=62.18) per participant (n=8). Within this, the total number of therapy hours was 53 hours (mean 6.63, SD=10.95). The total cost of all health and social care resource use was £16,100.98 (mean=£2,012.62 per participant) and £2,133 for therapy alone (mean=£266.63 per participant). The greatest cost drivers were visits from support workers (£13,395) and physiotherapist appointments (£1,140).

Table 5-4 Resource use and costs at 6 months post-intervention from the health and social care perspective, compared with baseline.

Health and social care costs or appointments	6 months post-intervention (data collected related to the previous 3 months)						
	Total (hours)	Mean (hours per participant)*	SD	Total cost	Mean (cost per participant)**	Difference from baseline	
						Hours	Cost (£)
Case manager	4	0.5	1.07	£180	£22.50	-0.20	-9.00
OT	13	1.63	1.69	£585	£73.13	-4.38	-196.88
Physiotherapist	30	3.75	8.36	£1,140	£142.50	-1.15	-43.70
SALT	6	0.75	2.12	£228	£28.50	-1.35	-51.30
Consultant psychologist	0	0	0	£0	£0	-1.60	-154.40
CBT	0	0	0	£0	£0	-0.70	-67.90
Psychologist	0	0	0	£0	£0	0	0
Consultant: surgical	0.5	0.06	0.18	£53.50	£6.69	-0.04	-4.01
Consultant: medical	0	0	0	£0	£0	-0.08	-7.95
GP	0.5	0.06	0.12	£121	£15.13	-0.23	-55.54
Support worker	235	29.38	54.11	£13,395	£1,674.38	+16.68	+950.48
Practice nurse	1	0.13	0.35	£42	£5.25	-1.18	-49.35
Advanced nurse practitioner	1	0.13	0.35	£53	£6.63	-0.78	-41.08
Orthotist	1	0.13	0.35	£38	£4.75	+0.13	+4.75
Medication	-	-	-	£265.48	£33.19	-	-18.68
Total therapy	53	6.63	10.95	£2,133	£266.63	**-9.37**	**-£523.17 ***(p=0.037)**
Total health and social care	292	36.5	62.18	£16,100.98	£2,012.62	**+6.03**	**+£255.44**

*Mean hours over 3 months for all participants (n=8); **Mean cost over 3 months for all participants (n=8); *** significant different ($p<0.05$), paired t test. OT: occupational therapist; SALT: speech and language therapist; CBT: cognitive behavioural therapist; GP: general practitioner; SD: standard deviation.

Compared to baseline resource use, at six months post-intervention, there was a mean decrease of 9.37 hours of total therapy appointments (per participant). This equated to a mean decrease of £523.17 per participant in therapy costs, which was significant (p=0.037, t test). However, there was a mean increase in total health and social care appointments from baseline (6.03 more hours per participant), leading to an increased cost of £255.44 (mean increase per participant), but this change was not significant. The main cost driver was an increase in social worker visits (additional £950.48 per participant). However, only three participants were visited by a support worker, meaning that the small sample of data is skewed.

5.4.5.2. Resource use at 12 months post-intervention.

Data relating to health and social care appointments was collected again at 12 months post-intervention and compared with the baseline and six-month data. A summary of the data collected at 12 months post-intervention is shown in Table 5-5. The total number of health/social care appointments was 182.08 hours at 12 months, which equated to an average of 30.35 hours (SD=43.50) per participant over three months (n=6). The total number of therapy hours was 15.5 hours (mean 6.63, SD=10.95). The total cost of all health and social care resource use was £10,1456.22 (mean=£1,742.70 per participant) and £794 for therapy alone (mean=£132.33 per participant). Again, the greatest cost driver was visits from support workers (mean of £1588 per participant). However, only two participants received support worker visits which contributed to the increase in costs and skewed the small amount of data.

Table 5-5 Resource use and costs at 12 months post-intervention from the health and social care perspective, compared with baseline and 6 months post-intervention.

Health and social care costs or appointments	12 months post-intervention								
	Total (hours)	Mean (hours)*	SD	Total cost	Mean cost (per participant)**	Difference from baseline		Difference from 6 months	
						Hours	Cost (£)	Hours	Cost (£)
Case manager	1	0.17	0.41	£45	£7.50	-0.53	-24.00	-0.33	-15.00
OT	3	0.50	0.84	£135	£22.50	-5.50	-247.50	-1.13	-50.63
Physiotherapist	6.5	1.08	1.02	£247	£41.17	-3.82	-145.03	-2.67	-101.33
SALT	2	0.33	0.52	£76	£12.67	-1.77	-67.13	-0.42	-15.83
Consultant psychologist	0	0	0	£0	£0	-1.60	-154.40	0.00	0.00
CBT	3	0.50	1.22	£291	£48.50	-0.20	-19.40	+0.50	+48.50
Psychologist	0	0	0	£0	£0	0.00	0.00	0.00	0.00
Consultant: surgical	0	0	0	£0	£0	-0.10	-10.70	-0.06	-6.69
Consultant: medical	0.33	0.06	0.14	£0	£0	-0.02	-7.95	+0.06	0.00
GP	0.25	0.04	0.10	£60.5	£10.08	-0.25	-60.58	-0.02	-5.04
Support worker	164	27.33	48.69	£9348	£1558	+14.63	+834.10	-2.04	-116.38
Practice nurse	2	0.33	0.82	£84	£14	0	-40.60	+0.21	+8.75
Advanced nurse practitioner	0	0	0	£0	£0	-0.90	-47.70	-0.13	-6.63
Orthotist	0	0	0	£0	£0	-0.97	0	-0.13	-4.75
Medication	-	-	-	£169.72	£28.29	-	-23.58	-	-4.90
Total therapy	15.5	2.58	2.27	£794	£132.33	**-13.42 ***(p=0.048)**	**-£657.47 ***(p=0.034)**	**-4.05**	**-£134.30**
Total health and social care	182.08	30.35	43.50	£10,456.22	£1,742.70	**-0.12**	**-£14.48**	**-6.15**	**-£269.92**

*Mean hours over 3 months for all participants (n=8); **Mean cost over 3 months for all participants (n=8); *** significant different ($p<0.05$), paired t-test. OT: occupational therapist; SALT: speech and language therapist; CBT: cognitive behavioural therapist; GP: general practitioner; SD: standard deviation.

Compared to baseline resource use, at 12 months post-intervention, there was a mean decrease of 13.42 hours of total therapy appointments (per participant), which was significant (p=0.048, t test). This equated to a mean decrease of £657.47 per participant in therapy costs, which was also significant (p=0.034, t test). There was also a small decrease in the use of health and social care resources, with a mean decrease of 0.12 hours, and although a minor change, it led to a mean decrease in costs of £14.48 per participant. This decrease in health and social care appointments and costs suggests that participants were using less services at the end of the study compared to baseline. This could linked to expected improvement over time, or the use of BiH. At 12 months, there was a mean decrease in total health and social care appointments (6.15 hours per participant), leading to a lower cost of £269.92 per participant. There was also a mean decrease of 4.05 hours of therapy appointments, which equated to a decrease of £134.30 per participant.

5.4.6. Intervention costs.

The cost of the intervention (BiH) provided during the study was calculated using the information detailed in Table 5-2. As I trained the participants and provided additional sessions where necessary, these costs were taken into account (equivalent to a research assistant hourly salary, University of Nottingham). The cost of a BiH trainer that would usually provide these sessions was deducted from the costs.

The overall cost of the intervention for the ten participants over 12 months was £4013, which equates to a mean cost of £401.30 per participant (Table 5-6).

Table 5-6 Cost of BiH intervention over 12 months.

Resource item	Total cost	Mean cost (per participant)
Standard individual BiH license for 12 months (without traffic light response or training)	£3120	£312
Training of research assistant (one off training provided by Brain in Hand Ltd., 2 x 4-hour sessions)	£400	£40
Training of participants by research assistant (10 x 2-hour sessions)	£340	£34
Additional sessions to deal with technical issues and difficulties associated with BiH (total of 9 hours provided by research assistant)	£153	£15.30
Total	**£4013**	**£401.30**

The total cost of therapy appointments decreased at six months, then again at 12 months. When the mean cost of the intervention is added to these values, therapy costs still remain low at 12 months post-intervention (£533.63 per participant). With the addition of the intervention, the cost of therapy plus BiH at six (£667.93 per participant) and 12 months (see above) is less than the mean baseline therapy costs (£789.80 without BiH). The cost of all health and social care resource use decreased slightly at 12 months post-intervention from baseline. When the mean cost of the intervention is added, the mean health and social care costs (plus BiH) at 12 months was £2144 per participant.

5.4.7. Summary of resource use and costs.

Overall, there was a decrease in all health and social care costs at 12 months, but there was a more obvious decrease in total therapy appointments and costs. The cost of health/social care increased from £1757.18 (mean average) to £2012.62 at six months, then decreased to £1742.70 at 12 months, per participant. However, therapy costs decreased from £7898 (mean average) to only £266.63 at six months, per participant. A further decrease to £132.33 per participant was recorded at 12

months. Therefore, there was a clear reduction in therapy services and costs during the study period.

5.5. Discussion

There is limited evidence to date on the cost-effectiveness of smart technology interventions for the ABI population, however this study provides a step in addressing the research gap. By conducting a feasibility of economic evaluation study, I was able to determine the key cost drivers associated with BiH use and inform the design of a future economic evaluation. Information about resource use and costs associated with the implementation of BiH were collected.

It is important to consider the impact of participants lost to follow-up and missing data when estimating the feasibility of collecting resource use data, and attributing costs in a future study. The findings of this study show that it is possible to collect economic data in the ABI population. As resource use was reported well by participants, it appears the SUQ is a feasible method of capturing relevant economic data in the ABI population. Although all questionnaires were completed in full, some participants found it difficult to recall the number of appointments they had in the past three months, and also struggled to report some medication details. As a result, a family member, carer, therapist or support worker helped them complete the necessary information. These issues may have been exacerbated by the cognitive impairment experienced by some participants. However, all participants were happy to disclose information about their financial situation, which has been reported as a barrier to data collection in other brain injury studies (i.e., people are unwilling to share such information) (Johnstone, Mount, & Schopp, 2003; Shigaki, Johnstone, & Schopp, 2009). It is important to keep these things in mind for a future study and the potential challenges the ABI population may face when reporting service use and

costs. In a future study, it would be recommended that someone supports the participant when completing the SUQ, especially recalling appointment frequency. Some questions may also need to be clearer (i.e., presented in a better way) to avoid further confusion.

Technology interventions are becoming increasingly used in healthcare, however it is one of the key drivers in growing healthcare costs (Okunad & Murthy, 2002; Sorenson, Drummond, & Bhuiyan Khan, 2013). As technology advances, devices and licenses for software inevitably become more expensive. The costs of BiH are relatively consistent in the autistic population, as most individuals receive the same level of support, which is well defined and structured. However, the findings from the case studies in Chapter 4 highlight the complexity of delivering BiH as a self-management tool in ABI. The system requires more input from carers, mentors or HCPs and needs a larger support system, ultimately leading to higher costs. ABI users may also require more training sessions to support their use of BiH. As cognitive impairment, lack of insight and poor motivation are common consequences of injury, individuals may require more ongoing support than those with autism. Therefore, it was important to collect preliminary information about the costs of BiH in comparison to resource use costs, and explore whether it could potentially save money in the long-term.

The main cost drivers identified in this study were the BiH license and cost of training/set-up sessions, but also the level of ongoing support required to facilitate BiH use and effectiveness. The initial cost of BiH is expensive and the support needed for ABI users will drive the costs up, but this may be offset by savings in therapy and social care costs. Although decline in therapy appointments is expected as rehabilitation progresses, there was a clear decrease in average therapy costs over 12 months. This suggests that BiH may have the potential to reduce health care

costs, but also decrease social care costs in the long-term. Intervention costs may increase with additional support, such as traffic light responders and ongoing IT support from the company. However, these findings should be approached with caution given the small sample size and uncertainty in the results. Thus, a future study is needed to evaluate the cost-effectiveness of BiH in comparison to usual care (such as paper-based methods) or a different technology.

One of the limitations of this study is that the resource data was not valued for the same currency year, i.e., in pound sterling (£) using published unit costs at 2017 prices. In a future study, where current unit costs are not available, a unit cost from a previous version (i.e., earlier edition of the Personal Social Services Research Unit (PSSRU)) should be used and inflated to current costs (i.e. 2018) using the Bank of England Inflation calculator (Bank of England, 2018). A further limitation was the small sample size, which meant the data was skewed and no clear conclusions could be drawn from the data, therefore a larger study is needed.

I propose that an RCT would be the most appropriate study design to test the clinical and cost-effectiveness of BiH and conduct an in-trial economic evaluation alongside this. In line with the NICE reference case (NICE, 2013), it is suggested that a NHS and Personal Social Services (PSS) perspective would be taken in a future economic evaluation (Table 5-7). Given the nature of ABI, a future study may need to look at costs from a wider societal perspective and include direct/indirect costs to family members, carers, agencies and charities, such as Headway. Any additional informal care costs (e.g. personal care, help in/around the house, help outside the home, child care etc.), as well as informal care given by a family member, relative or friend (i.e. productivity loss) should be considered. Also, travel costs associated with hospital outpatient/therapist appointments could be recorded. Further examination of the appropriate methods of data collection and an exploratory economic evaluation

could form part of a feasibility study prior to a definitive RCT where a full cost effectiveness analysis could be conducted. Whilst the economic evaluation would be shaped and refined as a result of this, a proposed structure, using the NHS reference case to frame key components to be considered is presented in Table 5-7.

I propose carrying out a cost-effectiveness analysis of the BiH intervention compared with usual care (i.e., alternative therapies regarded as current best practice) over 12 months. Whilst it is proposed that the EQ5D would be used in a definitive study to collect data about health-related quality of life and estimate the long-term cost-effectiveness of the BiH intervention in a definitive study, a feasibility study would assess the use of this measure in the ABI population further. In a definitive study, the EQ5D and the quality of life after brain injury (QOLIBRI) could be used to collect data about health-related quality of life and generate a cost per quality adjusted life year (QALY) to estimate the long-term cost-effectiveness of the BiH intervention. The QOLIBRI is a disease-specific measure of quality of life and covers areas of health typically affected following brain injury, which the EQ5D does not (Heiberg et al., 2018; Truelle et al., 2010).

5.6. Conclusions

This study shows that it would be possible to conduct an economic evaluation within a larger trial and the collection of resource use data would be feasible in this population. However, some individuals may need support when reporting appointment frequency and medication, to ensure the data obtained is accurate. The main cost drivers associated with the use of BiH are the cost of the technology.

Table 5-7 Framework for a future economic evaluation using the NICE reference case

Attribute	Reference case
Comparator(s)	Alternative therapies routinely used in the NHS that are regarded as current best practice (e.g. paper diaries).
Perspective on outcomes	All direct health effects on patients or, when relevant, carers.
Perspective on costs	• NHS and Personal Social Services (PSS) • Wider societal perspective, including costs to the family, carers, agencies and charities.
Type of economic evaluation	Cost-effectiveness analysis.
Time horizon	The BiH intervention will be provided for 12 months. Data will be collected at baseline, six and 12 months.
Synthesis of evidence on health effects	Based on systematic review and case studies.
Measuring and valuing health effects	Health effects will be expressed in QALYs. The EQ-5D (generic measure) and the Quality of life after brain injury (QOLIBRI; injury specific measure) will be used to collect data about health-related quality of life in adults. QALYs will be calculated from these measures.
Source of data for measurement of health-related quality of life	Reported directly by patients and/or carers.
Source of preference data for valuation of changes in health-related quality of life	Representative sample of the UK population.
Equity considerations	An additional QALY will be of equal value regardless of other characteristics of the individuals, such as their socio-demographic characteristics, their age, or their level of health.
Evidence on resource use and costs	Costs should relate to NHS and PSS resources and will be valued using the prices relevant to the NHS and PSS.
Discounting	An annual rate of 3.5% on both costs and health effects will be applied.

Chapter 6 Discussion

6.1. Chapter Overview

This chapter will summarise the overall findings from the thesis. The different studies presented in Chapters 2, 3, 4 and 5 have already been discussed separately, however they are all underpinned by the same theory. The overall findings will be explored and compared with literature. The strengths and limitations of the study will be considered, focussing on the design, intervention, outcomes and analyses. Finally, the implications for clinical practice and research will be discussed and future directions presented.

6.2. Summary of Study Aims

The thesis has been split into four studies: systematic review, engagement work, case studies and feasibility health economics evaluation. The first two parts were conducted with the purpose of informing the design of the case studies. The primary aim of the case studies was to explore the perspectives and experiences of people with ABI and HCPs after using BiH for self-management and improving functional outcomes following ABI. Also, to determine whether using BiH was associated with improved functional independence, quality of life, cognition, mood and participation in society using various measures and to determine the acceptability of BiH for the ABI population. The health economics evaluation aimed to determine the feasibility of collecting resource use and costs associated with ABI survivors and the implementation of BiH.

6.3. Summary of Key Findings

The systematic review presented in Chapter 2 identified a number of personal smart technologies for people with ABI and the various ways that they are being

implemented. The review highlighted the dearth of research in this area and rapid developments in technology. There is a need for more studies reporting the core, transferable components of interventions like BiH, so that this knowledge can be used to guide implementation research. Although there was an improvement in cognition and goal attainment for some of the technologies identified in the review, there was no significant difference from the control groups receiving paper-based interventions. This suggests that other factors influence the effectiveness of technology interventions and greater attention is needed on the barriers associated with use. I used the TIDieR guidelines to extract data about the different interventions, which influenced the design of the case studies and reporting of BiH. This review also highlighted the lack of studies focusing on some of the invisible sequelae of ABI such as lack of independence, fatigue, poor self-management and participation. These findings provided a rationale for the subsequent study.

The engagement study reported in Chapter 3 provided preliminary information about BiH and shed light on some of the potential barriers and facilitators associated with the intervention. It also highlighted the problems that BiH could potentially target and therefore appropriate outcomes to focus on in a subsequent study. I used the data collected from this engagement work to inform the design of the case studies in Chapter 4. This enabled me to understand more about the core components of BiH. I used the BCW in this study to analyse my findings and concluded that it is a useful tool for engagement, especially when designing questionnaires and developing topic guides. The model helped me to consider a wider perspective of the intervention function and its components.

The case studies reported in Chapter 4 form the main part of this thesis and have provided valuable information about BiH, its barriers and effectiveness, but also highlighted the need to consider contextual factors when designing and

implementing complex interventions. The findings from this mixed methods study identified the key facilitators to BiH effectiveness as: appropriate, ongoing support and structured training for users and HCPs, motivation to use the app and achieve goals, insight into impairments as a result of injury and a level of self-awareness, and technology that is easy to use and can be tailored to the individual. The factors affecting the context of the intervention were as important as the content of the technology.

