# Volume 1

# *'Smartphone Technology: Everyday prompts for those with prospective memory difficulties following brain injury'*

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# CONTENTS

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## 1. ABSTRACT

BACKGROUND: Prospective memory difficulties are one of the most common deficits following acquired brain injury. The application of smartphones as a compensatory aid to these difficulties has shown promising results. This study looked to investigate these benefits further.

OBJECTIVE: The aims of this study were to investigate whether receipt of reminder prompts through ones smartphone improved completion of pre-planned tasks, in addition to whether it also had secondary implications for participant's wellbeing, confidence, independent functioning, and whether it had any impact on caregiver strain levels.

METHOD: This study used an ABAB case series design with mild to moderate acquired brain injury. Task completion rates were monitored across four phases (prompts vs. no prompts). Quantitative questionnaires were administered pre, post and at three months follow up to assess coping with memory difficulties. A qualitative questionnaire explored the perceived impact of the smartphone reminders on everyday functioning, in addition to a 3 month follow up measure assessing attrition rates in smartphone use.

RESULTS: Visual inspection analysis suggested greater task completion when reminders were provided. The quantitative questionnaires showed increased use of a Smartphone as reminder device post intervention and at follow up. A basic thematic analysis highlighted a perception that the smartphone system increased task completion, confidence in coping with memory demands, supported emotional wellbeing and reduced dependence on others. As a memory aid it was also less stigmatising and promoted dignity. The three month follow up questionnaire highlighted that all participants continued to use their smartphone as a memory aid.

CONCLUSIONS: Use of a smartphone as a memory compensation aid may improve completion of pre-set tasks. Secondary benefits may include increased confidence in coping with memory demands, reduced dependence on others for help, and reduced anxiety or frustration around forgetting.

## 2. LITERATURE REVIEW

The aim of this review is to introduce and critically discuss the existing literature around the cognitive rehabilitation of prospective memory difficulties following Acquired Brain Injury (ABI). A summary of the ABI literature will be described giving an overview of the impact that brain injury may have on cognitive and emotional wellbeing. Memory impairment post injury will be discussed with a particular focus on prospective memory (the ability to remember to plan and complete future activities), a memory function that is commonly affected following ABI. As an emerging area of interest in clinical research, this review will look to trace the development of the current theoretical understanding of prospective memory. In addition, critical consideration of attempts to rehabilitate such deficits will be discussed. This will provide the opportunity to consider the area of cognitive compensation and the strengths and weaknesses of prospective memory aids over recent decades. This will include consideration of the role of smartphone technology in the general population and its potential for supporting neuropsychological rehabilitation. A critical review of recent research looking into smartphone use in cognitive rehabilitation will be discussed. It is hoped that this will set the background for the purpose of this study. The research hypotheses will be outlined and the design methodology implemented to test out these hypotheses will be described. The literature search terms can be found in Appendix 1.

### 2.1. Introduction to Brain Injury

*Definition of Brain Injury*

There are two common definitions currently used within the brain injury literature. The first is Acquired Brain Injury (ABI). An ABI is an umbrella term for all injuries to the brain following birth that result in changes on a cellular level, including injury caused by things other than blunt trauma. Blunt trauma injuries are commonly referred to as Traumatic Brain Injury (TBI). This is often understood to be an insult to the brain caused by an external force which can lead to an altered state or loss of consciousness and may cause impaired physical, cognitive, and emotional functioning (King and Tyerman, 2008; http://www.neuroskills.com/education/definition-of-brain-injury.php). The term ABI

does not include neurodegenerative disease such as Alzheimer's disease. While people with ABI may not recover fully from their injury, the changes that happen in the brain are not thought to be progressive or degenerative, but rather are considered 'stable' or 'static'.

The possible causes of ABI can include injuries sustained through any of the following: an external force applied to the head or neck (road traffic accident, assault, fall), starvation of oxygen to the brain (anoxia/hypoxia caused by cardiopulmonary arrest, carbon monoxide poisoning, haemorrhage), obstruction of the airways, intracranial surgery, vascular disruption, arterio-venous malformation (AVM), infectious diseases, metabolic disorders (e.g., hypo/hyperglycaemia, hepatic encephalopathy, uremic encephalopathy), seizure disorders (Epilepsy) and toxic exposure (e.g. substance abuse, ingestion of lead and inhalation of volatile agents) (King & Tyerman, 2008; http://www.neuroskills.com/education/definition-of-brain-injury.php). This is not an exhaustive list.

ABI of the traumatic nature can be divided into subtypes of severity ranging from Mild, to Moderate and Severe. A 'Mild' TBI is commonly understood to be a trauma to the head resulting in a confused state or a loss of consciousness for less than 30 minutes, a Glasgow Coma Scale score (GCS[1]) of 13 - 15, and posttraumatic amnesia (PTA[2]) of less than 24 hours. 'Moderate' TBI is a trauma to the head resulting in a loss of consciousness for between 30 minutes to 24 hours, a GCS of 9 – 12, and PTA between 24 hours and 7 days. A 'Severe' TBI is a trauma to the head that results in a loss of consciousness for more than 24 hours, a GCS of 3 - 8, and a PTA period of greater than 7 days (King & Tyerman, 2008). The severity of TBI as determined by these factors is not a precise indicator of prognosis; however it may give an idea as to the extent of deficits suffered. At present there are multiple systems used to categorise severity of TBI. Recovery post traumatic event plays a central role in the majority of these systems, however there are ABI's that do not follow a single traumatic event (i.e. epilepsy). Due to limitations in these categorisation systems, clinical research will frequently use the Mild, Moderate and Severe TBI distinctions noted above where applicable, and the degree of impairment to cognitive, physical,

[1] GCS is a rating scale used to categorise a patient's level of consciousness.
[2] PTA is a state of confusion in which individuals have difficulty establishing new memories and recalling recent events associated with their injury.

and behavioural functioning as a more general system when establishing severity across ABI in general.

*Incidence of Brain Injury in the UK*

It is estimated that between 1 and 1.4 million people in the UK attend hospital each year with a head injury. Of this number, around 135,000 people are admitted for treatment. A conservative estimate is that 1 million people living in the UK have experienced an acquired brain injury at some point in their life (Health Committee Third Report Head Injury; Rehabilitation, House of Commons Session 2000-1 HC307). The likelihood is that a significant portion of this number have experienced a mild ABI, however, severity does vary. The impact of ABI can result in impaired functioning across a range of physical, cognitive, emotional and behavioural domains. The most common difficulties experienced post ABI are outlined below.

*Common Deficits Following ABI*

Common cognitive deficits may include impaired functioning in planning, problem solving, attention, inhibition, and speed of processing. People may also experience changes in motor co-ordination, expressive and receptive language deficits and a range of impairments in memory (Anderson, Winocur, & Palmer, 2010). Secondary emotional and psychological difficulties can also be experienced as people come to terms with the loss of functioning in a range of skills (Ponsford, Sloan & Snow, 1995). The extent of these deficits can be different for each individual and the nature and extent of recovery varies considerably. The type of injury, time spent unconscious, period of PTA, age at injury, and pre-morbid functioning may all play a role in the impact the ABI has on an individual's life (Anderson, Winocur, & Palmer, 2010).

One of the most common difficulties experienced post ABI is impairment of memory functioning (Hutchinson, & Marquardt, 1997; Svoboda & Richards, 2009; Wilson, 2003). Impairment may take the form of deficits in autobiographical (memory for past events), semantic (memory for facts and learnt information), episodic (memory for experience), working (short term retention and manipulation of information) and

prospective memory (memory for future planned events) (Bradley, & Kapur, 2004). These deficits can significantly impact on an individual's ability to engage in everyday pre-morbid activities. The focus of this literature review will be to consider the impact of prospective memory deficits on those with an ABI. It will also outline some of the secondary impacts that the injury may have on family, friends or partners or those who support these individuals.

## 2.2. Prospective Memory Deficits following ABI

*Definition of Prospective Memory*

Prospective Memory (PM) is defined as the encoding, storage, and delayed retrieval of intended actions (Ellis, and Kvavilashvili, 2001). It has become an increasing focus of clinical research in the last 20–30 years, and is regarded as an emerging area to be explored within neuropsychological rehabilitation. PM is considered to be instrumental in an individual's ability to perform everyday activities such as remembering to take medication, keeping appointments, completing tasks at work, in the home, at school or socially (Shum, Fleming, & Neulinger, 2002). Due to its close relationship with everyday functioning, impaired PM following ABI is considered to be a significant contributor to occupational and psychological disability. It can limit participation in self-care, community, social and occupational activities. It is perhaps for this reason that PM has become a focus both clinically and as an area of research within the ABI field (Fleming, Shum, Strong, & Lightbody, 2005; Shum, Levin, & Chan, 2011). In considering how best to assess and support effective rehabilitation of PM, it may be important to review the current theoretical understanding of PM and its workings.

*Theoretical Understanding of Prospective Memory*

In trying to understand the processes involved in PM, one must first consider the role of episodic memory. Episodic memory (EM) is the encoding, storage and retrieval of information for events we have experienced in the past (Ellis, 1996). For example, if the following question was posed 'How did you celebrate your last birthday?', each individual would draw on their EM to come up with an answer. EM plays a key role in PM functioning as it holds information about intentions, experiences, and actions

from our past. The Six Component Model of Prospective Memory suggests that a number of cognitive processes must be performed effectively in order for identified tasks to be carried out in the future (Dobbs & Reeve, 1996). In order to plan to remember something at a given time in the future (prospective memory), the individual/one needs to retain knowledge of past experiences in the present so that it can be recalled at later time (episodic memory). In addition, they must retain awareness that the identified task has been completed, and have the motivation in the first instant to set the task (McDaniel, & Einstein, 2001). This places demands not only on EM, but also on executive functioning.