The feasibility of health economics evaluation presenting in Chapter 5 was conducted to inform the design of a future feasibility trial, alongside the findings from the case studies. This study found that it is feasible to collect resource use data from the ABI population as participants successfully completed the SUQ in full. However, people with ABI may need support from someone (e.g., family member, carer) when completing the questionnaire, to ensure accuracy of reporting, especially those with cognitive impairment. This is an important factor to consider for a future trial. The key cost drivers associated with BiH use were the cost of the technology and the support needed, however some of the costs were potentially offset by a saving in therapist appointments.

6.4. Discussion of Findings

Some of the common impairments seen following ABI are cognitive, physical and sensory disabilities, which can be difficult to manage, but are often well recognised by clinicians and family members. However, it is the invisible sequelae of ABI such as emotional/behavioural effects (e.g. anxiety, depression) that frequently go unnoticed. The biopsychosocial approach to treating the ABI population and providing rehabilitation focuses on interventions that aim to support these hidden effects of injury. The long-term impact of emotional issues experienced following ABI

can have consequences on social participation, ADL and independence. This can ultimately affect quality of life.

There is a lack of support for rehabilitation services in the UK and inadequate provision to ensure people with ABI are receiving the treatment they need (Barber et al., 2018; Wade, 2015a, 2015b). There is limited equipment (e.g. assistive technologies) available for HCPs to provide to their patients, which is surprising as rehabilitation is recognised as a fundamental part of healthcare in the UK. There are ongoing pressures on limited healthcare resources, which is reflected in the Five Year Forward view for the NHS, pushing for greater self-management. Many of these assistive aids have been shown to be cost-effective, which is important, as pressure on NHS resources continues to increase. There is a timely need for interventions that facilitate self-management and support independent living, to reduce the need for frequent therapy appointments and decrease social care reliance. Technologies like BiH may provide the necessary support people by facilitating independent living and self-management, which could reduce healthcare costs. This formed the theoretical basis of the thesis.

Rehabilitation interventions are complex and often difficult to evaluate. This means researchers frequently report negative results due to the heterogeneous nature of ABI, and challenges faced when implementing interventions like BiH. Academics sometimes fail to report the reasons for negative outcomes and the potential barriers of technologies, focusing more on the limitations of the study design. Disseminating the adverse effects and limitations of technologies is important and researchers need to use their findings to flag up these barriers. Otherwise, future studies and developers risk making the same mistakes. The systematic review concluded that the effects and harm of technologies are potentially underreported, and researchers need to better describe the limitations to intervention effectiveness. Taking this into

account, I provided a detailed evaluation of the barriers and facilitators that impacted on BiH and their mechanism of action. By recognising the limitations of the app and the system as a whole (i.e., contextual factors), improvements can be made to BiH. There is a hope that researchers will use the findings of my thesis to inform the development of similar interventions and avoid some of the barriers that have previously been underreported (e.g. lack of insight).

6.4.1. The use of theoretical frameworks.

The journey from evidence base to clinical implementation is usually long. It requires carefully designed research to ensure potential barriers are addressed early in the process. The MRC framework formed a fundamental part of this thesis and offered clear methodological and conceptual guidance. It was used to inform study design and provided a justification for the evaluation of the barriers/facilitators to BiH use. The MRC framework helped identify specific aims of the case studies and ensure this development-stage research had an appropriate focus. The research questions were chosen to explore the key factors influencing the use and effectiveness of BiH in the study population, but also to inform the development of the intervention. Alongside the MRC framework, the ICF formed an intrinsic part of this thesis and provided a solid theoretical basis for the case studies. It was used to guide study design (by selecting appropriate outcome measures) inform interview topic guides, facilitate consistent reporting of case studies and provided a matrix for qualitative analysis.

Using implementation frameworks to guide the evaluation of technologies is important to extract transferable knowledge about the intervention and inform future research. The BCW provided a useful way to evaluate where barriers arose and how they influenced the behavioural components. It also shed light on why some interventions like BiH are not successful in clinical practice. By taking a theory

informed approach to designing interview topic guides and analysing data, I was able to determine how motivation, capability and opportunity impact on the use and effectiveness of BiH. These components are necessary to bring about behaviour change and it was beneficial to observe how BiH acted on these to domains. By understanding the underlying mechanisms of intervention success, the barriers and facilitators to long-term implementation can be evaluated. The BCW is a well-known model and has been used successfully by researchers to evaluate complex interventions. The value of this model has been reflected in my findings and provided a coherent framework to explore the functions of BiH. It enabled me to determine what impact the app had on behaviour, but also on the wider environmental and personal factors.

The use of the ICF and BCW provided a common language to report the findings of the engagement work with stakeholders and case studies. These frameworks are useful for researchers and can facilitate the translation of findings to clinical practice. Studies often report technology barriers in terms of usability, accessibility, cost and acceptance, however these are not generalisable across rehabilitation interventions. There is a need for knowledge to be easily transferred between researchers and clinicians, highlighting the need for the common language (i.e., ICF and BCW). The findings of this thesis are presented in a more accessible way by linking them to clinically relevant frameworks and highlighting the core components of BiH that would require more focus in practice.

6.4.2. Contextual factors.

The importance of context and content was explored in Chapter 4, and the need for a greater understanding of the many factors that surround a complex intervention. The appropriate contextual factors were pivotal to the success of BiH and should be given more consideration when developing similar technologies. Both environmental

and personal factors can have a significant impact on the use and effectiveness of interventions, and in the case of BiH, these barriers often interact with other factors. One of the key barriers identified by the case studies was a lack of ongoing support for ABI participants and inadequate training of therapists. It could also be suggested that some of effects of BiH were hidden by the contextual factors (e.g., environment, support), which meant there was no clear change in most of the outcomes. Although the correct support and training has been highlighted by other studies as an important part of intervention success, the level of this required for BiH use in the ABI population was underestimated. There was minimal contact with therapists and basic training provided, which meant the application of BiH in their clinical role was limited. The contextual factors highlighted by the case studies should be explored in HCP training, to identify how the app could be implemented in or alongside conventional therapy.

Another key barrier was highlighted by the engagement work with stakeholders and case studies as a lack of insight and self-awareness. Those that could not recognise their own impairments, could not see a use for BiH. This either led to unrealistic expectations of the app or a lack of motivation to use the technology. Although this is a common effect of ABI, insight is not highlighted in the literature as a key limitation of intervention success. However, BiH has the potential to use these barriers and create positive outcomes. An individual with limited insight could use the app to facilitate self-awareness by monitoring their fatigue or anxiety levels. This supports the NHS Five Year Forward view, which is pushing for greater self-management tools (Maruthappu et al., 2014). However, therapists need to be mindful of this and use their clinical judgement to determine if an individual has the ability to progress. This theory could be applied to other similar interventions.

6.4.3. TIDieR guidelines.

The TIDieR guidelines were used to describe the intervention in a structured way and highlighted the importance of consistency throughout the case studies. The guidelines highlighted some of the core components of the technology and provided transferable knowledge that can be used to inform other interventions and their delivery. One of the key features of BiH, which was also identified as a facilitator by ABI participants, was the ability to tailor the technology to the individual. This is an important component of BiH and the systematic review (Chapter 2) highlighted a lack of tailoring and personalisation with similar interventions. However, the technologies may have provided this function, but researchers did not provide detail about this. By using the TIDieR guidelines, I have provided a coherent and structured description of BiH and the delivery of the intervention in the case studies. This combined with the theoretically informed analysis of findings, provides a valuable resource for researchers and should improve the development and implementation of technology interventions.

6.4.4. BiH as a rehabilitation tool.

The use of BiH in rehabilitation has great potential in terms of improving goal attainment and cognition, but also to facilitate self-management and independent living. In the long-term, BiH could help reduce healthcare costs and reliance on social care. Participants benefited from the app in many ways, with some returning to work or education, and others feeling empowered by having more control of the daily life. As the technology can be tailored to each individual and given the heterogeneous nature of ABI, it may be a valuable tool in community rehabilitation. The technology also provides a way to remotely monitor users, which could facilitate clinical practice. However, in order for the app to be effective, researchers and clinicians need to consider the wider picture prior to implementation. It is important that all contextual factors are addressed and appropriate actions taken to reduce

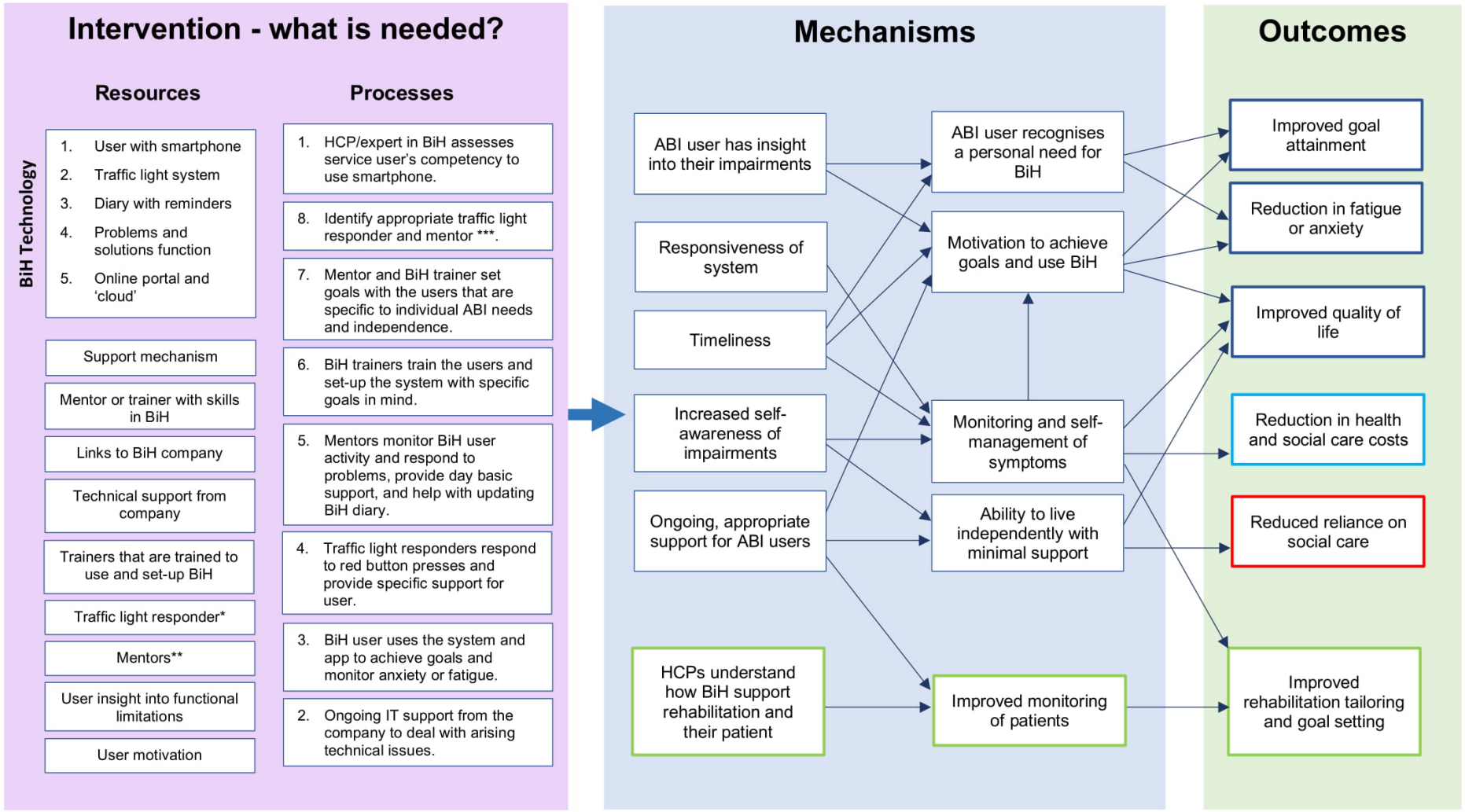
potential barriers. It is evident that BiH is not necessarily a standalone intervention and clinical input may be required, especially when it is first introduced. BiH may be implemented as an embedded part of rehabilitation, whereby the therapist uses the technology as a method to guide rehabilitation and goals, or it may be used as a standalone technology when the person with ABI becomes more aware of their limitations and has the ability to set goals. As BiH targets the components of behaviour change, the technology could eventually be used independently.

6.4.5. Logic model

The findings from this thesis highlight the complexity of implementing smart technologies like BiH to support independence and self-management of people with ABI. The process is complex and requires input from various people and resources (i.e., mentor, trainer, traffic light responder, IT support) to be effective. This research was necessary to gain an insight into the underlying mechanisms of the intervention and understand more about whether, and how it could work in practice. A logic model has been created to illustrate the multiple interacting components of BiH as a rehabilitation intervention (Figure 6-1). This model was developed using the findings of this thesis and shows the extensive number of resources needed for BiH to work. It also links to the idea of context and content. In the autistic population, BiH works well because of the clearly defined support structure (i.e., mentor, BiH trainer and a traffic light responder) and the nature of autism (i.e., individuals find it easy to use the technology and their daily challenges tend to be consistent). Cognitive difficulties are common in autism, especially impaired executive function such as planning, working memory and initiation, which are also common symptoms of ABI. However, the heterogeneous nature of ABI means that implementing a smart technology like BiH is inevitably more complex. It is important that individuals are competent at using a smartphone, have insight into their limitations and able to set realistic goals independently (i.e., BiH is a standalone technology) or alongside a therapist who can

assist with breaking the goal into an achievable part of an overall goal (i.e., BiH is embedded as part of their rehabilitation).

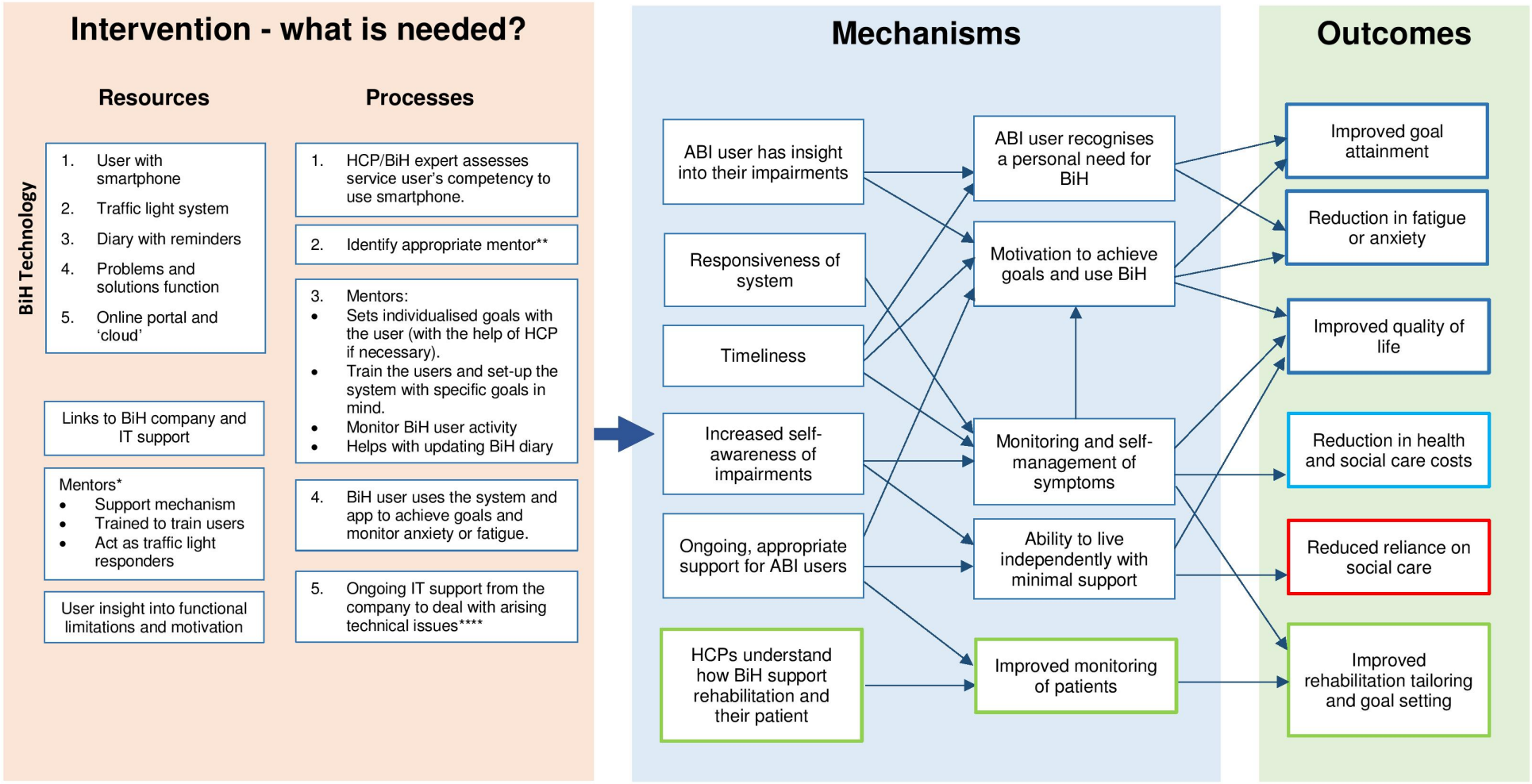
The logic model demonstrates how BiH could work in practice, however in order to improve implementation, the process needs to be simplified. Streamlining the intervention could potentially improve its effectiveness and cost-effectiveness. The complex logic model (Figure 6-1) is too resource intensive meaning that too many different people are involved, which could ultimately lead to increased resource use and associated costs. The system could be confusing for the participant/user as they do not know who to approach when they need help (i.e., who do they ask when they need technical support). Finally, the complex model relies on HCPs going out of their way to support the correct implementation of BiH and meet the needs of their patients. This would be unpaid and time is a huge restriction on HCPs, meaning they need to prioritise other tasks. The streamlined logic model (Figure 6-2) presents the ideal scenario for BiH use. There is a reduction in resources and support roles have been combined to limit the number of people involved. The mentor would take on the responsibilities of other roles, i.e., sets goals with user (with the help of a HCP where appropriate), trains the user, provides basic technical support and responds to red traffic light presses (if the user chooses this function).



* traffic light responder could be a family member, friend, carer, or charity volunteer (e.g., from Headway).
** mentoring could be provided by a family member, friend carer, or HCP. All users need to identify a mentor to support them in BiH use.
*** response time (e.g., 30 minutes), method (e.g., text, phone call) and level of support provided by traffic light responders should be defined during set-up. The role of the mentor should also be determined.

Figure 6-1 Brain-in-Hand logic model

The level and intensity of support required for an individual may vary depending on that user's specific needs, however the overall support structure would remain the same. It is important that barriers and facilitators to providing appropriate support alongside BiH use are considered. These resources need to be identified in the early stages to ensure the intervention is set-up correctly and relevant goals are identified. The mentor is a key player in the success of BiH, and inappropriate/lack of support was one of the main barriers to effective use in the case studies (Chapter 4). The underlying mechanisms of BiH involve individual users and their ability to recognise impairments and self-manage, but also the technology itself. BiH is responsive, enabling the user to identify and deal with problems as they arise. It also provides HCPs with a tool to monitor their patients in real time. In the long-term, BiH has the potential to improve goal attainment, quality of life and symptom management, and reduce reliance on social care. Overall, this may improve rehabilitation tailoring and outcomes for the ABI population, ultimately decreasing health and social costs. The long-term effect of BiH could potentially save costs by reducing the frequency of therapist appointments, and reducing reliance on social care. Although the BiH system and support mechanism needed (Figure 6-2) is expensive, in the long-term, this may be offset by savings in therapist appointments and social care. The idea being that BiH supports the user in everyday life and the mentor provides additional support when necessary, thus potentially decreasing cost.