Following ABI, deficits to EM are relatively common. The hippocampus and temporal cortex are thought to play an integral role in EM processes. Both areas have been shown to have vulnerability to damage through head injury (Svoboda, Richards, Leach & Mertens, 2012). Impaired EM can increase the likelihood of difficulties with PM. If information is not retained in the present, it is very difficult to plan and execute actions at a set time in the future. Even if this information is retained, planning and execution places demands on executive functioning processes. These functions are associated with processing in the frontal lobe. on activity in the frontal lobes. This is also an area that is frequently vulnerable to ABI, particularly in impact injuries. The vulnerability of the hippocampus and the frontal lobes to ABI provides a degree of neuroanatomical explanation for the high frequency of PM impairments post injury. (Lezak Howieson, and Loring, 2004). The role of executive functioning processes in PM impairment can be considered a little more closely.

*Role of Executive Functioning*

Executive functioning is a term often used to describe a group of processes including attention, planning, problem solving, initiation, monitoring, inhibition, sequencing, and motivation (Burgess, 2003). It is thought that PM also relies on executive processes to identify what needs to be recalled at a later time, to monitor intended actions and to cue recall when the identified time is experienced. Motivation to plan, monitor and retrieve this information is also a necessity (Ellis, & Kvavilashvili, 2001). Impaired executive functioning across these processes may therefore result in deficits in PM functioning. It is hypothesised that executive processes are predominantly performed within the frontal cortex, particularly although not exclusively within the dorsolateral

prefrontal cortex. Similarly to the hippocampus and temporal cortex, this is an area also vulnerable to damage through ABI due to high prevalence of shearing that can occur if the brain experiences a contra coup (movement of the brain from front to back), or swelling of ventricles which can increase pressure on the brain from the skull. It is now commonly thought PM difficulties arise due to impaired functioning in either EM , executive functioning or a combination of the two (Ellis, & Kvavilashvili, 2001).

When an individual experiences PM deficits post ABI, the ability to complete activities carried out prior to injury can be significantly impaired. The impact of PM impairment not only inhibits completion of specific everyday tasks, it is also widely considered that these difficulties can lead to secondary impairment in everyday functioning including deterioration in psychosocial wellbeing (Man, 2002; Jumisko, Lexell and Soderberg, 2002).

*Impact of Prospective Memory on Daily Functioning and Psychosocial Wellbeing*

Difficulties in completing intended actions can make daily tasks such as attending prearranged appointments, social events, completing correspondence, going shopping, preparing food and fulfilling a job a role very difficult. These are to name just a few of the impairments frequently reported by service users. These deficits may also be linked with secondary difficulties reported by individuals with ABI in relation to their close relationships, self-confidence, mood, and life aspirations. There can be increased reliance on others to help with daily functioning which can in turn reduce ones' sense of autonomy and independence (Tate, and Broe, 1999). Family and friends commonly take on caring roles to support a loved one with ABI. While supportive, research has also shown this to place those in a caring role at risk of personal deterioration in psychosocial wellbeing, commonly ascribed to increases in caregiver strain experienced (Ponsford et al 1995; Sander, 2005; Harris, Godfrey, Partridge, & Knight, 2001; Gillen, Tennen, Affleck, & Steinpreis, 1998).

Research has gone onto show that intimate relationships can be at risk of break down under increasing demands placed on those providing support to the individual with ABI. The high levels of separation and divorce rates reported in this population are reported to be correlated with care giver strain, changes in relationship dynamics,

and shifts in the nature of everyday life for those involved (Wood et al, 1997). Following ABI, the loss of independence and increase in reliance on others for support can leave individuals facing an uncertain sense of identity and future prospects (Tate & Broe, 1999; Ponsford, Sloan & Snow, 1995; Miller, 1993). Vulnerability to low mood and anxiety can increase which adds another challenge to individuals and their families in the adjustment to loss of functioning (Ponsford et al, 1995; Prigatano 1999).

The increase in cognitive and emotional difficulties reported following PM deficits has led research in this field to explore ways in which individuals with ABI can look to re-engage in daily living activities with the support of rehabilitation. Promotion of independent functioning and goal setting is viewed as being central to this process. Historically ABI rehabilitation focused on addressing individuals' physical and cognitive deficits. In doing so, it was hypothesised that secondary benefits would be achieved with regards to promoting positive emotional/psychological wellbeing. For the purpose of this review, it may be important to understand what neuropsychological rehabilitation is, and how it supports people with PM difficulties post ABI.

### 2.3. Rehabilitation of Prospective Memory

Barbara Wilson (1999, pg. 13) provides a useful summary of rehabilitation within a ABI context:

> 'Rehabilitation is a two way process. Unlike treatment, which is given *to* a patient, rehabilitation is a process in which the patient, client, or disabled person takes an active part. Professionals work together with the person to achieve the optimum level of physical, social, psychological and vocational functioning. The ultimate goal of rehabilitation is to enable the person with a disability to function as adequately as possible in his or her most appropriate environment'.