* Mentors could be family members, HCPs, friends, carers or provided by an individual not involved in the users everyday life such as charity volunteers (e.g., Headway).
** All users need to identify a mentor to support them in BiH use.
*** Response time (e.g., 30 minutes), method (e.g., text, phone call) and level of support provided by mentors should be defined during set-up.
**** Users should be able to access IT support from the company when necessary either via the app (FAQ section or online chat function) or calling a helpline.

Figure 6-2 Ideal Brain-in-Hand logic model (streamlined)

6.4.6. Implications of findings.

6.4.6.1. Clinical implications.

- There is currently limited evidence of the effectiveness of technologies, like BiH in improving functional outcomes compared to usual care practice. Other studies have shown positive effects on goal attainment and cognition, which have also been found following the use of BiH.
- BiH has the potential to be a valuable tool in community rehabilitation by facilitating independent living for people with ABI and providing a way to self-monitor and manage their fatigue/anxiety.
- BiH can provide HCPs with a tool to remotely monitor their patients and determine if they are completing tasks, working towards goals or recording high anxiety/fatigue levels. This could be a valuable tool to identify where problems are arising and subsequently guide rehabilitation strategies. Not only would this save time in the clinical setting, but it would improve service provision by relying less on poor patient reporting/paper diaries.
- A lack of insight and the inability to set realistic goals are a barrier to BiH use and its effectiveness in the ABI population. Clinicians and support workers should be aware of this factor when implementing BiH for their patient, and identify solutions to overcome this. In the case of those lacking some insight into their impairments (e.g. high fatigue), BiH can be used to encourage self-monitoring using the traffic light system, and therefore facilitate insight (e.g. I should take a rest).
- Goal setting when implementing BiH should be conducted by an experienced professional to avoid some of the barriers associated with setting goals for people with ABI. It is important for clinicians to implement realistic and achievable goals, and link them to BiH in a coherent and measurable way.

- It is important to identify the appropriate support for individuals using BiH in order to facilitate effective use of the app. When implementing the technology, clinicians should consider who the best mentor for that person is and ascertain if a family member is the most appropriate option. Sometimes individuals with ABI will not use the traffic light system honestly if they feel it will affect their relationship (i.e., a partner or family member).

6.4.6.2. Research implications.

- The rapid advances in technology and drivers for self-management following ABI mean that new technologies are emerging all the time. Without understanding and reporting the core components of interventions, and transferring information about factors impacting on their effectiveness, these key findings will be missed by technologists. Also, researchers will not be able to evaluate the true effectiveness of their interventions if certain factors are not being addressed, therefore delaying clinical application.
- The use of theoretical frameworks are important when designing and evaluating complex interventions, as they provide a common language for researchers and facilitate consistent reporting. The ICF and BCW are valuable tools for informing the design of mixed methods studies and useful to guide qualitative analysis.
- The TIDieR guidelines provide a way to consistently describe the key components of an intervention and potential factors that contribute to its effectiveness (e.g. training, procedures and frequency of use). Researchers should use these guidelines when detailing their interventions and highlight where barriers occurred, so these common limitations can be addressed. In the long term, this will contribute to more effective clinical application of interventions like BiH.

- Contextual factors play a pivotal role in the use and effectiveness of BiH and require more focus early in the implementation of similar interventions. It is important to identify key barriers and facilitators within these contextual factors to help guide the development of BiH and improve the long-term implementation of smart technologies.
- The findings from this study have implications for long-term implementation of complex interventions like BiH. Future research needs to consider the interactions between personal and environmental factors, especially the support provided to participants and their level of insight/self-awareness. Researchers should be mindful of the barriers associated with these factors and design their studies to avoid such setbacks.
- A larger study needs to be conducted to compare BiH with usual care to understand whether the technology is having an effect on outcomes, or whether it is expected improvement over time. This would need to be focused on certain outcomes of interest such as cognition and independence.
- Ongoing support and more structured training for ABI users was necessary for the frequent use and effectiveness of BiH. A lack of support impacted on an individual's motivation to use BiH and influence goal setting. Researchers need to consider the appropriate level of support required for different populations when implementing BiH or similar interventions. They also need to understand how inappropriate or insufficient support will impact on other factors
- Structured training for therapists, rehabilitation services and mentors appears to be essential to the success of BiH for people with ABI. Although HCPs understood how to use the technology, they did not always comprehend the potential for BiH within or alongside their clinical role. Researchers need to consider the impact therapists have on the effectiveness of an intervention and design their training accordingly.

6.5. Future Research

This thesis has improved the evidence base for the barriers and facilitators to the long-term implementation of smart technologies. The findings of the studies will inform the development of BiH and guide improvements to the intervention, making it more appropriate for the ABI population. The conclusions drawn from the studies may also inform the design of future research and technologies. There was a clear gap in the consistent reporting of intervention components and delivery. Researchers need to use the TIDieR guidelines to facilitate description of interventions. Future studies need to report the barriers to implementation and measure the potential effects and harms of their interventions. The dearth of research in this area and rapid developments in technology mean that the indication of intervention effectiveness is often limited. More studies need to report the core components that contribute to the effectiveness of these technologies.

Additional research is required to determine the effectiveness of BiH in the ABI population. Studies would need to address the key barriers identified in this thesis and develop the theoretical model to understand more about the underlying mechanisms of context. A larger, more varied sample of people with ABI (such as those with mild TBI) would provide alternative perspectives of BiH and its wider clinical applications. Given the lack of reporting of therapist training for interventions like BiH, and a recognised need for more structured guidance, a future study should focus on addressing this barrier.

Although results from the case studies have identified various barriers that need to be addressed prior to implementation in this population, there remains a considerable amount of preliminary work to be carried out. Such work needs to specifically determine who BiH could work for and in what context, although some of these factors

have already been alluded to in the findings. Individuals with some insight into their impairments would benefit from using BiH to develop self-awareness and better manager symptoms. BiH would also be suited to those with cognitive impairments, especially to support planning, remembering appointments, decision making and initiation. Unsurprisingly, the same impairments are seen in autism. Further developments need to be made to the technology, training manuals and logic model prior to a larger study. The next stages could involve the development of a training package for therapists by drawing on the findings of this thesis and identifying key facilitators to BiH success. Focus groups with HCPs would help identify the core components required to provide intervention training and guide the development of a manual. Following the development of a training package, a future study would test the feasibility of delivering the BiH intervention and measuring its effects in the ABI population.

As a future study, BiH could be tested in a pilot feasibility trial comparing it to usual care (e.g., paper-based methods) to determine whether the technology has an effect on outcomes, or whether any reminding or planning strategy achieves the same change in function. Given the small improvement in cognitive scores observed in the case studies, it would be reasonable to choose cognitive function as the primary outcome, alongside a measure of self-awareness and independence. A population that could be targeted is mild TBI, as these participants were missed in the case studies and may benefit more from technologies like BiH, as their symptoms better reflect those seen in autism (e.g., difficulties planning and multitasking). A cost-effectiveness analysis could be conducted alongside this study to compare health and social care costs associated with BiH, in comparison to usual care (as discussed in Chapter 5). A pilot feasibility study would inform the design of a larger study and also enable me to refine the logic model.

Chapter 7 Conclusion

The aim of this thesis was to evaluate ABI survivors and HCPs perspectives and experiences of using BiH and increase the evidence base on the barriers and facilitators associated with the use and effectiveness of smart technologies like BiH. The nature of ABI is heterogeneous, leading to various impairments and has an impact on quality of life, social participant, mood and independence. The invisible sequelae of ABI such as anxiety, depression and fatigue are among some of the effects that receive less support and often go unnoticed. The pressure on the NHS continues to grow and there is a timely need for interventions that facilitate self-management following ABI and reduce reliance on social care. There is a recognised benefit of reminding devices to improve cognition, however, there is a limited evidence for technologies to support functional outcomes and independence. Studies inconsistently report details of their interventions and there is a need to highlight barriers and limitations of technologies, so that researchers can avoid making the same mistakes. BiH was provided to ten participants in a series of case studies, which used a mixed methods approach to evaluate its use and effectiveness. The quantitative findings showed no effect of the intervention on mood, participation, quality of life, or fatigue. However, there was a significant improvement in goal attainment between baseline and six months. There was a slight improvement in cognitive function, which is corroborated by various studies and a small decrease in functional independence, which may have been due to an increased awareness of limitations (in terms of ADL). Some participants used the reminding function consistently to structure their day, remember to take medication or complete rehabilitation exercises. Others benefitted from using the traffic lights to monitor their anxiety or fatigue levels, and as a result became more self-aware. The qualitative findings provided a greater insight into the barriers and facilitators associated with BiH. The importance of context (personal and environmental factors)

and its impact on the effectiveness of the technology was evident in all interviews. It is important for researchers and clinicians to consider the contextual factors when implementing BiH and their interaction with the individual appropriate support, insight and motivation appeared to be intrinsic to the use of the technology and its benefit to the participant. BiH requires clinical support especially during the early stages, to ensure people with ABI are using the app effectively. The findings from this thesis and integration of mixed methods has provided new knowledge about the barriers and facilitators associated with BiH and similar technologies. It also provides an insight into the interactions of contextual factors and their impact on complex interventions. The context of an intervention requires as much focus as the content, something that is a clear focus for the future development of BiH.

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Appendices

Appendix 1: Example search strategy

1. randomi?ed controlled trial.pt.
2. controlled clinical trial.pt.
3. randomi?ed.ab.
4. placebo.ab.
5. randomly.ab.
6. trial.ab.
7. groups.ab.
8. or/1-7
9. Brain Injuries/
10. Brain Concussion/
11. Brain Hemorrhage, Traumatic/
12. Brain Injury, Chronic/
13. Diffuse Axonal Injury/
14. brain injur*.ti,ab.
15. (TBI or TBIs).ti,ab.
16. (hypoxic brain damage or diffuse axonal injur* or DAI or DAIs).ti,ab.
17. head injur*.ti,ab.
18. (brain adj2 trauma*).ti,ab.
19. (head adj2 trauma*).ti,ab.
20. concussion.ti,ab.
21. brain contusion.ti,ab.
22. cerebrovascular disorders/ or basal ganglia cerebrovascular disease/ or exp brain ischemia/ or carotid artery diseases/ or carotid artery thrombosis/ or intracranial arterial diseases/ or cerebral arterial diseases/ or exp intracranial embolism and thrombosis/ or exp stroke/
23. (isch?emi$ adj6 (stroke$ or apoplex$ or cerebral vasc$ or cerebrovasc$ or cva)).tw.
24. ((brain or cerebr$ or cerebell$ or vertebrobasil$ or hemispher$ or intracran$ or intracerebral or infratentorial or supratentorial or middle cerebr$ or mca$ or anterior circulation) adj5 (isch?emi$ or infarct$ or thrombo$ or emboli$ or occlus$ or hypoxi$)).tw.
25. or/9-24
26. exp Cellular Phone/
27. Computers, Handheld/
28. (handheld or hand-held) adj1 (computer? or pc?).mp.
29. cell$ phone?.mp.
30. mobile phone?.mp.
31. smartphone?.mp.
32. smart-phone?.mp.
33. (personal digital assistant? or PDA?).mp.
34. palmtop computer?.mp.
35. (Tablet adj3 (device? or comput$)).mp.
36. Blackberry.mp.
37. Nokia.mp.
38. Symbian.mp.
39. (windows adj3 (mobile? Or phone?)).mp.
40. sidekick.mp.
41. Android.mp.
42. (phone adj3 call*).mp. OR ((cell* or mobile or smart or google or nexus or iphone) adj3 (phone* or telephone*)).mp. OR smart-phone*.mp. OR smartphone*.mp. OR (blackberr* not extract).mp. OR (black-berr* not extract).mp. OR (mobile adj3 health)
43. (mobile adj3 technol*).mp. OR ((mobile or smartphone or smart-phone or phone or software) adj3 app*).mp. OR MMS.mp. OR multimedia messaging service.mp. OR SMS.mp. OR short

messag* service.mp. OR (text* adj messag*).mp. OR text-messa*.mp. OR voice messag*.mp. OR interactive voice response.mp. OR IVR.mp. OR Telemedicine/ OR cellular phone/ OR Text Messaging/

44. MP3-Player/
45. iphone$.tw.
46. ipad.tw.
47. ipod.tw.
48. (mhealth or m-health or m health).tw.
49. mobile health.tw.
50. Samsung.mp.
51. Or/26-50
52. exp rehabilitation/
53. (rehab* or (activit* adj2 daily living)).tw.
54. (re-abl* or reabl* or enablement or empower* or restor* or re-learn* or relearn*).tw.
55. recovery of function/
56. ((recover* or optim* or maintain* or increas* or improv* or independen* or ability or outcome*) adj3 function*).tw.
57. ((enabl* or recover* or maintain* or develop* or living) adj3 independen*).tw.
58. Occupational therapy/
59. exp “activities of daily living”/
60. exp rehabilitation, vocational/ or Rehabilitation/ or Self care/
61. exp leisure activities/
62. exp “recovery of function”/
63. exp work/ or Human activities/
64. Social adjustment/ or Social behavior/ or Social facilitation/
65. Social environment/ or Social support/
66. Goals/
67. occupational therap$.tw.
68. (activities of daily living or adl$ or eadl$).tw.
69. rehabilitation.tw.
70. ((self or personal) adj5 (care or manage $)).tw.
71. (dressing or feeding or eating or toilet$ or bathing or mobil$ or driving or public transport$).tw.
72. ((daily or domestic or house or home) adj5 (activit$ or task$ or skill$ or chore$)).tw.
73. leisure.tw.
74. (recover$ adj5 function$).tw.
75. (social adj5 (activit$ or function$ or support$ or skill$ or adjust$ or behavio?r or facilitat$)).tw.
76. (counsel?ing or goal$ or work or employment).tw.
77. or/52-76
78. 25 and 51 and 77
79. animals/not (humans/ and animals/)
80. 78 not 79

80 and 8

Appendix 2: Databases searched.

Database	Dates searched
Cochrane Central Register of Controlled Trials (CENTRAL, The Cochrane Library)	(issue 7, 2017)
Ovid MEDLINE(R), Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid OLDMEDLINE(R)	Inception to 31 March 2018
Embase Classic + Embase (OvidSP)	Inception to 31 March 2018
CINAHL Plus	Inception to 31 March 2018
PsycINFO (OvidSP)	Inception to 31 March 2018
PubMed (limited to references not indexed in MEDLINE)	Inception to 31 March 2018
HMIC (Ovid) Health Management Information Consortium	Inception to 31 March 2018
AMED (Ovid) (Allied and Complementary Medicine)	Inception to 31 March 2018
The Joanna Briggs Institute EBP Database	Inception to 31 March 2018
EBSCO ERIC (Education Resource Information Centre)	Inception to 31 March 2018
National Institute for Health Research (UK) (www.portal.nihr.ac.uk)	31 March 2018
UK Clinical Research Network (www.public.ukcrn.org.uk).	31 March 2018

Appendix 3: Bespoke data extraction tool.

Data Extraction Tool **Study ID:**

Characteristics of Study Participants

	Description	Location in text
Participant population [P1]		
Description of Study Setting and Context [S1]		
Inclusion Criteria [X1]		
Exclusion Criteria [X2]		
Recruitment and randomisation [R1]		
Is there an informed consent obtained?	Yes / No / Unclear	
Total number of study participants [P2]		
Age [P3]		
Gender [P4]		
Severity of acquired brain injury [D1]		
Participant comorbidities [D2]		
Other relevant demographic data		
Variations in participant baseline characteristics [P5] **(if applicable)**		
Intervention used (brief description) [T1]		
Withdrawals and exclusions from the study (if any) [X3]		
Missing data (if any)		
Study Outcome(s) (detailed description, definition, measures, and/or classification)	Primary outcomes [O1]:	
	Secondary outcomes [O2]:	

Specific Quantitative Measures:	Independence [A1]:	
	Functional outcomes (i.e. ADL) [A2]:	
	Quality of life [A3]:	
	Goal Attainment [A4]:	
	Intervention use and satisfaction [B1]:	
	Psychological function [B3]:	
	Cognitive function [B2]:	
	Participation or social function [B4]:	
Comparators [C1 & C2]		
Results of the study (summary)		
Any other benefits or harms identified by the study [B5]		
Any reported limitations of study methods and results by the authors		
Miscellaneous data:		

Appendix 3 (continued): Bespoke data extraction tool. Adapted from (Hoffmann et al., 2014)

Intervention Details = TIDieR guidleines

	Description	Location in text
Brief Name [I1]		
WHY [I2] Describe any rationale, theory, or goal of the elements essential to the intervention.		
WHAT [I3] **Materials**: Describe any physical or informational materials used in the intervention. **Procedures**: Describe each of the procedures, activities, and/or processes used in the intervention.		
WHO PROVIDED [I4]		
HOW [I5] Describe the modes of delivery (e.g. face-to-face or by some other mechanism.		
WHERE [I6] Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.		
WHEN and HOW MUCH [I7] Describe the number of times the intervention was delivered and over what period of time.		
TAILORING [I8] If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when, and how.		
MODIFICATIONS [I9] If the intervention was modified during the course of the study, describe the changes (what, why, when, and how).		
HOW WELL [I10] Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them. Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.		

Appendix 4: Exclusion of studies summary table

	Study Reference	Primary reason for Exclusion
1	Archer, K. R., Coronado, R. A., Haislip, L. R., Abraham, C. M., Vanston, S. W., Lazaro, A. E., . . . Obremskey, W. T. (2015). Telephone-based goal management training for adults with mild traumatic brain injury: study protocol for a randomized controlled trial. Trials [Electronic Resource], 16, 244.	Not original research with results - protocol
2	Audebert, H. J., Boy, S., Jankovits, R., Pilz, P., Klucken, J., Fehm, N. P., & Schenkel, J. (2008). Is mobile teleconsulting equivalent to hospital-based telestroke services? Stroke, 39(12), 3427-3430.	Not RCT
3	Audebert, H. J., Wimmer, M. L. J., Schenkel, J., Ulm, K., Kolominsky-Rabas, P. L., Bogdahn, U., . . . Haberl, R. L. (2004). [Telemedicine stroke department network. Introduction of a telemedicine pilot project for integrated stroke management in South Bavaria and analysis of its efficiency]. Nervenarzt, 75(2), 161-165.	Not RCT
4	Baldwin, V. N., & Powell, T. (2015). Google Calendar: A single case experimental design study of a man with severe memory problems. Neuropsychol Rehabil, 25(4), 617-636.	Not RCT
5	Bedell, G. M., Wade, S. L., Turkstra, L. S., Haarbauer-Krupa, J., & King, J. A. (2016). Informing design of an app-based coaching intervention to promote social participation of teenagers with traumatic brain injury. *Dev Neurorehabil*, 1-10. doi:10.1080/17518423.2016.1237584	Not adults with ABI
6	Bell, K., Brockway, J., Hart, T., Whyte, J., Sherer, M., & Fraser, R. (2011). Scheduled telephone intervention for traumatic brain injury: A multicenter randomized controlled trial. Arch Phys Med Rehabil, 92(10), 1552-1560.	Not personal smart technology
7	Bell, K. R., Brockway, J. A., Fann, J. R., Cole, W. R., De Lore, J. S., Bush, N., . . . Temkin, N. (2015). Concussion treatment after combat trauma: Development of a telephone based, problem solving intervention for service members. Contemporary Clinical Trials 40 (pp 54-62), 2015, Date of Publication, January 01.	Not original research with results - protocol
8	Bell, K. R., Fann, J., Brockway, J. A., Cole, W. R., Bush, N., Dikmen, S., . . . Temkin, N. (2015). Telephone problem solving treatment for active duty service members with mild traumatic brain injury. PM and R, Conference, 2015 Annual Assembly of the American Academy of Physical Medicine and Rehabilitation Boston, MA United States.	Not personal smart technology
9	Benvenuti, F., Stuart, M., Cappena, V., Gabella, S., Corsi, S., Taviani, A., . . . Weinrich, M. (2014). Community-based exercise for upper limb paresis: a controlled trial with telerehabilitation. Neurorehabilitation & Neural Repair, 28(7), 611-620.	Not RCT
10	Bergman, M. M. (2008). US5601432.	Not adults with ABI
11	Bishop, D., Miller, I., Weiner, D., Guilmette, T., Mukand, J., Feldmann, E., . . . Springate, B. (2014). Family Intervention: Telephone Tracking (FITT): A pilot stroke outcome study. Topics in Stroke Rehabilitation Vol, 21(Supp1), S63-S74.	Not personal smart technology
12	Boman, I., Bartfai, A., Borell, L., Tham, K., & Hemmingsson, H. (2010). Support in everyday activities with a home-based electronic memory aid for persons with memory impairments. Disability & Rehabilitation: Assistive Technology, 5(5), 339-350 312p.	Not RCT
13	Bombardier, C. H., Bell, K. R., Temkin, N. R., Fann, J. R., Hoffman, J., & Dikmen, S. (2009). The efficacy of a scheduled telephone intervention for ameliorating depressive symptoms during the first year after traumatic brain injury. Journal of Head Trauma Rehabilitation, 24(4), 230-238 239p.	Not personal smart technology
14	Bourgeois, M. S., Lenius, K., Turkstra, L., & Camp, C. (2007). The effects of cognitive teletherapy on reported everyday memory behaviours of persons with chronic traumatic brain injury. Brain Injury Vol, 21(12), 1245-1257.	Not personal smart technology
15	Brown, R., Pain, K., Berwald, C., Hirschi, P., Delehanty, R., & Miller, H. (1999). Distance education and caregiver support groups: comparison of traditional and telephone groups. Journal of Head Trauma Rehabilitation, 14(3), 257-268.	Not adults with ABI
16	Chang, Y.-J., Chen, S.-F., & Chou, L.-D. (2012). A Feasibility Study of Enhancing Independent Task Performance for People with Cognitive Impairments Through the Use of a Handheld Location-Based Prompting System. IEEE Transactions on Information Technology in Biomedicine, 16(6), 1157-1163.	Not RCT
17	Charters, E., Gillett, L., & Simpson, G. K. (2015). Efficacy of electronic porTable assistive devices for people with acquired brain injury: a systematic review. *Neuropsychol Rehabil, 25*(1), 82-121.	Not original research with results – systematic review
18	Choi, Y.-H., & Paik, N.-J. (2018). Mobile Game-based Virtual Reality Program for Upper Extremity Stroke Rehabilitation. *J Vis Exp*(133). doi:https://dx.doi.org/10.3791/56241	Not RCT
19	Chumbler, N. R., Quigley, P., Li, X., Morey, M., Rose, D., Sanford, J., . . . Hoenig, H. (2012). Effects of telerehabilitation on physical function and disability for stroke patients: a randomized, controlled trial. Stroke (00392499), 43(8), 2168-2174 2167p.	Not personal smart technology
20	Chumbler, N. R., Rose, D. K., Griffiths, P., Quigley, P., McGee-Hernandez, N., Carlson, K. A., . . . Hoenig, H. (2010). Study protocol: home-based telehealth stroke care: a randomized trial for veterans. Trials [Electronic Resource], 11, 74.	Not original research with results - protocol
21	Crotty, M., Killington, M., van den Berg, M., Morris, C., Taylor, A., & Carati, C. (2014). Telerehabilitation for older people using off-the-shelf applications: acceptability and feasibility. Journal of Telemedicine & Telecare, 20(7), 370-376.	Not adults with ABI
22	Culley, C., & Evans, J. J. (2010). SMS text messaging as a means of increasing recall of therapy goals in brain injury rehabilitation: a single-blind within-subjects trial. Neuropsychol Rehabil, 20(1), 103-119.	Not RCT
23	Daggett, V., Bakas, T., Murray, L., Woodward-Hagg, H., Williams, J. G., Maddox, K., . . . Ellis, R. D. (2014). Feasibility and satisfaction with the VETeranS Compensate, Adapt, REintegrate (VETS-CARE) intervention. *Brain Inj, Conference*, 10th World Congress on Brain Injury of the International Brain Injury Association San Francisco, CA United States. Conference Start: 20140319 Conference End: 20140322. Conference Publication: (var.pagings). 20140328 (20140315-20140316) (pp 20140554-20140555).	Could not retrieve full text
24	de Joode, E., van Heugten, C., Verhey, F., & van Boxtel, M. (2010). Efficacy and usability of assistive technology for patients with cognitive deficits: a systematic review. Clin Rehabil, 24(8), 701-714.	Not RCT
25	Dean, P., Perkins, L., McNamara, A., Sauseng, P., & Sterr, A. (2014). A novel method for acquiring cognitive data after brain injury and during follow-up: The use of mobile technology in a visuospatial working memory task. Brain Inj, Conference, 10th World Congress on Brain Injury of the International Brain Injury Association San Francisco, CA United States.	Not RCT

26	Demaerschalk, B. M., Raman, R., Ernstrom, K., & Meyer, B. C. (2012). Efficacy of telemedicine for stroke: pooled analysis of the Stroke Team Remote Evaluation Using a Digital Observation Camera (STRokE DOC) and STRokE DOC Arizona telestroke trials. Telemedicine Journal & E-Health, 18(3), 230-237.	Not personal smart technology
27	Depompei, R., Gillette, Y., Goetz, E., Xenopoulos-Oddsson, A., Bryen, D., & Dowds, M. (2008). Practical applications for use of PDAs and smartphones with children and adolescents who have traumatic brain injury. NeuroRehabilitation, 23(6), 487-499.	Not adults with ABI
28	Des Roches, C. A., Balachandran, I., Ascenso, E. M., Tripodis, Y., & Kiran, S. (2014). Effectiveness of an impairment-based individualized rehabilitation program using an iPad-based software platform. Front Hum Neurosci, 8, 1015.	Not RCT
29	Dowds, M. M., Lee, P. H., Sheer, J. B., O'Neil-Pirozzi, T. M., Xenopoulos-Oddsson, A., Goldstein, R., . . . Glenn, M. B. (2011). Electronic reminding technology following traumatic brain injury: effects on timely task completion. *J Head Trauma Rehabil, 26*(5), 339-347.	No measure of primary outcomes
30	Dry, A., Colantonio, A., Cameron, J. I., & Mihailidis, A. (2006). Technology in the lives of women who live with memory impairment as a result of a traumatic brain injury. Assistive Technology, 18(2), 170-180.	Not RCT
31	Dubey, D., Amritphale, A., Sawhney, A., Amritphale, N., Dubey, P., & Pandey, A. (2014). Smart phone applications as a source of information on stroke. J Stroke, 16(2), 86-90. doi:10.5853/jos.2014.16.2.86	Not RCT
32	Dybus, A., Paul, L., Wyke, S., Brewster, S., Alexander, G., Gill, J., . . . Rico Williamson, J. (2014). Increasing physical activity in stroke survivors using STARFISH, an interactive mobile phone application: A feasibility study. *Cerebrovascular Diseases, 37*(Supplement 1), 299.	No measure of primary outcomes
33	Fish, J., Evans, J. J., Nimmo, M., Martin, E., Kersel, D., Bateman, A., . . . Manly, T. (2007). Rehabilitation of executive dysfunction following brain injury: "Content-free" cueing improves everyday prospective memory performance. Neuropsychologia, 45(6), 1318-1330.	Not RCT
34	Franzén, C., Brulin, C., Stenlund, H., & Björnstig, U. (2009). Injured road users' health-related quality of life after telephone intervention: a randomised controlled trial. Journal of Clinical Nursing, 18(1), 108-116 109p. doi:10.1111/j.1365-2702.2008.02436.x	Not personal smart technology
35	Gilles, N., Zelonis, S., Beving, L., Burton, D., Ventura-DiPersia, C., Kunnakkat, S., . . . Levine, S. (2015). A national survey of preferences for mobile applications (APPS) among stroke survivors & caregivers. J Neurol Sci, Conference, 22nd World Congress of Neurology, WCN 2015 Santiago Chile. Conference Start: 20151031 Conference End: 20151105. Conference Publication: (var.pagings). 20151357 (pp e20151100).	Not RCT
36	Goodwin, R., Lincoln, N., das Nair, R., & Bateman, A. (2017). External memory aids for memory problems in people with multiple sclerosis: A systematic review. *Neuropsychol Rehabil, 27*(8), 1081-1102.	Not adults with ABI
37	Hermens, H., Huijgen, B., Giacomozzi, C., Ilsbroukx, S., Macellari, V., Prats, E., . . . Vollenbroek-Hutten, M. (2008). Clinical assessment of the HELLODOC tele-rehabilitation service. Annali Dell'Istituto Superiore di Sanita, 44(2), 154-163.	Not personal smart technology
38	Huijbregts, M. P. J., McEwen, S., & Taylor, D. (2009). Exploring the feasibility and efficacy of a telehealth stroke self-management programme: a pilot study. Physiotherapy Canada, 61(4), 210-220 211p. doi:10.3138/physio.61.4.210	Not RCT
39	Jhaveri, M. M., Benjamin-Garner, R., Rianon, N., Sherer, M., Francisco, G., Vahidy, F., . . . Savitz, S. (2017). Telemedicine-guided education on secondary stroke and fall prevention following inpatient rehabilitation for Texas patients with stroke and their caregivers: a feasibility pilot study. *BMJ Open, 7*(9), e017340.	Not RCT
40	Jin, W., Chen, J., Shi, F., Yang, W., Zhang, Y., Liu, Y., . . . Ren, C. (2015). Home-based tele-supervising rehabilitation for brain infarction patients (HTRBIP): Study protocol for a randomized controlled trial. Trials 16 (1) (no pagination), 2015, Article Number, 61. Date of Publication: February 25.	Not original research with results - protocol
41	Johansson, B., & Tornmalm, M. (2012). Working memory training for patients with acquired brain injury: effects in daily life. Scand J Occup Ther, 19(2), 176-183 178p. doi:10.3109/11038128.2011.603352	Not RCT
42	Joubert, J., Christie, A., Laing, J., Wilks, B., Barnes, I., De Bustos Medeiros, E., & Moulin, T. (2013). Telestroke: Long-term risk factor management - Part II. European Research in Telemedicine, 2(2), 57-67.	Not original research with results – systematic review
43	Kamal, A. K., Shaikh, Q., Pasha, O., Azam, I., Islam, M., Memon, A. A., . . . Khoja, S. (2015). A randomized controlled behavioral intervention trial to improve medication adherence in adult stroke patients with prescription tailored Short Messaging Service (SMS)-SMS4Stroke study. *BMC Neurol, 15*(1), 212. doi:10.1186/s12883-015-0471-5	No measure of primary outcomes
44	Kiefer, S., Schafer, M., Schera, F., Niederlander, H., & Rohm, K. (2002). "Saar Stroke Teleservice--pilot study for stroke after care with a home care platform. Biomedizinische Technik Biomedical engineering, 2(pp 958-962).	Not RCT
45	Kim, H. J., Burke, D. T., Dowds, M. M., Jr., Boone, K. A., & Park, G. J. (2000). Electronic memory aids for outpatient brain injury: follow-up findings. Brain Inj, 14(2), 187-196.	Not RCT
46	Kizony, R., Weiss, P. L., Elion, O., Harel, S., Baum-Cohen, I., Krasovsky, T., . . . Shani, M. (2014). Development and validation of tele-health system for stroke rehabilitation. International Journal on Disability and Human Development, 13(3), 361-368.	Not personal smart technology
47	Koh, G. C., Yen, S. C., Tay, A., Cheong, A., Ng, Y. S., De Silva, D. A., . . . Phan, S. W. (2015). Singapore Tele-technology Aided Rehabilitation in Stroke (STARS) trial: Protocol of a randomized clinical trial on tele-rehabilitation for stroke patients. BMC Neurology Vol, 15, 161.	Not original research with results - protocol
48	Lakshminarayan, K., Westberg, S., Ezzeddine, M., Speedie, S., Fuller, C., & Grimm, R. (2017). An innovative mHealth-based care model for improving hypertension control in stroke survivors. *Stroke, 48*(Supplement 1).	No measure of primary outcomes
49	Laver, K. E., Schoene, D., Crotty, M., George, S., Lannin, N. A., & Sherrington, C. (2013). Telerehabilitation services for stroke. Cochrane Database of Systematic Reviews, (12). Retrieved from http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD010255.pub2/abstract doi:10.1002/14651858.CD010255.pub2	Not RCT
50	Lemoncello, R., Sohlberg, M. M., Fickas, S., Albin, R., & Harn, B. E. (2011). Phase I evaluation of the television assisted prompting system to increase completion of home exercises among stroke survivors. Disability & Rehabilitation: Assistive Technology, 6(5), 440-452 413p. doi:10.3109/17483107.2010.542571	Not personal smart technology
51	Linder, S. M., Rosenfeldt, A. B., Bay, R. C., Sahu, K., Wolf, S. L., & Alberts, J. L. (2015). Improving quality of life and depression after stroke through telerehabilitation. American Journal of Occupational Therapy Vol, 69(2), 1-9.	Not personal smart technology
52	Lutz, B. J., Chumbler, N. R., Lyles, T., Hoffman, N., & Kobb, R. (2009). Testing a home-telehealth programme for US veterans recovering from stroke and their family caregivers. Disability & Rehabilitation, 31(5), 402-409.	Not RCT
53	Mallet, K., Shamloul, R., Lecompte-Collin, J., Winkel, J., Donnelly, B., & Dowlatshahi, D. (2017). Telerehab for patients with post-stroke communication deficits using mobile technology: A randomized controlled trial. *International Journal of Stroke, 12*(4 Supplement 1), 18.	No measure of primary outcomes