Wilson (1999) suggests that in order to understand the role of rehabilitation in ABI, there is a need to make the distinction between remediation and compensation of functioning post injury. This is considered below.

*Cognitive Remediation vs. Cognitive Compensation – The Debate*

In discussions around rehabilitation, the following question is frequently asked: '*Is the aim of rehabilitation to restore functioning to the level experienced prior to injury, or is it to find methods of compensating for the loss in functioning in a way that enables engagement in activities to the optimum of an individual's potential?'* These distinctions have been discussed at length in the cognitive remediation versus cognitive compensation debate (Wilson, 1999). Remediation is based on the principle that post ABI the brain can be retrained to complete the functions impaired as a consequence of the event. It is proposed that over time this remediation training enables the individual's brain to re-learn the processes required to complete pre-morbid cognitive and physical processes and actions (Anderson, Winocur, & Palmer, 2010; Wilson, 1999).

Compensation is based on the principle that the ABI results in damage or death to cell matter, therefore, remediation of cognitive functioning post injury may be somewhat limited by the physiological changes that have been experienced (Robertson & Murre, 1999). In contrast to remediation, it is proposed that rehabilitation yields greater benefits if a focus is given to compensation for loss of functioning, rather than a sole focus on remediation (Robertson & Murre, 1999). It is suggested that finding ways to complete processes and actions by using compensatory strategies can help individuals achieve rehabilitation aims. These strategies can be internal and/or external in nature. For example, use of external aids such as diaries, notepads or watches to record and prompt activities or internal aids such as mental strategies using first letter cueing or chaining of newly learnt information into story form (Wilson, 2003). Within neuropsychological rehabilitation it is believed that this support through compensation is most effective if put in place soon after ABI to compliment the natural recovery process.

*Compensation & Natural Recovery*

Natural recovery is widely described as the process in which individuals with ABI experience gradual restoration of some pre-morbid physical and cognitive skills. This process is not well understood and can differ greatly in nature, speed and longevity depending on the individual and type of ABI experienced according to King & Tyerman (2003). It is suggested that this process may be the brain's adjustment to the traumatic experience, with optimum restoration occurring during the first 12 to 18 months post injury. However, this time period has been hotly debated and research has suggested that natural recovery may continue beyond this period at a slower pace (Wilson, 1999). Wilson (2003) proposed that initiating appropriate compensation strategies alongside targeted remediation is thought to best support this recovery process. With this in mind, research in the area has sought to explore ways in which daily activities can be completed with the assistance of internal and external strategies.

This endeavour has prompted a surge in research looking into how compensatory aids may support engagement in tasks that would be otherwise hindered by impairments acquired through ABI (Wilson, 2003). It was hypothesised that compensation aids could effectively enable individuals to interact with their environment in a way that is somewhat congruent with their life pre-morbidly. Compensatory aids were thought to support cognitive rehabilitation by scaffolding everyday tasks which in turn provided greater levels of stimulation and confidence in completing pre-morbid activities (Anderson, Winocur, & Palmer, 20010).

Developments in cognitive rehabilitation have been supported by the emergence and application of the memory systems model. This model has supported greater understanding of memory processes. It provided a framework to identify vulnerabilities of memory processes to ABI. This in turn has enabled clinicians to develop compensatory strategies that work within the cognitive resources of those who have suffered such impairments to maximise memory functioning. One important development in the literature is that of the dual implicit/explicit memory pathways. These pathways have significantly guided cognitive rehabilitation approaches over the years (Baddeley & Wilson, 1994).

*The Role of Implicit and Explicit Memory Pathways*

Through conducting research looking into memory performance post injury, Baddeley & Wilson (1994) proposed that there are two pathways in memory formation. See Figure 1.