54	Mallon, B., & Houtstra, T. (2007). Telephone technology in social work group treatment. Health & Social Work Vol, 32(2), 139-141.	Not RCT
55	Man, D. W. K., Soong, W. Y. L., Tam, S. F., & Hui-Chan, C. W. Y. (2006). A randomized clinical trial study on the effectiveness of a tele-analogy-based problem-solving programme for people with acquired brain injury (ABI). NeuroRehabilitation Vol, 21(3), 205-217.	Not RCT (quasi-design)
56	Mawson, S., & Mountain, G. (2011). The SMART rehabilitation system for stroke self-management: Issues and challenges for evidence-based health technology research. Journal of Physical Therapy Education, 25(1), 48-53.	Not RCT
57	Mawson, S., Nasr, N., Parker, J., Zheng, H., Davies, R., & Mountain, G. (2014). Developing a personalised self-management system for post stroke rehabilitation; utilising a user-centred design methodology. Disability & Rehabilitation Assistive Technology, 9(6), 521-528.	Not RCT
58	McCormick, S. A., & Holmes, P. S. (2016). See, imagine, move - upper limb action therapy (SIMULATe): Ipad-based mental and physical motor (re)learning for stroke recovery. Stroke, Conference, American Heart Association/American Stroke Association 2016 International Stroke Conference and State-of-the-Science Stroke Nursing Symposium Los Angeles, CA United States. Conference Start: 20160216 Conference End: 20160219. Conference Publication: (var.pagings). 20160247 (no pagination).	Not RCT
59	McDonald, A., Haslam, C., Yates, P., Gurr, B., Leeder, G., & Sayers, A. (2011). Google Calendar: a new memory aid to compensate for prospective memory deficits following acquired brain injury. *Neuropsychol Rehabil, 21*(6), 784-807. doi:10.1080/09602011.2011.598405	Pre-crossover data not available
60	Meyer, B. C., Raman, R., Chacon, M. R., Jensen, M., & Werner, J. D. (2008). Reliability of site-independent telemedicine when assessed by telemedicine-naive stroke practitioners. Journal of Stroke & Cerebrovascular Diseases, 17(4), 181-186.	Not personal smart technology
61	Middleton, D. K., Lambert, M. J., & Seggar, L. B. (1991). Neuropsychological rehabilitation: microcomputer-assisted treatment of brain-injured adults. Percept Mot Skills, 72(2), 527-530.	Not RCT
62	Nagao, K. J., Koschel, A., Haines, H. M., Bolitho, L. E., & Yan, B. (2012). Rural Victorian Telestroke project. Internal Medicine Journal, 42(10), 1088-1095.	Not personal smart technology
63	Novak, I. (2011). Effective home program intervention for adults: a systematic review...Occupational Therapy Australia, 24th National Conference and Exhibition, 29 June - 1 July 2011. Aust Occup Ther J, 58, 105-105 101p. doi:10.1111/j.1440-1630.2011.00939.x	Not RCT
64	Oddsson, S. (2017). Effects of a gamified mobile application to support a lifestyle-change program in adults: A controlled pilot. *Diabetes, 66*(Supplement 1), A42.	Not adults with ABI
65	Oupra, R., Griffiths, R., Pryor, J., & Mott, S. (2010). Effectiveness of Supportive Educative Learning programme on the level of strain experienced by caregivers of stroke patients in Thailand. Health & Social Care in the Community, 18(1), 10-20 11p. doi:10.1111/j.1365-2524.2009.00865.x	Not adults with ABI
66	Patel, S., Hughes, R., Hester, T., Stein, J., Akay, M., Dy, J. G., & Bonato, P. (2010). A Novel Approach to Monitor Rehabilitation Outcomes in Stroke Survivors Using Wearable Technology. Proceedings of the IEEE, 98(3), 450-461. doi:http://dx.doi.org/10.1109/JPROC.2009.2038727	Not RCT
67	Paul, L., Wyke, S., Brewster, S., Sattar, N., Gill, J. M. R., Alexander, G., . . . Dybus, A. (2016). Increasing physical activity in stroke survivors using STARFISH, an interactive mobile phone application: A pilot study. *Top Stroke Rehabil, 23*(3), 170-177.	Not RCT
68	Pavliscsak, H., Little, J. R., Poropatich, R. K., McVeigh, F. L., Tong, J., Tillman, J. S., . . . Fonda, S. J. (2016). Assessment of patient engagement with a mobile application among service members in transition. Journal of the American Medical Informatics Association, 23(1), 110-118.	Not adults with ABI
69	Piron, L., Turolla, A., Tonin, P., Piccione, F., Lain, L., & Dam, M. (2008). Satisfaction with care in post-stroke patients undergoing a telerehabilitation programme at home. Journal of Telemedicine & Telecare, 14(5), 257-260.	Not personal smart technology
70	Powell, J. M., Fraser, R., Ann, J., Brockway, A., Temkin, N. R., & Bell, K. R. (2014). A telehealth approach to improving outcomes for caregivers of adults with traumatic brain injury. Arch Phys Med Rehabil, Conference, 2014 American Congress of Rehabilitation Medicine Annual Conference, ACRM 2014 Toronto, ON Canada. Conference Start: 20141007 Conference End: 20141011. Conference Publication: (var.pagings). 20141095 (20141010) (pp e20141061).	Not adults with ABI
71	Powell, L. E., Glang, A., Ettel, D., Todis, B., Sohlberg, M. M., & Albin, R. (2012). Systematic instruction for individuals with acquired brain injury: Results of a randomised controlled trial. Neuropsychol Rehabil, 22(1), 85-112.	Not personal smart technology
72	Powell, L. E., Harwick, R., Glang, A., & Todis, B. (2012). Systematic instruction of assistive technology for cognition following brain injury: A manual for trainers. Journal of Head Trauma Rehabilitation, Conference, 10th Annual Conference on Brain Injury of the North American Brain Injury Society's, NABIS 2012 Miami, FL United States. Conference Start: 20120912 Conference End: 20120915. Conference Publication: (var.pagings). 20120927 (20120915) (pp E20120928).	Not adults with ABI
73	Pugliese, M., Johnson, D., Dowlatshahi, D., & Ramsay, T. (2017). Mobile Tablet-based therapies following stroke: A systematic scoping review protocol of attempted interventions and the challenges encountered. *Systematic Reviews, 6*(1), 219.	Not original research with results – systematic review
74	Ridley, D., & Bailey, C. (2012). Tablets and smartphones as compensatory memory strategies. *Journal of Head Trauma Rehabilitation, 27*(5), E10-E11.	Could not retrieve full text
75	Riegler, L. J., Neils-Strunjas, J., Boyce, S., Wade, S. L., & Scheifele, P. M. (2013). Cognitive intervention results in web-based videophone treatment adherence and improved cognitive scores. Medical Science Monitor, 19(1), 269-275.	Not RCT
76	Rietdijk, R., Togher, L., & Power, E. (2012). Supporting family members of people with traumatic brain injury using telehealth: A systematic review. J Rehabil Med, 44(11), 913-921.	Not original research with results – systematic review
77	Rochette, A., Korner-Bitensky, N., Bishop, D., Teasell, R., White, C., Bravo, G., . . . Wood-Dauphinee, S. (2013). Best practices when facing daily challenges after a first mild stroke: You call or we call? Stroke, Conference, 2013 Canadian Stroke Congress Montreal, QC Canada. Conference Start: 20131017 Conference End: 20131019. Conference Publication: (var.pagings). 20131044 (20131012) (pp e20131221-e20131222).	Not personal smart technology
78	Rochette, A., Korner-Bitensky, N., Bishop, D., Teasell, R., White, C., Bravo, G., . . . Wood-Dauphinee, S. (2010). Study protocol of the YOU CALL--WE CALL TRIAL: impact of a multimodal support intervention after a "mild" stroke. BMC Neurol, 10, 3.	Not original research with results - protocol
79	Roots, A., Bhalla, A., & Birns, J. (2011). Telemedicine for stroke: A systematic review. British Journal of Neuroscience Nursing, 7(2), 481-489.	Not RCT
80	Rous, R., Adams, M., Fish, J., Manly, T., & Adlam, A. (2012). Prospective memory intervention for adolescents with acquired brain injury: Developmental and psychosocial factors affecting outcomes. Brain Impairment, Conference, 9th	Not adults with ABI

	Annual Conference of the Special Interest Group in Neuropsychological Rehabilitation of the World Federation for NeuroRehabilitation, WFNR 2012 Bergen Norway.	
81	Rubin, M. N., Wellik, K. E., Channer, D. D., & Demaerschalk, B. M. (2013). Role of telemedicine in providing tertiary neurological care. Curr Treat Options Neurol, 15(5), 567-582.	Not original research with results - opinion piece
82	Salaris, M., de Vries, R., Jordan, L. A., Quinn, R., Young, A. D., Paisley, E., & Janssen, H. (2014). How frequently and for what purpose is Tablet technology being used during stroke recovery? *International Journal of Stroke, Conference*, 10th Australasian Nursing and Allied Health Stroke Conference, Smart Strokes 2014 Sydney , NSW Australia. Conference Start: 20140828 Conference End: 20140829. Conference Publication: (var.pagings). 20140829 (pp 20140827-20140828).	Not original research with results – protocol abstract
83	Saposnik, G., Chow, C.-M., Gladstone, D., Cheung, D., Brawer, E., Thorpe, K. E., . . . i, H. R. T. f. t. S. O. R. C. W. G. (2014). iPad technology for home rehabilitation after stroke (iHOME): a proof-of-concept randomized trial. International Journal of Stroke, 9(7), 956-962.	Not RCT
84	Saywell, N., Vandal, A. C., Brown, P., Hanger, H. C., Hale, L., Mudge, S., . . . Taylor, D. (2012). Telerehabilitation to improve outcomes for people with stroke: study protocol for a randomised controlled trial. Trials [Electronic Resource], 13, 233.	Not original research with results - protocol
85	Schoenberg, M. R., Ruwe, W. D., Dawson, K., McDonald, N. B., Houston, B., & Forducey, P. G. (2008). Comparison of functional outcomes and treatment cost between a computer-based cognitive rehabilitation teletherapy program and a face-to-face rehabilitation program. Professional Psychology: Research and Practice Vol, 39(2), 169-175.	Not personal smart technology
86	Singer, J., Weingast, S., Stefanov, D., Gilles, N., Girouard, S., Faysel, M., . . . Levine, S. (2017). Developing a mobile application for stroke caregivers. *Neurology, 88*(16 Supplement 1).	Not adults with ABI
87	Smith, G. C., Egbert, N., Dellman-Jenkins, M., Nanna, K., & Palmieri, P. A. (2012). Reducing depression in stroke survivors and their informal caregivers: a randomized clinical trial of a Web-based intervention. Rehabilitation Psychology, 57(3), 196-206.	Not personal smart technology
88	Stapleton, S., Adams, M., & Atterton, L. (2007). A mobile phone as a memory aid for individuals with traumatic brain injury: A preliminary investigation. . Brain Inj, 21(4), 401-411.	Not RCT
89	Suffoletto, B., Wagner, A. K., Arenth, P. M., Calabria, J., Kingsley, E., Kristan, J., & Callaway, C. W. (2013). Mobile phone text messaging to assess symptoms after mild traumatic brain injury and provide self-care support: a pilot study. *Journal of Head Trauma Rehabilitation, 28*(4), 302-312.	No measure of primary outcomes
90	Sureshkumar, K., Murthy, G. V., Munuswamy, S., Goenka, S., & Kuper, H. (2015). 'Care for Stroke', a web-based, smartphone-enabled educational intervention for management of physical disabilities following stroke: feasibility in the Indian context. BMJ Innov, 1(3), 127-136. doi:10.1136/bmjinnov-2015-000056	Not RCT
91	Sweetapple, A., & Gilbert, J. (2014). Photography and technology: The introduction and sharing of a new leisure activity for stroke survivors. International Journal of Stroke, Conference, 10th Australasian Nursing and Allied Health Stroke Conference, Smart Strokes 2014 Sydney, NSW Australia. Conference Start: 20140828 Conference End: 20140829. Conference Publication: (var.pagings). 20140829 (pp 20140830).	Not RCT
92	Szymkowiak, A., Morrison, K., Gregor, P., Inglis, E. A., Shah, P., Evans, J. J., & Wilson, B. A. (2005). A memory aid with remote communication: Preliminary findings. Technology and Disability, 17(4), 217-225.	Not RCT
93	Taylor, D. M., Stone, S. D., & Huijbregts, M. P. (2012). Remote participants' experiences with a group-based stroke self-management program using videoconference technology. Rural & Remote Health, 12, 1947.	Not RCT
94	Tornas, S., Lovstad, M., Solbakk, A.-K., Evans, J., Endestad, T., Hol, P. K., . . . Stubberud, J. (2016). Rehabilitation of Executive Functions in Patients with Chronic Acquired Brain Injury with Goal Management Training, External Cuing, and Emotional Regulation: A Randomized Controlled Trial. *Journal of the International Neuropsychological Society, 22*(4), 436-452.	No measure of primary outcomes
95	van Hoof, J., Kort, H., Rutten, P., & Duijnstee, M. (2010). Ageing-in-place by use of smart home technology...Fourth European Nursing Congress. Journal of Clinical Nursing, 19, 101-101 101p. doi:10.1111/j.1365-2702.2010.03444.x	Not adults with ABI
96	van Til, J., Drossaert, C., Renzenbrink, G., Snoek, G., Dijkstra, E., Stiggelbout, A., & Ijzerman, M. (2010). Feasibility of web-based decision aids in neurological patients. J Telemed Telecare, 16(1), 48-52.	Not RCT
97	Vloothuis, J., Mulder, M., Nijland, R. H., Konijnenbelt, M., Mulder, H., Hertogh, C. M., . . . van Wegen, E. (2015). Caregiver-mediated exercises with e-health support for early supported discharge after stroke (CARE4STROKE): Study protocol for a randomized controlled trial. BMC Neurology Vol, 15(1), 193.	Not original research with results - protocol
98	White, C. L., Ihegword, B., Patterson, M., Motz, D., Williamson, R., Caron, J. L., & Birnbaum, L. A. (2016). Feasibility testing of mhealth for brainhealth: A mobile intervention to support secondary stroke prevention. *Stroke, 47*.	Not RCT
99	Wild, M., & Schwartz, S. H. (2008). Memory compensation using the pocket PC: Making cognitive connections for brain injury survivors. Journal of Head Trauma Rehabilitation, Conference, North American Brain Injury Society's 6th Annual Conference on Brain Injury New Orleans, LA United States. Conference Start: 20081002 Conference End: 20081004. Conference Publication: (var.pagings). 20081023 (20081005) (pp 20081352-20081353).	Not RCT
100	Wilson, B. (2010). Rehabilitation of memory disorders. Journal of Neurology, Neurosurgery and Psychiatry, Conference, Section of Neuropsychiatry of RCPsych and British Neuropsychiatry Association Joint Conference London United Kingdom. Conference Start: 20100210 Conference End: 20100212. Conference Publication: (var.pagings). 20100281 (2010	Not RCT

Appendix 5: PEDro scale of quality for included studies

	PEDro Item Number											
Study ID	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**Total**
De Joode, 2013	I	I	I	I	0	0	0	I	I	I	I	8
Gracey, 2017	I	I	I	I	0	0	I	0	I	I	I	8
Kim, 2012	I	I	0	I	0	0	0	I	0	I	I	6
Lannin, 2014	I	I	I	I	0	0	I	I	I	I	I	9
Hart, 2017	I	I	0	I	0	0	I	I	I	I	I	8
Emmerson, 2017	I	I	I	I	0	0	I	I	0	I	I	7

I = satisfied item criterion, 0 = did not satisfy item criterion

Item 1: Eligibility criteria were specified; *Item 2*: Subjects were randomly allocated; *Item 3*: Allocation was concealed; *Item 4*: Groups were similar at baseline regarding the most important prognostic indicators; *Item 5*: There was blinding of all subjects; *Item 6*: There was blinding of all therapists who administered the therapy; *Item 7*: There was blinding of all assessors who measured at least one key outcome; *Item 8*: Measures of at least one key outcome were obtained from more than 85% of the subjects initially allocated to groups; *Item 9*: All subjects for whom outcome measures were available received the treatment or control condition as allocated or data for at least one key outcome was analysed by "intention to treat"; *Item 10*: The results of between-group statistical comparisons are reported for at least one key outcome; *Item 11*: The study provides both point measures and measures of variability for at least one key outcome.

Appendix 6: Engagement activity questionnaire for ABI survivors and carers

1. Are you….? ☐ Acquired brain injury survivor ☐ Carer

2. Age group: ☐ 18-30 ☐ 31-50 ☐ 51+ (please tick one box)

3. Gender: ☐ Male ☐ Female

4. Can you see a use for the Brain in Hand smartphone app? ☐ Yes ☐ No

5. What do you think Brain in Hand would be most useful for?

.....

.....

.....

6. What do you think the app could target or aid?
(please tick all boxes that apply)

- ☐ Memory problems
- ☐ Self-confidence
- ☐ Independence
- ☐ Activities of daily living
- ☐ Problem solving
- ☐ Goal setting
- ☐ Other (please state) .....
- ☐ Anxiety/stress management
- ☐ Depression
- ☐ Behaviour monitoring
- ☐ Anger/irritability
- ☐ Managing routine

7. How could you use Brain in Hand for yourself or for someone else?

.....

.....

.....

8. At what stage post-injury do you think Brain in Hand would be useful?

.....

.....

9. How long do you think you would use the app?

☐ 0-6 months ☐ 6-12 months ☐ 12 months+

Think about your initial impressions of the Brain in Hand app…

10. Did it make you want to use it? (please circle a number on the scale)

Not at all				Definitely
1	2	3	4	5

11. How appropriate do you think the app is for someone with a brain injury?
(please circle a number on the scale)

Inappropriate				Appropriate
1	2	3	4	5

12. Would you feel confident using the app? (please circle a number on the scale)

Not at all				Definitely
1	2	3	4	5

13. Would you pay for the app? ☐ Yes ☐ Maybe ☐ No

If yes, how much? .....

14. Please rate each point using the scale. Tick one box for each question.

	Inappropriate ← → Appropriate				
	1	**2**	**3**	**4**	**5**
a) Visual (e.g. clear text, bright, stimulating)					
b) Language (e.g. easy to understand)					
c) Design (e.g. appearance, layout, colours)					
d) Using the app (e.g. clear menu)					
e) Navigating the app (e.g. accessing solutions)					

15. What do you think are the most appealing or useful parts of the app?

- ☐ Traffic light system
- ☐ Mentor/support service
- ☐ Structured diary
- ☐ Monitoring progress
- ☐ Feedback online
- ☐ Personalised problems/solutions
- ☐ Other (please state):.....
  .....

17. What would stop you from using the app?

.....

.....

.....

18. How do you think the app could be improved?

.....

.....

.....

.....

.....

Appendix 7: Engagement activity questionnaire for professionals

1. Are you….? ☐ NHS Professional (please tick one box)
☐ Private company
☐ Other (please state) .....

2. Age group: ☐ 18-30 ☐ 31-50 ☐ 51+

3. Gender: ☐ Male ☐ Female

4. Can you see a use for the Brain in Hand smartphone app? ☐ Yes ☐ No

5. At what stage post-injury do you think the app could be introduced?

.....

.....

.....

6. How long do you think the app would be used for?

☐ 0-6 months ☐ 6-12 months ☐ 12 months+

7. What do you think the app could target or aid?
(please tick all boxes that apply)

☐ Memory problems
☐ Activities of daily living
☐ Problem solving
☐ Anxiety management/stress
☐ Depression
☐ Goal attainment
☐ Behaviour monitoring
☐ Anger/irritability
☐ Routine
☐ Other (please state):
.....

8. How might Brain in Hand help your patients or clients?

.....

.....

.....

.....

9. Do you think the app is appropriate for someone with a brain injury?

- ☐ Yes, it is appropriate
- ☐ Maybe, but needs some changes
- ☐ No, it does not seem appropriate

10. What do you think are the most appealing or useful parts of the app?

- ☐ Traffic light system
- ☐ Mentor/support service
- ☐ Structured diary
- ☐ Monitoring progress
- ☐ Feedback online
- ☐ Personalised problems/solutions
- ☐ Other (please state):.....

.....

11. Would you be happy to pay for the app? ☐ Yes ☐ Maybe ☐ No

12. How do you think the app could be improved?

.....

.....

.....

.....

13. What would stop you from recommending the app to your patients/clients?

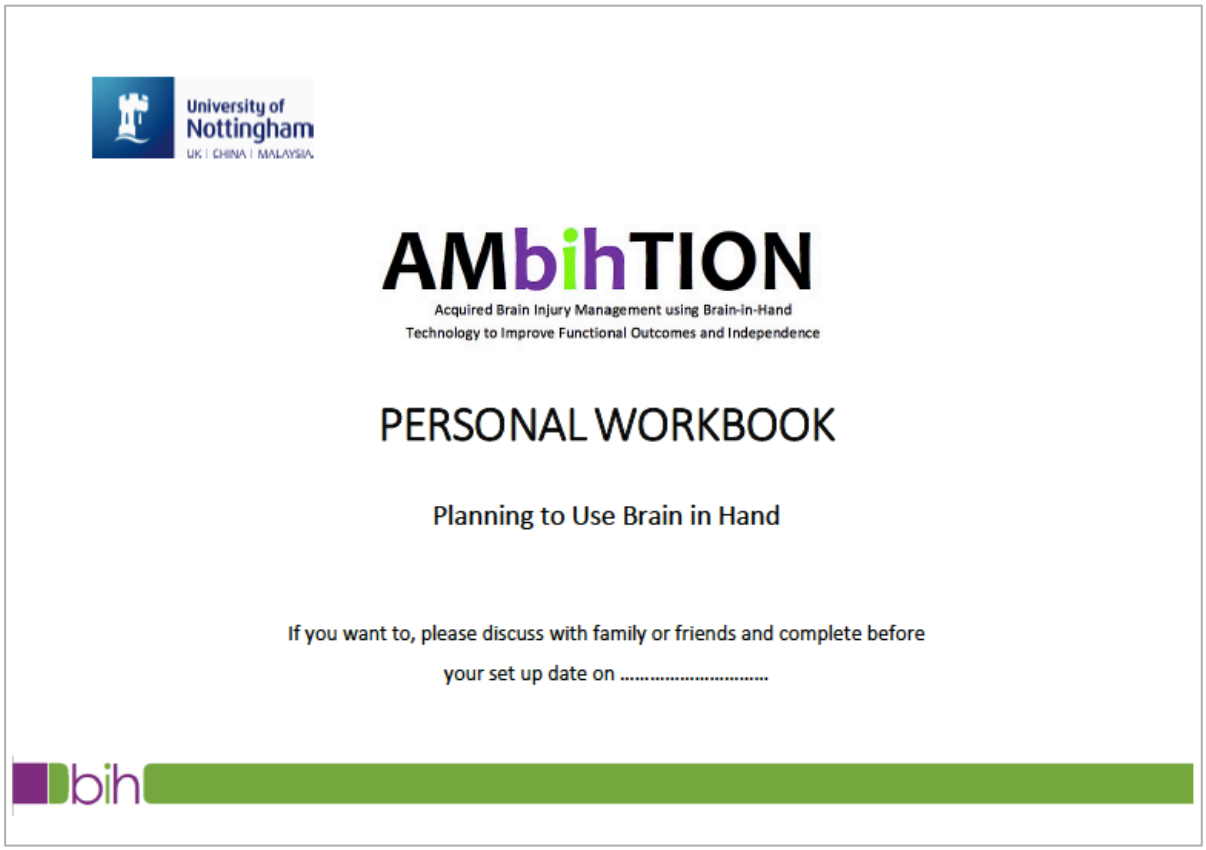
.....