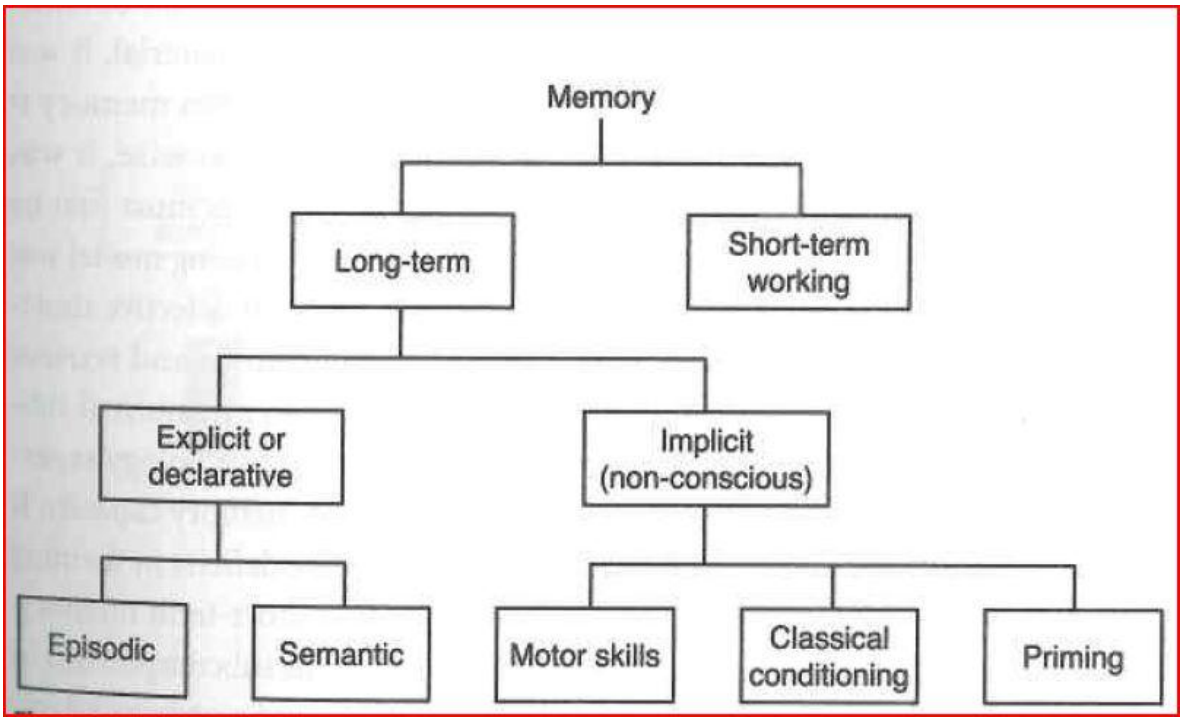


*Figure 1. Memory Systems Model (with thanks to John Hodges, 2007)*

The first pathway is explicit memory processing. This is the conscious learning, retention and recall of facts, actions, past experiences, and future intentions (Bradley & Kapur, 2003). The second pathway is that of implicit memory formation. Baddeley & Wilson (1994) proposed that this is a pre-conscious memory pathway whereby over learned skills and knowledge (I.e. riding a bike, driving a car) become almost instinctual. Take for example driving a car, this activity is an example of a well learnt set of skills and knowledge that are called upon, with limited demands placed on conscious memory processes in order to complete the intended action (I.e. getting to the destination). It has been hypothesised that while explicit memory processes (episodic, semantic, and autobiographical memory) are vulnerable to deficit through ABI, implicit memory is far more robust due to processing taking place in alternative anatomical regions to that of explicit memory (Baddeley & Wilson, 1994; Svoboda &

Richards, 2009,). It is therefore proposed that well learnt pre-morbid knowledge and skill sets can be easier to recall and reproduce post injury.

In addition to developments in understanding implicit and explicit memory processes, research within cognitive rehabilitation has also looked to assess the benefits of compensatory approaches to support impaired functioning post ABI. These compensatory approaches have explored the benefits of internal (mnemonics, visualisation, and first letter cueing) and external (notepads, diaries, and watch alarms) compensatory strategies as a means of supporting everyday memory functioning (Wilson, 2003, Kapur, Glisky & Wilson, 2004). For the purpose of this review, focus will be given to the use of external rather than internal compensatory aids.

## 2.4. Compensation for Prospective Memory Difficulties

*External Compensatory Aids – A Critical Review*

Historically neuropsychologists have looked to encourage the use of compensation strategies to aid memory performance. These include use of calendars, notepads, to do lists, watches, and notice boards amongst others (Kapur, 1995; Kapur, Glisky, & Wilson, 2004). Each strategy looks to support an individuals' ability to participate in activities of daily living. However, despite some positive outcomes in case examples and controlled research studies, the uptake and effective use of compensatory aids can vary. A frequently reported problem is that these strategies were not employed prior to injury, they are often difficult to use, or deemed to be embarrassing. As a result, the effective implementation of these strategies in daily life can be inconsistent, with attrition rates being quite high (Baldwin et al., 2011). The very nature of the memory difficulty means that use of these non-cueing strategies can fall foul of forgetting (Macdonald Haslam, Yates, Gurr, Leeder, and Sayers, 2012). Prospective memory is required in order to ensure that the notepad, to do list, or diary is packed in the bag at the start of the day. In addition, executive functioning processes are relied upon to monitor and cue the individual when it is time to use or check the diary at the appropriate time and place. It is for these reasons that effectiveness of memory aids can vary and fluctuate for each individual. As technology has advanced, researchers and clinicians have attempted to address this

issue by exploring the take up and use of memory aids that provide a reminder/cue at a pre-set time (Macdonald et al., 2012). This has prompted consideration of the potential that electronic devices may hold as compensatory devices.

## 2.5. Electronic Devices & Prospective Memory Compensation.

*Memory Cueing Devices*

In an attempt to test the potential benefits of cueing devices, digital watches have been used to explore whether pre-set alarms alerting an individual at set times would assist them in completing intended actions (Van Hulle, & Hux, 2006). However, while alarm cues placed lower demands on executive functioning processes through time based prompting, individuals found it difficult to recall the task they had been cued to carry out. In addition, these alarms offered only a limited number of cues in one day. While they reminded the individual they had a set task to complete, recall of more than one or two of these tasks over the course of the day could be problematic. It should also be considered whether such cueing without detail provides a reminder of one's memory limitations without consistently assisting completion of an intended activity. This experience may have secondary implications for emotional wellbeing and confidence in coping with memory difficulties as the ineffective use of a digital watch alarm may have served only to remind individuals of their memory difficulties.

Recommendations for future research in this area highlighted the need to ensure that gains achieved through compensatory devices had to provide sufficient information to support engagement in intended activity and be offset against the potential negative impact of repeated reminders of one's memory limitations. As the field grew wise to the limitations of digital watches and pen and paper strategies, a breakthrough assistive memory system in the form of NeuroPage reported promising outcomes (Wilson, Evans, Emslie, and Malinek, 1997; Evans, Emslie, & Wilson, 1998; Wilson, Emslie, Quirk, & Evans, 2001; Wilson, Scott Evans, Emslie, 2003; Emslie, Wilson, Quirk, Evans, & Watson, 2007; Fish, Manly, Emslie, Evans, & Wilson, 2008).

*NeuroPage*

The NeuroPage Project is a paging system that employs a centralised computer from which reminder prompts are sent to the user at set intervals throughout the day (Wilson et al., 1997). The pager cues the individual to read the message which in turn can support recall of an intended action. The messages received are pre-programmed once a week by the ABI individual and their family/caregiver. These are telephoned through to an operator at a centralised computer system. Throughout the week, this computer activates the beeper and displays a cueing message at a time specified by the individual and their family. There have been a significant number of studies showing this system to be of benefit in enabling clients with prospective memory difficulties to engage in a range of tasks they would not otherwise have the cognitive capability to recall to do (Wilson et al., 1997; Evans et al., 1998; Wilson et al., 2001; Wilson et al., 2003; Emslie et al., 2007; Fish et al., 2008).

However, while NeuroPage had shown promising outcomes for improving pre identified task completion, as a service it had limited uptake across clinical settings. This may have been in part due to the limited flexibility in setting and altering reminder prompts. As the reminders were sent by a central computer, it was common for such prompts to be set on a weekly basis. This could have failed to accommodate changes in routine/schedule that emerged as the days passed (Wright, Rogers, Hall, Wilson, Evans, Emslie, & Bartram, 2001). Secondly, commissioning of the NeuroPage service was variable. While NeuroPage was funded by some NHS trusts, others would not fund it due to costing. In addition, due to time demands on human input of schedules at the centralised base, it was seen by some to be a very helpful yet expensive intervention to provide (Macdonald et al., 2012) .With these limitations in mind, research in this field sought a less expensive and more flexible approach to providing personalised cues for prospective events. As mobile phone ownership and use increased, researchers started to explore the potential benefits of phone and text message reminders.

*Mobile Phones & SMS Text Messages*

As mobile phone handsets became everyday accessories, research explored the potential for use as external memory compensation devices. Wade & Troy (2001)

carried out a within subjects case series (n=5) reporting promising results which indicated that reminders delivered by the calendar function on the mobile phone aided completion of everyday tasks. This study however consisted of a small sample, thus limiting generalisation of findings. Fish, Evans, Nimmo, Martin, Kersel, Bateman, & Manly (2007) went onto to explore whether text messages with the word STOP aided 20 participants with ABI in their ability to complete pre-set phone call tasks when compared with no reminders. The findings suggested content free cueing aided task completion in people with prospective memory difficulties. However, the monitoring of task completion was limited to completion of phone calls which may not have captured the range of activities that people are required to carry out as part of everyday life. In more recent years, Culley & Evans (2010) conducted a single blind within subjects study (n=11) to explore whether text message reminders improved recall of therapeutic goals. Results indicated that reminders had a positive effect on recall at seven days and 14 days. Interest in this area grew out of the critique of paging systems. Mobile phones were seen as cheaper, eliciting less stigma, and easier to update to meet the needs of the user on a daily basis when compared with digital watches and paging systems (Macdonald et al., 2012). As computer technology has advanced, research has also started to explore the potential of Personal Digital Assistants (PDA's) as memory compensation devices.

*Personal Digital Assistants (PDA's)*

Despite the strengths of NeuroPage and mobile phones as memory cueing systems, both forms of technology have also shown limitations. It was these drawbacks that encouraged researchers to explore the benefits of the Personal Digital Assistant (PDA) in brain injury rehabilitation, and more specifically, memory cueing. The PDA is a micro-computer system which has built in diary/calendar functions. These functions enable the user or caregiver to enter reminders into the device which will then activate an alarm and message display at an allocated time. A number of studies have reported increased task completion rates when using the PDA when compared against paper pen diaries or reliance on memory alone.