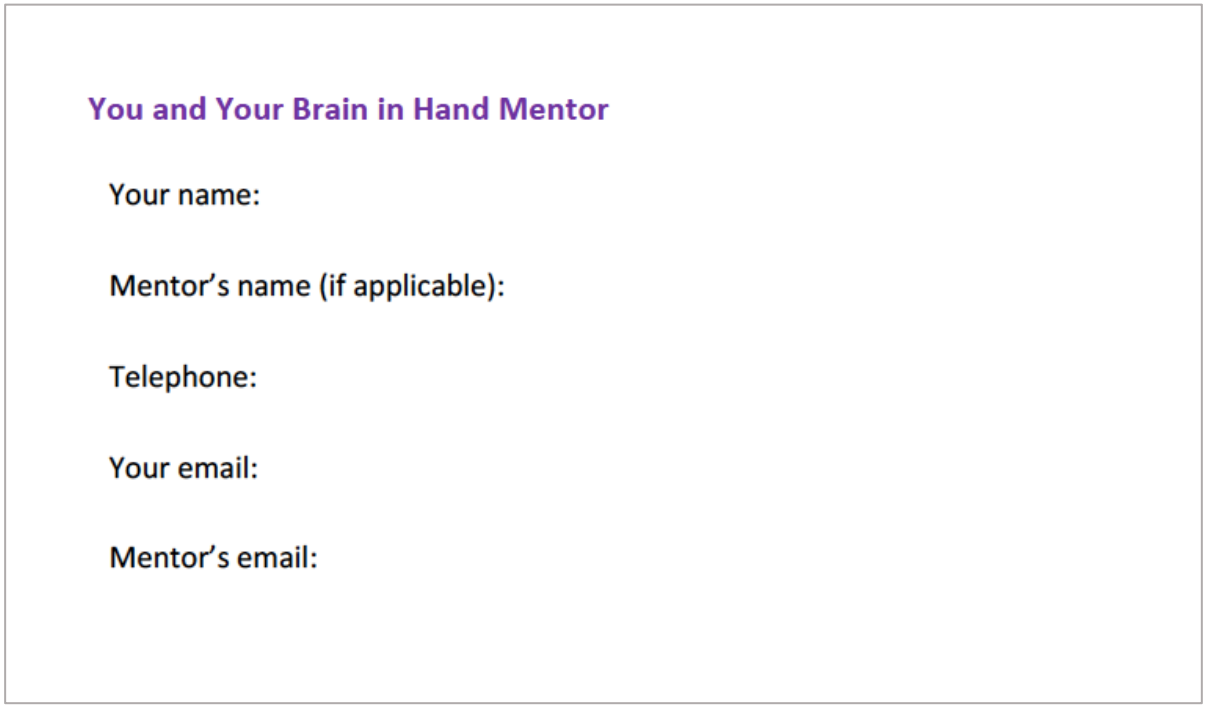
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Appendix 8: Personal Workbook for BiH provided to ABI participants before their set-up/training session





Your Goals With Brain in Hand

Name 3 goals you would like Brain in Hand to help you achieve:
(For example, this might be attending all appointments, managing fatigue, structuring your day etc.)

1.

2.

3.

Planning your Diary

Brain in Hand will provide you with a diary and 'recipes' for difficult to remember tasks to ensure vital elements of your day aren't missed.

You can enter appointments and routines for each day into the diary section of the system.

To make the most of your Brain in Hand, you will need to think about activities you do on a daily basis and potential problems you may encounter when doing these.

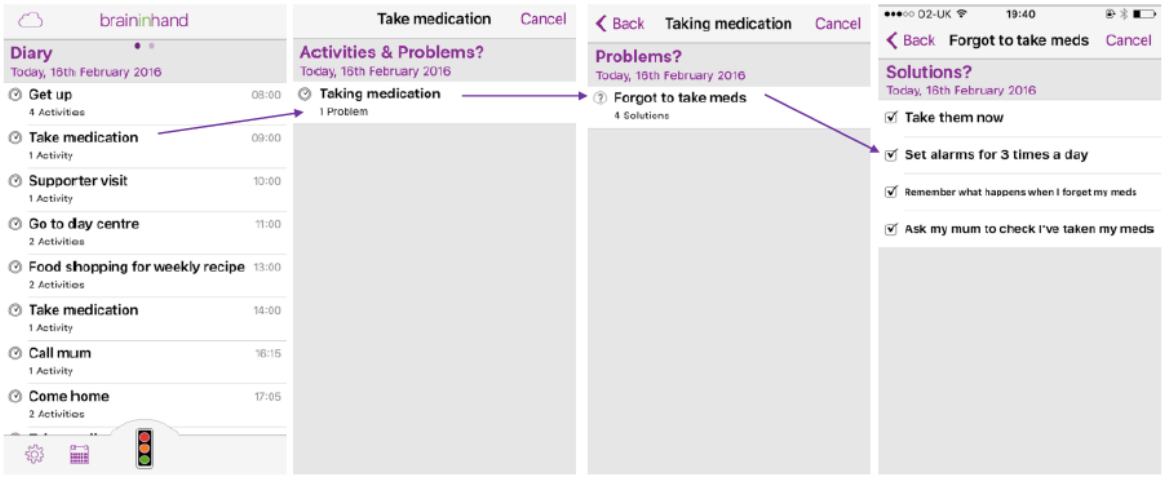
On the next page you can make a list of things you do during the day. It may be useful to think about activities you often forget to do that are important.

Planning your Diary

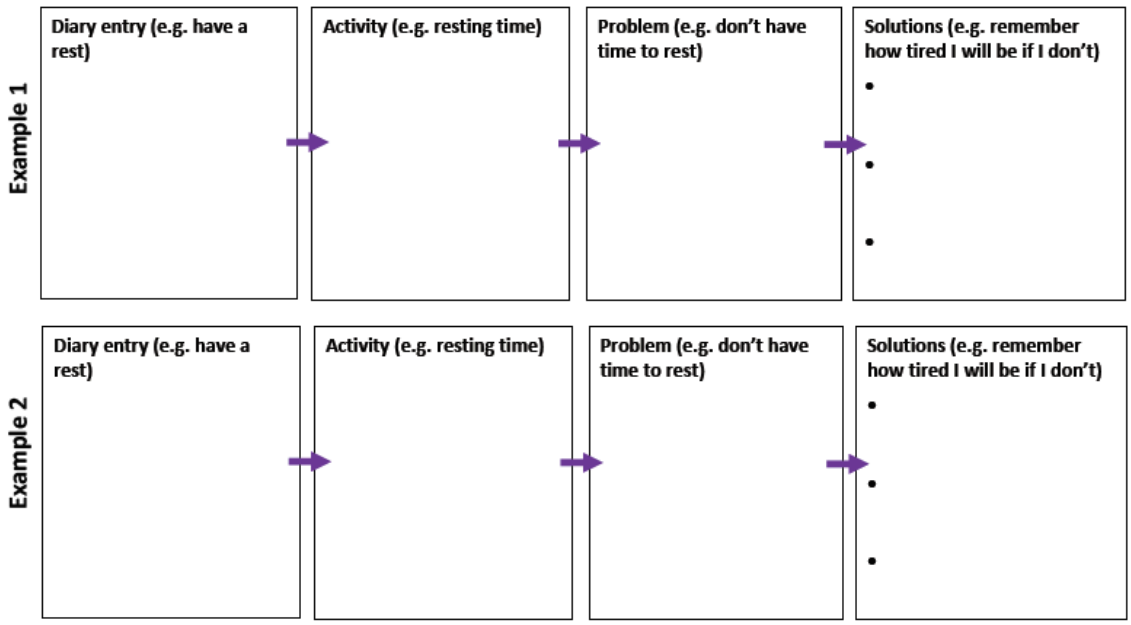
Add activities to the grid below that you do on a daily or weekly basis:
(e.g. make dinner, have a rest, go to the gym, take medication, go food shopping, do therapy exercises etc.)

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
AM							
PM							
Evening							

Example diary entry



Try to fill in a few diary entries below, think about problems you may face and potential solutions.



Your Unplanned Page

Your unplanned page can be used for things that can happen at any time. These might be things that happen unexpectedly or trigger anxiety, fatigue, anger etc. For example, forgetting to attend appointments, getting to the gym, losing your keys and unexpected changes. Your unplanned page can also be used for things that you do when you feel like it, rather than according to a schedule. Examples include hobbies, visiting a friend and household chores.

Here is an example of a possible unplanned item:

Unplanned Item	Problem	Solution
e.g. Unexpected Changes	1. Appointment cancelled	1. Call to re-book
	2. Cannot find the hospital when I get off the bus	2. Use maps on my phone

Your Unplanned Page

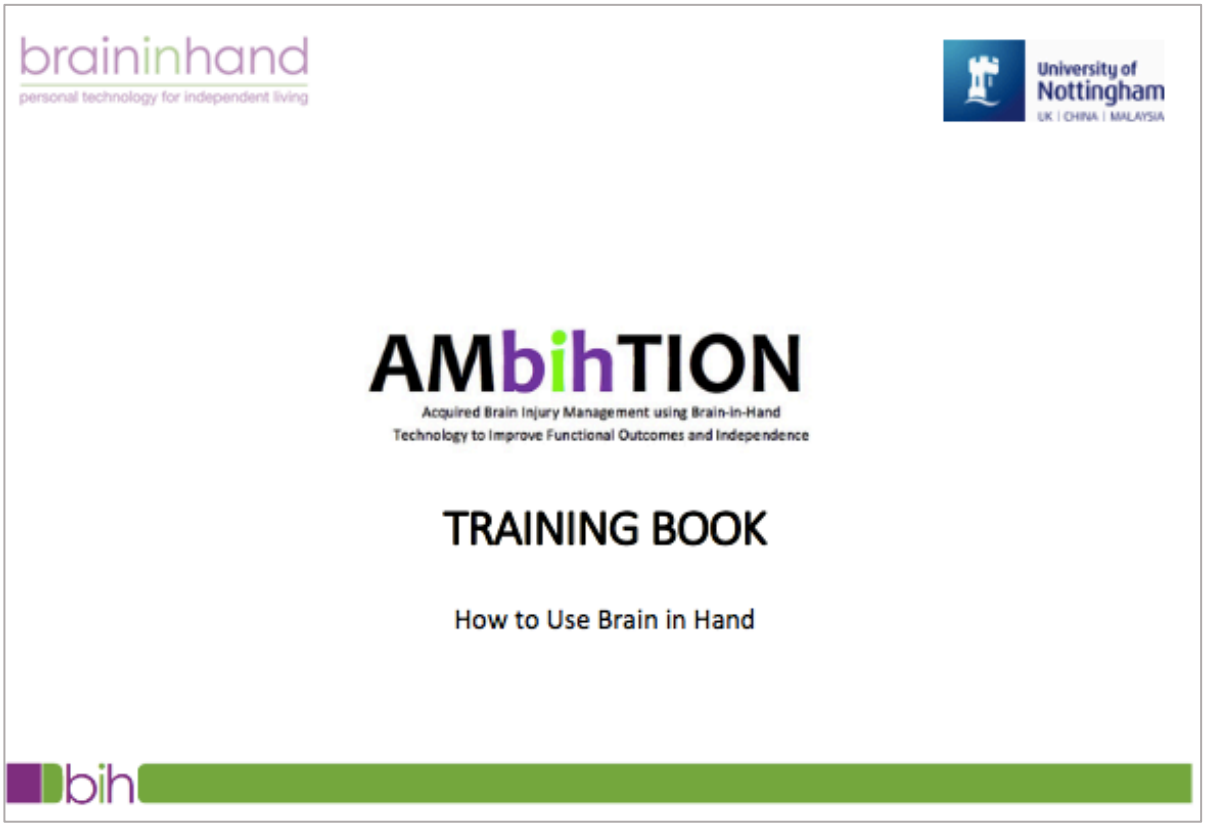
Please make a list below of activities that sometimes increase your levels of anxiety, fatigue, frustration etc. or list things that may happen during the day that are not always planned. Some examples are missing appointments, losing items, forgetting to take medication etc. Ask family or friends to help you think about problems you have been faced with and didn't have a solution.

- .....
- .....
- .....
- .....
- .....
- .....
- .....

Appendix 9: Checklist for training and set-up session with ABI participants

Date: Participant ID:	Trained	Competent?
1. Discuss and recap on goals that were set		
2. Identify if biggest problem is fatigue or anxiety		
3. Who will be listed as the mentor? Are they happy for them to access timeline?		
4. Identify activities that need reminders		
5. Discuss events that happen unplanned (i.e., getting angry, forgetting things)		
6. Give an overview of Brain in Hand and how the online portal works		
7. Create an account		
8. Login to their account and ask to change password if necessary (check competency)		
9. Go through different sections of the portal (check competency)		
10. Add personal details if applicable		
11. Diary set up – add some daily reminders		
12. Add some one off reminders e.g. next appointment		
13. Add a problem and set of solutions to a diary entry		
14. Add diary entry without reminders		
15. OPTIONAL - Show duplicate function (if understanding the system well)		
16. Ask participant to add another reminder to diary (check competency)		
17. Download app onto their phone and log in (check competency)		
18. Explain how to change prompts and update, navigate between screens, traffic lights (check competency)		
19. Click on a reminder or traffic light and allow to sync with online portal, check this works		
20. Explain timeline and how this works, how to update		
21. Unplanned page – discuss potential activities that can be added here • Add first unplanned event if one is identified (check competency)		
22. Give support booklet		

Appendix 10: Training Book for BiH provided to ABI participants during their set-up/training session



braininhand
personal technology for independent living

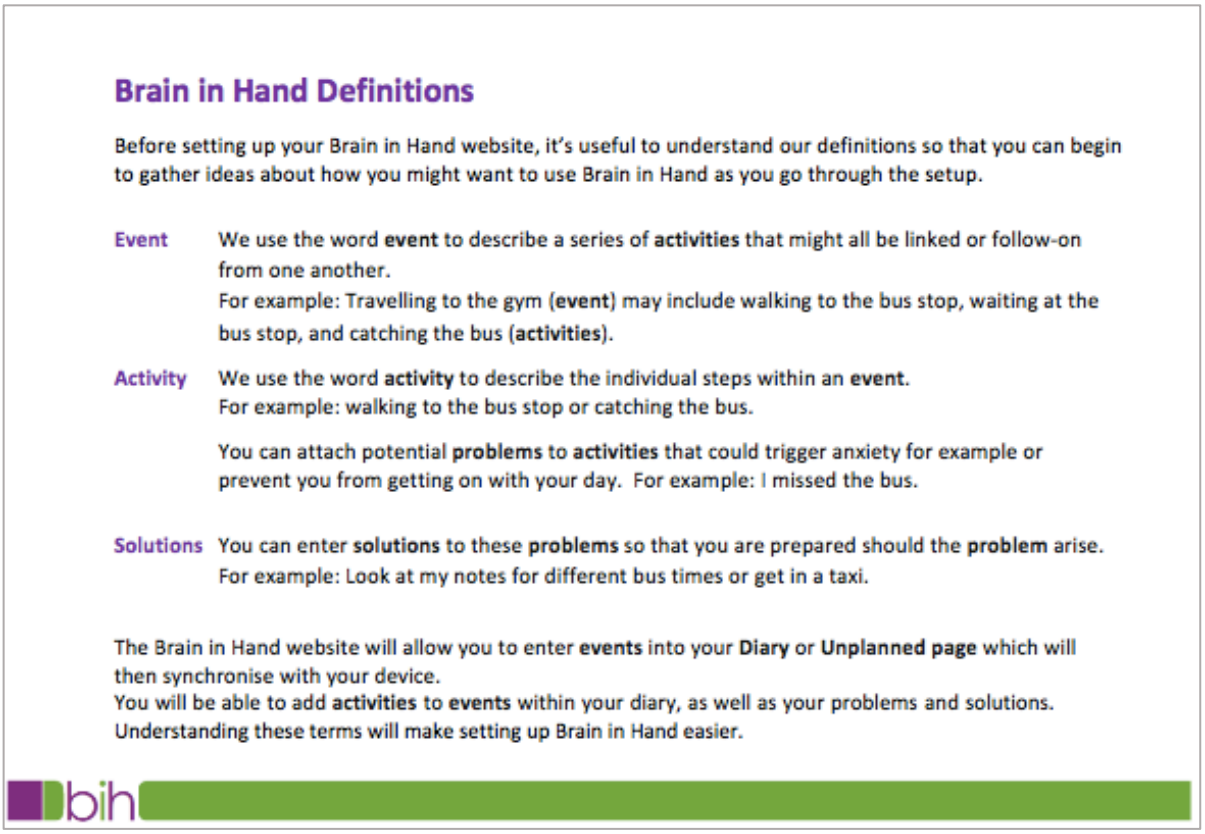
University of Nottingham
UK | CHINA | MALAYSIA

AMbihTION
Acquired Brain Injury Management using Brain-in-Hand Technology to Improve Functional Outcomes and Independence

TRAINING BOOK

How to Use Brain in Hand

bih



Brain in Hand Definitions

Before setting up your Brain in Hand website, it's useful to understand our definitions so that you can begin to gather ideas about how you might want to use Brain in Hand as you go through the setup.

Event We use the word **event** to describe a series of **activities** that might all be linked or follow-on from one another.
For example: Travelling to the gym (**event**) may include walking to the bus stop, waiting at the bus stop, and catching the bus (**activities**).

Activity We use the word **activity** to describe the individual steps within an **event**.
For example: walking to the bus stop or catching the bus.

You can attach potential **problems** to **activities** that could trigger anxiety for example or prevent you from getting on with your day. For example: I missed the bus.

Solutions You can enter **solutions** to these **problems** so that you are prepared should the **problem** arise.
For example: Look at my notes for different bus times or get in a taxi.

The Brain in Hand website will allow you to enter **events** into your **Diary** or **Unplanned page** which will then synchronise with your device.
You will be able to add **activities** to **events** within your diary, as well as your problems and solutions.
Understanding these terms will make setting up Brain in Hand easier.

bih

Your Brain in Hand Account

You will be given your own login for your Brain in Hand account. This will allow you to access your diary via the website. When you feel comfortable using Brain in Hand you will be able to change your diary and update any activities or solutions yourself.