Kim, Burke, Dowds, & George (1999) conducted a single case study to look at whether reminders provided through the PDA would increase requests for medication for one client. Positive results were recorded, however the small sample size, and

limited range/type of tasks restricted generalisation of findings. Thone-Otto, & Walther (2003) later conducted an ABAC case series design (n= 12 men) with ABI looking into the successful execution of planned tasks, and, the perceived usefulness of the device as a memory aid. Results reported reduced forgetfulness for the planned tasks and a sense that the device had compensatory benefits. However, there was no follow up initiated by the researchers. Kirsch, Shenton, & Rowan (2004) followed up with a study reporting that PDA reminders could assist in route learning (n=1), and Gentry, Wallace, Kvarfordt, & Lynch, (2008) went onto report positive outcomes in two quasi experimental studies (n=23, n=20) comparing occupational performance and everyday participation with baselines scores after a period of receiving reminders for daily tasks via the PDA. The self-report methodology in these studies may however raise questions around placebo effects.

In more recent years, DePompei, Gillette, Goetz, Xenopoulos-Oddsson, Bryen, & Dowds (2008) and Gillette & DePompei (2008) reported that PDA's improved adherence to timetabled events in adolescents with ABI and Learning Disabilities in a school setting (n=35); while Dowds, Lee, Sheer, O'Neil-Pirozzi, Xenopoulos-Oddsson, Goldstein& Glenn (2011) reported that PDA use improved task completion rates in adults with ABI (n=36). Research looking at PDA use as a compensatory device has yielded positive outcomes and increasing sample sizes have enabled greater generalisation across the ABI population. However, the PDA also requires a degree of input and monitoring of reminders on the clients part. If the client forgets to input a reminder, the device may be redundant. Additional limitations to PDA use are the cost to purchase the device and the new learning often required to effectively operate its functions. As noted earlier, new learning can be particularly problematic post ABI. Implicit learning can be limited as the use of PDA's pre-morbidly within this population is often small (Wright, Rogers, Hall, Wilson, Evans, Emslie, & Bartram (2001); Macdonald et al., 2012). Time taken to learn the new skills required to operate the device effectively can often result in high attrition rates.

These limitations touch on the well debated issue of why some compensatory strategies are taken up and maintained, while others are not. This has been an area of interest for clinicians and researchers working in the field of cognitive rehabilitation for some time (Kapur, Glisky, & Wilson, 2004). In theory, one may think that if a strategy offers scaffolding to support execution of a task or process that has been

impaired by an ABI, uptake and use of this strategy should be high. However, this is frequently not the case in clinical practice. It is therefore important to consider why some strategies are taken up and used more than others. A qualitative study conducted by Baldwin, Powell, & Lorenc (2011) looked to develop further understanding as to which compensatory strategies are employed by whom and for what reason. This study also raised awareness as to why particular compensatory aids may be ineffective or unappealing to those with memory impairments post ABI.

### 2.6. Memory Aid Uptake & Attrition

Baldwin, Powell, & Lorenc's (2011) qualitative research study proposed that a number of key factors may influence successful uptake of compensatory strategies (Baldwin et al, 2011; Kapur, Glisky & Wilson, 2004). A common theme emerged within interviews suggesting that people with ABI must have an intrinsic motivation to use a particular compensation aid, i.e. the perceived benefits of using the memory aid need to outweigh the costs of implementing them. This motivation may differ from individual to individual and over time. As highlighted earlier, executive dysfunction is also a common deficit post brain injury. It is widely thought that limited insight as a result of executive dysfunction can impact on motivation levels, which in turn may influence uptake and maintenance of compensatory strategies (Baldwin et al., 2011).

A second theme that emerged is that of perceived or experienced stigma associated with using compensatory aids. Those with memory difficulties may see the potential benefits of using notepads, diaries or PDA's to assist functioning. However, the use of such devices may identify them to others as having cognitive difficulties (Baldwin et al., 2011; Macdonald et al., 2012). The perception that others may therefore see them as incompetent or lacking intelligence can be a barrier to use of aids. This may tie in with sense of identity. The use of compensatory aids may not be congruent with ones sense of identity pre-injury. Individuals with ABI can at times have difficulty shifting from a position of independence and autonomy to a position in which there is a reliance on a series of compensatory aids.