To start with, you will set up your account with the researcher and your nominated mentor. During this training session you will create your online diary consisting of **activities, problems and solutions**.

Please make a note of your login in details below (keep this booklet somewhere safe):

Username: .....

Password: .....

bih

Your Brain in Hand website

1. Go to www.braininhand.co.uk ther 

2. Login using your email address and password (ask your Brain in Hand Supporter if you do not have this information).
3. Explore your website with your Supporter so that you are confident knowing what each page does.

(Tick the checkbox when you are confident with each page)

- ☐ **Home** Is the first page you see when you login.
- ☐ **Timeline** Is where your smart device use will be recorded once you're up and running. It will be empty to start off with.
- ☐ **Activities** Is where you can list different aspects of an event that you might find difficult, and your strategies for coping should a problem arise.
- ☐ **Diary** Is where you can plan out your events that occur at a certain time or on a certain day.
- ☐ **Unplanned** Is where you'll list things that might come up at any time, such as socialising.
- ☐ **Profile** Contains your contact details, information and preferences.

bih

Viewing your diary event on the app

Now you can have a closer look at the diary event that you added to your Brain in Hand app.

Tap on the event in your diary, and this will take you to the activities within that event.

Tap on the activities to view the problem that could arise. Tap on a problem to view the solutions you could use to resolve the problem. Tap on your chosen solution to return to the diary page.

To make your website sync with your app, click on "Settings", scroll down, and tap on "Update Now"

Tap on the calendar icon to navigate to a different date



After you have pressed on a solution, have a look at the Timeline page on your website.

bih

Inputting into your website

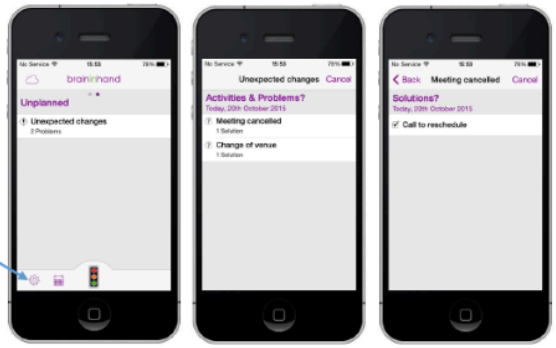
The next thing to do is to add this unplanned item to your Unplanned page on your website:

- **STEP 1** Click on the Unplanned tab and click "add unplanned"
- **STEP 2** Type the name of your unplanned item and click "create"
- **STEP 3** Click on "new problem" and type in the problems you mapped out for your unplanned item, then press enter
- **STEP 4** Add your possible solutions to your problems

Now you can view your unplanned item on your Brain in Hand app.

Login to the app on your smartphone or tablet and swipe sideways to view your unplanned page. This will take you to the potential problems within that unplanned item. Tap on the problem to view your possible solutions, then tap on your chosen solution.

Remember: To make your website sync with your app, click on "Settings", scroll down, and tap on "Update Now"



Remember: You can also attach activity-problem-solution sets (from your Activities page) to unplanned items.

bih

Appendix 11: Coding matrix applied to interviews with ABI participants and HCPs.

Barrier or Facilitator (coded separately for each node/sub-node)	**Behaviour Component**		**Motivation**
			Opportunity
			Capability
	Body Function/ Structure		**Sensory**
			Speech
			Medication
			Type of injury
			Time since injury
			Severity of injury
			Mental function
			Fatigue
	Environmental Factors	**Aids**	**Non-technology**
			Technology
			Environment
			Services
			Relationships
			Support
	Participation		**Productivity**
			Employment
			Home
			Social
	Personal Factors		**Independence**
			Acceptance
			Goals
	Activities		**Domestic**
			Mobility
			Leisure
			Kitchen

Appendix 12: Framework of key themes applied to interviews with ABI participants and HCPs.

Themes	ABI Participants		HCPs	
	Barriers	**Facilitators**	**Barriers**	**Facilitators**
Context				
Insight				
Motivation				
Support and training				
Technology				
Opportunity				
Capability				
Goals				

Appendix 13: Example interview topic guide for ABI participants.

AMbihTION

Acquired Brain Injury Management using Brain-in-Hand Technology to Improve Functional Outcomes and Independence

AMBiHTION Interview Topic Guide ABI participants

I am a researcher working on the Brain-in-Hand study at the University of Nottingham and understand that you have kindly agreed to take part. We want to ask you some questions to understand a bit more about your experiences of using Brain-in-Hand and your opinions about the technology. We are particularly interested in how and if Brain-in-Hand has helped you in your daily life, but also any issues you have experienced whilst using the technology. We value your feedback and hope to improve Brain-in-Hand to meet the needs of the ABI population. Your name will not be mentioned on any published documents, and any names or places you might refer to will be anonymised when transcribed. All information you provide will be used to develop our understanding and kept confidential. Are you still happy to go ahead with the interview and answer some questions?

Questions	Prompts	Links to framework
I already know a bit about your brain injury, could you tell me specifically how it affects your daily life.	• What problems do you experience as a result of your ABI? - Fatigue - Structure - How do you overcome these problems? • How does your brain injury/problems limit daily activities? - Structuring day, managing fatigue? • How does your ABI restrict your participation? (e.g. work, social life) - What is your social life like now, in comparison to before your injury? - Are you doing any voluntary work?	ICF - Body functions/structure, activities, participation BCW – Capability, opportunity (social)
What did you hope Brain in Hand would help you achieve?	• How is BiH helping you achieve things you want to do? • One of your goals was managing routine better (bedtime and morning routine) how has BiH helped with this? - Reminders for bed? Previously going to bed very late. - Recording bedtime the morning after. • Another goal was taking control of planning your day, how has BiH helped you achieve this? - How is it helping you feel more independent? • You mentioned that you wanted to remember daily tasks/appointments, how is BiH helping with this? - Are you remembering to do things and why? - Are you relying less on support workers? • If it has not helped you achieve these goals, why do you think that is? - How would you benefit from ongoing goal setting?	ICF – personal factors, environmental factors BCW – motivation, capability, opportunity

What do you consider the most helpful aspects of Brain in Hand?	• Has it been helpful with things you didn't realise you had problems with? • Tell me a bit about your use of the traffic lights (using for fatigue)? - We can see that you are pressing different colours, how has it been useful? - If you could monitor something else, what would that be? - Could you see yourself using it more for a different purpose? • We can see that you have used the problems and solutions feature, have you found it useful? - How could it be improved? - Has someone helped you update these problems and solutions? Therapist? • What other strategies have you been using to help with ADL? - How did you feel about using the app in public? - What would need to be changed for you to use it more? • Can you think about how BiH could help other people with brain injuries? - How could any changes help motivate other people?	BCW - motivation
What problems have you experienced when using Brain in Hand?	• Is there anything that has stopped you from using BiH regularly? - The app shows that you are completing most tasks each day, are you doing these tasks? - How could it be changed to encourage you to complete more tasks? - Have you experienced any technical difficulties? (phone not working, no charge) - Did you find it difficult to use? • Did you have other strategies in place to deal with your brain injury before the study? - Is BiH better or worse and why? - Would you feel happy continuing to use BiH without support of your other strategy (i.e. phone reminders)? • Can you think of any improvements that need to be made to BiH? • If these improvements were made, how would you use BiH differently?	BCW – capability, motivation, opportunity
Can you tell me a bit about your living situation and who you have most contact with?	• What have people's attitudes been towards BiH? • What support have received over the past 6 months when using Brain in Hand from the people around you? • Can you tell me a bit about your initial set up and who was present. - Was it helpful? - Did you feel confident using it after this session? - What continuous support have you had and what could you benefit from? • You nominated your support workers as your mentors, has it been helpful having a mentor? - If not how could your mentor help you more? • Do you think you would have benefitted from additional training and in what way? - Do you think one set up session was enough to explore all aspects of BiH? - If you had more support do you think you would have used it more?	BCW – opportunity ICF- environmental

Appendix 14: Example interview topic guide for HCPs.

AMbihTION

Acquired Brain Injury Management using Brain-in-Hand Technology to Improve Functional Outcomes and Independence

AMBiHTION Interview Topic Guide HCPs

I am a researcher working on the Brain-in-Hand study at the University of Nottingham and understand that you have kindly agreed to take part. We want to ask you some questions to understand a bit more about your experiences of Brain-in-Hand and your opinions about the technology. We value your feedback and hope to improve Brain-in-Hand to meet the needs of the ABI population. Your name will not be mentioned on any published documents, and any names or places you might refer to will be anonymised when transcribed. All information you provide will be used to develop our understanding and kept confidential. Are you still happy to go ahead with the interview and answer some questions?

Questions	Prompts	Links to framework
Can you tell me a bit about how you have been involved in this study?	• What has your role been? • What daily problems does the person you care for experience? • Do you know what strategies [participant] used before the study to help with everyday problems?	Environmental factors Personal factors
What do you consider the most useful aspects of Brain in Hand?	• How has BiH been useful for your [participant]? • What have they used it for? • What do you think about the traffic light system? • Do you think it is useful? • Is it appropriate and how could it be improved? • Do you think there needs to be an option to monitor more symptoms? • Can you tell me what you think about the problems and solutions function? • Can you tell me how BiH has helped you in your role? If not, why not? • Do you look through their timeline? • Does it help with planning? • How do you think BiH helped with [participant's] rehabilitation? Have you noticed any improvements since they started using BiH? Who else would BiH be suitable for?	BCW – motivation, opportunity Personal factors Environmental factors Technological factors
What problems have you experienced with Brain in Hand?	• Is there anything that has stopped you or [participant] from using BiH? • Have you experienced any technical difficulties? • Can you think of any improvements that need to be made to BiH? • If these improvements were made, how could BiH be used differently?	BCW – capability, motivation, opportunity Technological factors

How do you see technology like this being integrated alongside the support/rehabilitation you provide?	• Could BiH become an integral part of your role? - If yes, how? If no, what would prevent this? • What do you foresee as the barriers or enablers to the use of the BiH with people with ABI in the longer term? - Training, set up, cost, technology etc. • For people no longer in rehab, how do they see them being supported in its use and by whom? • Who would it be useful for? Types of people? • Can you see it being used in your service and how? • At what point could BiH be introduced? Early stages? • What role should a mentor have? Who should the mentor be? • How do you think of data reports that would be useful for you? • What data would you like to be able to access from the 'cloud'?	BCW – opportunity, capability Environmental factors Technological factors
Talk me through the training you received to use BiH.	• How was this useful for you? • Do you feel more training was needed and why? • What's the best way to do this? • How would it be beneficial if there was a 2-stage set up with patient and support worker? • In what ways could the set up be changed to make it more appropriate for your patient?	Opportunity Support (contextual factors) Capability Environmental factors

Appendix 15: Case 1 summary table.

		Participant ID	Case 1 – Liam
CONTEXTUAL FACTORS	**Personal Factors**	Gender	Male
		Age	32
		Education	Trained chef
		Profession before injury	Chef lecturer at the time of injury, previously head chef at successful restaurant.
		Personality	Happy, positive outlook on life, likes to talk, sociable person.
	Environmental Factors	Relationships	Wife stated she wanted a divorce the day of his injury, not currently in a relationship. Divorce was ongoing during recovery from TBI. Lives alone, parents live nearby. Parents worry about him a lot and often call, trying to let go of some responsibility and allow him to be more independent.
		Support	Buddy visits twice each week, does not need a carer
		Environment	Recently moved into own flat, living alone
		Services (e.g. rehab)	Received occupational therapy after his injury and still has visits from OT but not very often (review sessions).
		Assistive technology	Uses reminder app on his iPhone to plan each day, he would not be able to cope without this and would forget appointments, meetings etc.
BODY	**Body Function**	Type of injury	TBI, fell down stairs when snowing
		Severity of injury	Coma in ITU, parents were told they might need to consider turning off his life support machine.
		Time since injury	March 2013, 2-3 years
		Mental functions	No significant cognitive impairment (MSNQ score 22, below impairment cut off of 27), uses reminders on phone for everything. Talks excessively. Lacks a little insight when planning such as cooking for one when he was used to cooking in bulk (previous job). Not anxious or depressed (HADS scores low and in normal range)
		Sensory functions and pain	No pain
		Speech	Speech normal
		Medication	Detrunorm XL (bladder problems)
	Body Structure	Physical	Hearing impairment, has hearing aid. Does not experience high fatigue, FAS score very low 11 (min score 10)
ACTIVITIES & PARTICIPATION	**Activities**	Mobility	Can easily get around, no issues with walking (max score on NEADL 18/18)
		Kitchen	Can make himself hot and cold food, can make drinks easily and carry them between rooms (max score on NEADL 15/15)
		Domestic	Can wash clothing and carry out household chores with ease (max score on NEADL 15/15)
		Leisure	Can go out socially on his own with ease. (NEADL 15/18)
		Limitations	Cannot drive
	Participation Baseline CIQ score = 25/29	Social	Likes running and has joined a running club to meet new people in the area. Invites friends and family round for meals.
		Employment	Cannot return to his previous job but has received a full pension. He would like to return to work at some point but only for a limited number of hours each week.
		Home	Does his own food shopping
		Productivity (e.g. voluntary work)	Volunteers at Portland college every Thursday in the kitchen

Appendix 16: Case 2 summary table.

		Participant ID	Case 2 - Daniel
CONTEXTUAL FACTORS	**Personal Factors**	Gender	Male
		Age	48
		Education	Photography training
		Profession before injury	Photographer, self-employed
		Personality	Happy, sociable person, seems slightly
	Environmental Factors	Relationships	♦ Lives at home with wife and daughter. ♦ Wife is a consultant surgeon and has a very busy schedule. He relies on wife to do a lot of things in the house, wife is becoming very tired especially with working situations and their young daughter.
		Support	No carer needed
		Environment	Lives with wife and daughter.
		Services (e.g. rehab)	Not currently receiving rehab. Was seeing neuropsychologist.
		Assistive technology	Uses phone for some reminders but nothing else, relies on wife
BODY	**Body Function**	Type of injury	ABI, childhood cancer laser therapy, adult brain tumour removal – removed twice, brain surgery caused ABI second time
		Severity of injury	(?)
		Time since injury	2014
		Mental functions	Slight cognitive impairment interferes with life quite often and he is easily distracted, loses track of what people are saying (MSNQ score 32, cut off 27). Finds it difficult to keep track of multiple things at once. Not anxious or depressed, within normal range (HADS <7). Experiences fatigue as he does not take proper rests and tries to do too many things, struggles with pacing or prioritising tasks. FAS score moderate 21/50 (higher indicates more fatigue).
		Sensory functions and pain	No pain
		Speech	No speech impairment
		Medication	Epilim
	Body Structure	Physical	No physical impairments
ACTIVITIES & PARTICIPATION	**Activities**	Mobility	Slight problems walking around and getting in/out of the car. Otherwise can cross roads and use public transport easily.
		Kitchen	Can make himself a hot snack, make hot drinks and do the washing up.
		Domestic	Can manage his own money when out, do housework, do the shopping and a full clothes wash.
		Leisure	Can drive, go out socially, manage garden and read papers/books. Likes cycling.
		Limitations	No significant limitations.
	Participation Baseline CIQ score = 27/29	Social	Can look after own money and pays bills, has a best friend he can speak to, runs a cycling club after school and like to meet up with cycling friends. Appears to have a good social life and interacts with a variety of people.
		Employment	Works part time as a photographer, returned to work gradually but less responsibility than previously, books less weddings/events.
		Home	Does his own food shopping, prepares meals, cares for daughter and does the housework while wife is at work. He also arranges social gatherings with family and friends. (CIQ home score 10/10)
		Productivity (e.g. voluntary work)	Works part time, volunteers at a school cycling club more than 5 times a month, leaves the house almost every day. Wife states that he tries to do too many things and often becomes very tired.

Appendix 17: Case 3 summary table.

		Participant ID	Case 3 - Hannah
CONTEXTUAL FACTORS	Personal Factors	Gender	Female
		Age	24
		Education	Psychology student at the time of injury
		Profession before injury	Student
		Personality	Happy person, seems relatively positive/motivated but slightly anxious. Mood sometimes low but not often. Proactive and keen to be involved in research, this may be linked to studies at the time of injury.
	Environmental Factors	Relationships	♦ Parents are a big part of her life, lives at home with them. Proactive family and like to be involved in research. ♦ Does not need parents to do anything for her other than drive her to appointments, not yet confident enough to travel places completely alone.
		Support	No carer needed
		Environment	Lives at home with parents.
		Services (e.g. rehab)	Currently seeing physiotherapist, OT, case manager, S&L therapist
		Assistive technology	Uses phone for reminders
BODY	Body Function	Type of injury	TBI, car accident
		Severity of injury	Coma for 8 weeks, ITU, 6 months as inpatient
		Time since injury	April 2015
		Mental functions	Slight cognitive impairment and easily distracted (MSNQ score 33, above impairment cut off of 27), uses reminders on phone to remember appointments. Parents often have to remind her to do things, she struggles to initiate tasks unless told to do it. Has anxiety but normal levels of depression (HADS scores 12 for anxiety and 6 for depression, normal level 0-7, abnormal 12+) Experiences fatigue and struggles to concentrate on long tasks. Needs to take more rests and prioritise tasks.
		Sensory functions and pain	Slight pain, not too often
		Speech	Struggles with speech at times especially on the phone, receiving SALT to improve this. Sometimes finds it difficult to get her point across but generally speaks well. Voice is quiet and SALT encouraging her to speak louder, especially when using the phone.
		Medication	Baclofen
	Body Structure	Physical	Left side limited movement, can now move face a little more but has slight problems with walking and shuffles a little. Left arm has limited movement and does everything one handed. Slight problem with washing or dressing but does not need help.
ACTIVITIES & PARTICIPATION	Activities	Mobility	States she has slight problems walking about. Needs help to walk around outside, cross roads and travel on public transport (scores 10/18 NEADL)
		Kitchen	Can feed herself easily and do the washing up with difficulty, can make a hot snack with help (scores 6/15 on NEADL)
		Domestic	Can manage own money when out, can wash small items of clothing, can do own housework with difficulty, can do shopping and full clothes wash with help (scores 10/15 NEADL)
		Leisure	Can read books, can use the phone with difficulty, can write letters and go out socially (scores 11/18 NEADL)
		Limitations	Cannot make a hot drink, take hot drinks from one room to another, drive or manage own garden.
	Participation Baseline CIQ score = 8/29 (low)	Social	Meets up with friends from uni/school, tries to arrange different things but struggles and usually leaves to someone else to organise. Visits friends/family 1-4 times a month. Does not have a best friend. Scores low on social integration (CIQ social = 3/12)
		Employment	Wants to return to university and determined to finish dissertation. Therapist feels she needs to determine whether she can concentrate for long enough to return to university and is concerned it will be too much. Was not employed at the time of injury.
		Home	Someone else does the shopping and normally does everyday housework. She helps prepare meals. Someone else often organises social arrangements. (scores low on CIQ home integration 1/10)
		Productivity (e.g. voluntary work)	Volunteers more than 5 times a month. Travels outside the home almost every day. Scores better on CIQ productivity (4/7)

Appendix 18: Case 4 summary table.

		Participant ID	Case 4 - Peter
CONTEXTUAL FACTORS	Personal Factors	Gender	Male
		Age	48
		Education	No information provided.
		Profession before injury	No information provided.
		Personality	Appears to have a positive outlook on life, likes to talk but not excessively.
	Environmental Factors	Relationships	Lives at home with his son who he takes to work every day. Uncle cares for him and has control of his money, this appears to be causing some tension and he is trying to regain his independence.
		Support	Uncle cares for him and manages his finances.
		Environment	Lives at home with son.
		Services (e.g. rehab)	Still seeing OT, long time post injury did not receive any long-term rehab after injury
		Assistive technology	Uses calendar on phone
BODY	Body Function	Type of injury	TBI, motorbike accident
		Severity of injury	Coma, ITU
		Time since injury	20 years post-injury
		Mental functions	Cognitive impairment (MSNQ score 40, above impairment cut off of 27), needs reminding to do things and is often distracted and forgetful Disorganised and struggles to structure day, needs some guidance. Borderline anxiety and depression (HADS scores 9 anxiety and 9 depression). FAS score moderate 27/50 (higher indicates more fatigue).
		Sensory functions and pain	Slight pain
		Speech	Speech normal
		Medication	Levetiracetam
	Body Structure	Physical	No physical impairment.
ACTIVITIES & PARTICIPATION	Activities	Mobility	Has slight problems walking around but otherwise can climb stairs easily, get in and out of the car easily, cross roads (max score on NEADL 18/18)
		Kitchen	Can make himself hot and cold food, can make drinks easily and carry them between rooms (max score on NEADL 15/15)
		Domestic	Can wash clothing and carry out household chores with ease (max score on NEADL 15/15)
		Leisure	Can read books easily, can use the phone easily and can drive easily (NEADL 10/18)
		Limitations	Does not go out socially, cannot manage own garden, needs help writing letters.
	Participation Baseline CIQ score = 15/29	Social	Someone else manages his finances, he goes shopping 1-4 times a month, never takes part in any leisure activities and if he does it is usually alone, he does not have a best friend or anyone he can confide in. He does visit friends or relatives 1-4 times a month. (CIQ social low = 2/12)
		Employment	Not working but actively looking for voluntary work.
		Home	Does his own food shopping, prepares meals, does housework (CIQ home = 9/10)
		Productivity (e.g. voluntary work)	Actively looking for voluntary work.

Appendix 19: Case 5 summary table.

		Participant ID	Case 5 - Colin
CONTEXTUAL FACTORS	Personal Factors	Gender	Male
		Age	38
		Education	Training to be support worker
		Profession before injury	Support worker, secure units
		Personality	Seems very anxious and always apologising for being late or saying the wrong thing, friendly person, appears to be struggling with accepting his injury.
	Environmental Factors	Relationships	Lives at home with wife and child. Mother also lives nearby by and helps out at home.
		Support	No carer needed but mother provides support.
		Environment	Lives at home with wife and child.
		Services (e.g. rehab)	Still seeing OT, needs support with returning to work. Has 1 x CBT a month, GP weekly and counsellor when needed.
		Assistive technology	None
BODY	Body Function	Type of injury	TBI, bike accident
		Severity of injury	Coma
		Time since injury	12-18 months
		Mental functions	Cognitive impairment (MSNQ score 48, above impairment cut off of 27), is slow when tryng to solve problems, needs to have instructions repeated, needs to be reminded to do tasks, finds it difficult to control impulses and talk excessively/about himself a lot. Highly anxious (OT aware) and borderline depressed (HADS scores 18 anxiety and 10 depression). FAS score quite high 32/50 (higher indicates more fatigue).
		Sensory functions and pain	Slight pain
		Speech	Speech normal
		Medication	Propanolol, mirtazapine, domperidone
	Body Structure	Physical	No physical impairment
ACTIVITIES & PARTICIPATION	Activities	Mobility	Has slight problems walking around but otherwise no mobility problems. (NEADL max 18/18)
		Kitchen	Can make himself hot and cold food, can make drinks easily and carry them between rooms (max score on NEADL 15/15)
		Domestic	Can wash clothing and carry out household chores with ease (NEADL 13/15)
		Leisure	Can read books easily, can use the phone easily and can drive easily (NEADL 16/18)
		Limitations	Needs help to go out socially and needs help managing money when out.
	Participation Baseline CIQ score = 11/29	Social	Someone else manages his finances, he goes shopping 1-4 times a month, never takes part in any leisure activities and if he does it is usually alone. He has a best friend and visits friends or relatives 5+ times a month. (CIQ social low = 5/12)
		Employment	Not working but actively looking for work at the time of baseline assessment. November 2016 he returned to work as an OT assistant, appears to be struggling with this. Cannot use phone at work which is an issue for BiH. OT suggested he speaks to employers to negotiate phone use.
		Home	Does his own food shopping, someone else prepares meals, he and someone else does housework and someone else (wife/mother) acres for child. Someone else usually arranges any social plans. (CIQ home = 3/10)
		Productivity (e.g. voluntary work)	Travels outside the home almost every week but not every day, does not volunteer but wanted to return to work. (CIQ productivity = 3)

Appendix 20: Case 6 summary table.

		Participant ID	Case 6 – James
CONTEXTUAL FACTORS	**Personal Factors**	Gender	Male
		Age	50
		Education	School
		Profession before injury	Company director, based in Thailand
		Personality	James was a friendly person who enjoyed having long conversations about his life before the injury.
	Environmental Factors	Relationships	Lives at home with son, other son lives nearby, still speaks to ex-wife and frequently speaks to Thai girlfriend via skype. Girlfriend is visiting soon.
		Support	Has a carer/buddy who visits 2 times a week, son helps with other things around the house.
		Environment	Lives at home with son.
		Services (e.g. rehab)	Still seeing OT.
		Assistive technology	Uses memory board (not tech)
BODY	**Body Function**	Type of injury	TBI, hit by a car in Thailand
		Severity of injury	Coma, needed neurosurgery, ITU
		Time since injury	September 2014
		Mental functions	Severe cognitive impairment (MSNQ score 59/60, above impairment cut off of 27), most things are very disruptive to his daily life. Easily distracted, finds it hard to listen to people, forgets appointments and relies on memo board for everything. Often forgets to eat, has difficulty answering questions and cannot always understand the point of what someone is saying. Talks excessively and usually about himself. Anxious and depressed (HADS scores 16 anxiety and 15 depression).
		Sensory functions and pain	Moderate pain, experiences a lot of headaches
		Speech	Speech slurred at times and a little slow.
		Medication	Sertraline, losartan potassium
	Body Structure	Physical	Slight visual impairment
ACTIVITIES & PARTICIPATION	**Activities**	Mobility	Has moderate problems walking around needs help outside and with crossing roads. Needs help to use public transport. Can climb stairs with difficulty (NEADL mobility 8/18)
		Kitchen	Can make himself hot and cold food, can make hot drinks easily and carry them between rooms with difficulty (NEADL 13/15)
		Domestic	Can manage own money with difficulty, can wash clothing and carry out household chores with ease (NEADL 14/15)
		Leisure	Can use the phone easily and manage garden with help (NEADL low 4/18)
		Limitations	Cannot go out socially, cannot drive, cannot write letters or read books.
	Participation Baseline CIQ score = 11/29	Social	Can manage his own finances, he goes shopping 1-4 times a month, never takes part in any leisure activities and never visits friends/relatives. He has a best friend and usually takes part in activities with friends who have head injuries (group at the hospital). One friend visits him regularly. (CIQ social = 6/12)
		Employment	Not working at the moment but is still trying to manage the website he created before his injury. Would like someone to take over.
		Home	Does his own food shopping, he and someone else prepares meals, he and someone else does the housework. Someone else usually arranges any social plans. (CIQ home = 5/10)
		Productivity (e.g. voluntary work)	Rarely travels outside the home, does not volunteer and not looking for work. (CIQ productivity = 0). He bought a puppy after the baseline measure so leaves the house most days now.

Appendix 21: Case 7 summary table.

		Participant ID	Case 7 – Steve
CONTEXTUAL FACTORS	Personal Factors	Gender	Male
		Age	32
		Education	School, construction training?
		Profession before injury	Construction worker
		Personality	Happy personality, likes to see the funny side of things and still tries to enjoy the things he used to. Positive outlook on life.
	Environmental Factors	Relationships	Lives alone, visits aunt every weekend.
		Support	Has different support workers that visit on a daily basis, provided as part of a compensation claim.
		Environment	Lives alone
		Services (e.g. rehab)	Neuropsychologist twice a month, OT approx. once a month, advanced practitioner 3 times a month, case manager once a month, social worker once a month, ophthalmologist
		Assistive technology	Uses paper diary (not tech)
BODY	Body Function	Type of injury	TBI, work incident skull crushed on construction site
		Severity of injury	Induced coma, needed neurosurgery, ITU
		Time since injury	12-18 months
		Mental functions	Cognitive impairment (MSNQ score 30, above impairment cut off of 27. Often distracted, often finds it hard to listen to people and forgets appointments. General memory problems but doesn't disrupt life. Not anxious or depressed (HADS scores 5 anxiety and 3 depression). FAS score 20/50 (higher indicates more fatigue).
		Sensory functions and pain	Slight pain, often headaches
		Speech	No speech impairment
		Medication	None
	Body Structure	Physical	Slight visual impairment
ACTIVITIES & PARTICIPATION	Activities	Mobility	No problems walking around and does not need help climbing stairs, crossing roads etc. (NEADL mobility 18/18)
		Kitchen	Can make himself hot and cold food, can make hot drinks easily and carry them between rooms, can do the washing up (NEADL 15/15)
		Domestic	Can manage own money with help, can wash clothing and carry out household chores with ease, needs helps with shopping (NEADL 11/15)
		Leisure	Can use the phone easily and manage garden with help, can go out socially with ease, write letters and read with ease (NEADL 13/18)
		Limitations	Cannot drive.
	Participation Baseline CIQ score = 17/29	Social	Someone else managers his finances, he goes shopping more than 5 times a month, takes part in any leisure activities 1-4 times a month – often goes to the cinema or for dinner with support worker. Often visits family and friends, usually every weekend, has a best friend. Goes to pottery every week. (CIQ social = 9/12)
		Employment	Not working at the moment and not looking for work, possibly due to compensation claim.
		Home	Does his own food shopping with someone else, he and someone else prepares meals, he and someone else does the housework. He usually arranges any social plans. (CIQ home = 6/10)
		Productivity (e.g. voluntary work)	Travels outside the home almost every day, does not volunteer but may do in the future. (CIQ productivity = 2).

Appendix 22: Case 8 summary table.

		Participant ID	Case 8 - Martin
CONTEXTUAL FACTORS	Personal Factors	Gender	Male
		Age	58
		Education	Information not provided.
		Profession before injury	Business man, manager
		Personality	Happy and positive person, limited speech but likes to laugh at things and has a good sense of humour. Seems to have accepted his injury and wants to get better at doing things.
	Environmental Factors	Relationships	Lives at home with wife, children live nearby and grandchildren come round regularly.
		Support	Wife acts as carer
		Environment	Lives at home with wife.
		Services (e.g. rehab)	No longer seeing OT, case manager
		Assistive technology	None
BODY	Body Function	Type of injury	Hypoxia from cardiac arrest
		Severity of injury	Information not provided.
		Time since injury	12-18 months
		Mental functions	Cognitive impairment (MSNQ 39, above cut off of 27) often forgets appointments, needs to be reminded to do tasks. Wife explained that she will send him to the shop with a list and he will still come back with the wrong item, he won't ask anyone for help either. Struggles to keep track of 2 things at once. Not anxious and depressed (HADS scores 6 anxiety and 7 depression). Suffers from fatigue and struggles to plan rests (FAS score 33/50)
		Sensory functions and pain	Slight pain
		Speech	Dysarthria, can understand what he is trying to say but often slow and more yes/no answers
		Medication	None
	Body Structure	Physical	No physical impairment
ACTIVITIES & PARTICIPATION	Activities	Mobility	No problems walking around, mobility is fine. Does not travel on public transport. (NEADL 12/18)
		Kitchen	He can make a hot drink, hot snack, carry hot drinks between rooms and do the washing up himself but with difficulty (NEADL 10/15)
		Domestic	Can do the housework himself but with difficulty (NEADL low 2/15)
		Leisure	Can read books, use the phone with difficulty mainly due to speech impairment, can go out socially with ease and manage own garden with difficulty (NEADL 10/18)
		Limitations	Cannot drive, write letters, do a full clothes wash, do own shopping or manage own money when out.
	Participation Baseline CIQ score = 14/29	Social	Goes to church every Sunday with wife and attends a social event after. Tries to meet up with friends frequently, they go to football games and out for dinner etc. He has a best friend, goes shopping (with wife), takes part in leisure activities and visits friends/relatives more than 5 times a month. His friends are people without head injuries. However, wife now has to manage finances (CIQ social high = 10/12)
		Employment	Not working at the moment but still employed by the company he was working for, currently on sick leave.
		Home	Someone else usually does the shopping, prepares meals and plans social arrangements. He and someone else does the housework, wife states he is 'always' hoovering. Wife cares for their grandchildren when they visit (CIQ home = 1)
		Productivity (e.g. voluntary work)	Volunteers 1-4 times a month, cannot work at the moment but still employed. (CIQ productivity = 3)

Appendix 23: Case 9 summary table.

		Participant ID	Case 9 – Danielle
CONTEXTUAL FACTORS	**Personal Factors**	Gender	Female
		Age	52
		Education	Information not provided.
		Profession before injury	Store manager
		Personality	Seems quite anxious, but is a friendly person and likes to laugh.
	Environmental Factors	Relationships	Lives at home with boyfriend
		Support	Does not need a carer, boyfriend helps with daily tasks when necessary
		Environment	Lives at home with boyfriend, town centre
		Services (e.g. rehab)	Neuropsychologist, psychology assistant (CBT) and OT
		Assistive technology	None
BODY	**Body Function**	Type of injury	Haemorrhage
		Severity of injury	Information not provided.
		Time since injury	12-18 months
		Mental functions	Cognitive impairment (MSNQ 47, above cut off of 27), finds she gets very easily distracted and this disrupts her life, she forgets what she has read and talks excessively. She forgets appointments and needs to be reminded to do things, finds it difficult to concentrate on more than one task. Experiences anxiety and depression (HADS score 14 anxiety and 14 depression), changed medication and seems to be coping better. Suffers from severe fatigue (FAS score 42/50)
		Sensory functions and pain	Slight pain
		Speech	No impairment
		Medication	None
	Body Structure	Physical	No physical impairment
ACTIVITIES & PARTICIPATION	**Activities**	Mobility	No problems with walking around, climbing stairs but does need help when crossing roads (cannot decide whether to cross or not) and needs help getting on public transport. (NEADL 14/18)
		Kitchen	Can easily make a hot drink and do the washing up, finds it difficult to make a hot snack (NEADL 14/15)
		Domestic	Can manage own money when out, can do clothes washing easily, can do the food shopping but finds it difficult at times and often goes with boyfriend (NEADL 14/15)
		Leisure	Can use the phone easily, going out socially is difficult but enjoys doing this, finds writing letters difficult. (NEADL 7/18)
		Limitations	Cannot drive, manage own garden or read books/newspapers.
	Participation Baseline CIQ score = 17/29	Social	Goes out every Saturday and Sunday night with friends/family. She and someone else manages finances, she goes shopping more than 5 times a week, does leisure activities 1-4 times a month and visits friends/family 1-4 times a month. She tends to do these things with family members. She has a best friend. (CIQ social = 8/12)
		Employment	Working part time at a church at the moment, couldn't return to previous job. Finds it hard to not do anything as previous job was so busy.
		Home	She and someone else does the shopping and plans social arrangements. She usually does the housework herself. (CIQ home = 6/10)
		Productivity (e.g. voluntary work)	Doesn't leave the house very often unless it is for something important. Working part time. (CIQ productivity = 3)

Appendix 24: Case 10 summary table.

		Participant ID	Case 10 – Robert
CONTEXTUAL FACTORS	**Personal Factors**	Gender	Male
		Age	66
		Education	University?
		Profession before injury	Power station manager, nationwide
		Personality	Good sense of humour, tries to enjoy life as much as he did before stroke although difficult, optimistic and determined to improve speech, generally happy person
	Environmental Factors	Relationships	Lives at home with wife
		Support	Wife acts as carer, needs help with various ADL
		Environment	Lives at home with wife, wife drives him around
		Services (e.g. rehab)	Physiotherapist, speech and language therapy, orthopaedic surgery
		Assistive technology	Abel X, Saebo Glove, iPad speech therapy
BODY	**Body Function**	Type of injury	Stroke
		Severity of injury	Stroke unit
		Time since injury	Over 4 years
		Mental functions	No significant cognitive impairment (MSNQ 23, below cut off of 27), sometimes finds it difficult to concentrate when people are speaking. Sometimes forgets appointments and has to be reminded to do things, more of an initiation problem than a memory problem. Not anxious or depressed (HADS score 2 anxiety and 2 depression)
		Sensory functions and pain	No pain
		Speech	Aphasia, limited speech
		Medication	Clopidogrel, atorvastatin, folic acid, levetiracetam
	Body Structure	Physical	Left side limited movement, cannot move left arm
ACTIVITIES & PARTICIPATION	**Activities**	Mobility	Some mobility limitations, can walk around outside easily and climb stairs (his personal opinion), needs help walking on uneven ground, crossing roads and travelling on public transport. (NEADL 11/18)
		Kitchen	Can feed himself easily, make a hot drink, do the washing up (if asked to do it), needs help to make a hot snack (NEADL 13/15)
		Domestic	Can manage money when out with help, can wash small items of clothing but needs help to do a full clothes wash, could do shopping with help but wife often does this as it is quicker and easier. (NEADL 9/15)
		Leisure	Can read books and enjoys doing this, can use the phone with difficulty due to his aphasia, can go out socially with help – often goes out with wife for dinner and movies (NEADL low 6/18)
		Limitations	Cannot drive or manage own garden. Can do most tasks but often does not do them. Wife stated she often 'takes over'
	Participation Baseline CIQ score = 10/29	Social	Goes out frequently with wife to restaurants and they enjoy going to the cinema. Son and daughter visit frequently. Few friends nearby, all seem to have disappeared since stroke. Wife now looks after finances, he never goes shopping but could do with help if he needed to, does leisure activities more than 5 times a week, visits friends/relatives 1-4 times a month and activities are usually with family members. His wife is his best friend. (CIQ social 4/12)
		Employment	Retired
		Home	Someone else does the shopping, he and his wife do the housework together, someone else usually arranges social activities. (CIQ home= 3/10)
		Productivity (e.g. voluntary work)	Leaves the house almost every day, retired due to age but volunteers 1-4 times a month (CIQ productivity = 3)