A third theme is the ease with which the device or strategy can be used. Participants reported that compensatory aids need to show positive gains that outweigh the efforts required to implement them. It is for this reason that learning an entirely new system

or technological device can be problematic. Time taken to familiarise with the device/system may lead to a period in which gains do not outweigh costs. The strategy is then terminated without potential benefits being realised. This is felt to be an important factor with the movement of research in this area. Finding a system or device that is easy to use, quick to implement and shows positive gains over a short period of time may enhance motivation and increase sustained use. (Baldwin et al., 2011)

The cost of compensatory aids is also reported to be an influential factor in determining long term use of strategies. In order for compensatory strategies to be maintained, the system needs to be affordable. As highlighted earlier, while effective, NeuroPage has its limitations due to the cost of the system to the NHS service, or the individual (Wright et al, 2001; Macdonald et al, 2012). In an era of austerity and cost saving, health providers are reluctant to pay for interventions that are expensive and non-essential. Individuals and families of people with ABI may struggle to self-fund given the indefinite period in which the system is needed, and the financial strains often faced post injury. This client group is vulnerable to financial difficulties due to the impact of ABI on one's ability to return to full time employment held prior to injury.

In addition, integration of compensatory aids into daily lifestyle can be a determinant of success in maintaining helpful strategies. Clients with ABI report that introducing strategies that were not part of their daily life prior to injury can be difficult. Systems to aid memory can take time to adjust to and can be vulnerable to error or breakdown (McKerracher, Powell, & Oyebode, 2005; Wright et al., 2001). These time demands and errors can undermine the benefits of strategy use and lower motivation levels for on-going implementation. It has also been reported that the logistics of remembering to carry and use notepads, diaries and scraps of paper can place significant demands on the executive and memory systems. If one fails to take the aid at the start of the day, the whole system is redundant.

It is important to consider these themes when exploring the potential for new strategies to be effective in neuropsychological rehabilitation. The issue of how a smartphone device as a compensatory aid may address rehabilitation needs with these factors in mind will be discussed with these factors in mind.

## 2.7. Smartphones – A Compensatory Aid

*Definition – What is a Smartphone?*

A smartphone is loosely defined as a device that combines a mobile phone with a hand held computer. The device will typically provide internet access, data storage, email capabilities, an inbuilt camera, Global Satellite Navigation (GPS) capabilities and the capacity to download and run computer programmes commonly referred to as 'applications (Apps)'. A smartphone is available in a number of models produced by a range of manufacturers. It is a device that offers a colour display with the option of touch screen inputting. The applications/programs built in and available for download commonly include calendar functions with an alarm reminder, voice activation, notepads, navigation maps, sound recording, music players, video calling, and online journals to name just a few. There are currently hundreds of thousands of applications available across software providers.

*The Potential of Smartphones In ABI Rehabilitation*

There has been increasing interest in the potential benefits of using smartphones within brain injury rehabilitation due to the functional capabilities that these devices may provide. As noted, common deficits post brain injury can range from difficulties with verbal and non-verbal memory, prospective memory, autobiographical memory, to planning, problem solving, and self-monitoring of daily tasks. The flexibility and functional capabilities of smartphones may offer opportunities to compensate for some of these difficulties (Svoboda & Richards, 2009; Svoboda, Richards Posinelli, & Guger, 2010; Svoboda, Richards, Leach & Mertens, 2012; Macdonald et al 2012).

The increasing potential for using smartphones within brain injury rehabilitation may also be supported by the rising rate of device ownership in the UK and across the world. According to OFFCOM (2012) it is estimated that 39% of adults in the UK now own a smartphone device and it is predicted that this will continue to rise over the years. As ownership levels increase, the running costs of the devices have fallen. Smartphones are now available to buy outright at a cost of between £50.00 and £400.00, while monthly costs (within 24 month contracts) can range from £7.00-

£60.00 (estimates from leading providers). Increased smartphone ownership may suggest that in the coming years there will also be an increase in the number of people who access rehabilitation services who have owned and used a smartphone prior to injury.

*Smartphones and Memory Deficits*

The functions available on a smartphone are highly compatible for supporting common memory and executive functioning deficits reported post ABI. As discussed, literature to date suggests that people with ABI can find learning to use new unfamiliar compensatory aids difficult. There is a need for these aids to be cost effective, non-stigmatising, congruent with self-identity, and logistically feasible for everyday use (Baldwin et al, 2011; Macdonald et al., 2011; Svoboda et al., 2009; 2010; 2012). The smartphone may be able to meet some if not all of these needs. In addition, memory systems literature highlights the role of capitalising on well learnt implicit memory to meet task demands (Svoboda et al., 2009). Pre morbid everyday use of smartphones may enhance the ability to apply this skill set unconsciously. Use of and navigation around a smartphone post injury may tap into well learnt implicit memory pathways that are robust to ABI (Baddeley & Wilson, 1994). There may however be a need for support in re-familiarising an individual with their smartphone device. It is hypothesised that post injury smartphone use may depend on how often an individual used the device prior to injury. Frequent navigation of a smartphone pre-injury would build up implicit/procedural memory for this skill. Following brain injury, these implicit memories are often retained and can be re-accessed with a little re-training. For example, a frequent computer user prior to injury will retain the ability to navigate around a PC and keyboard with only a little start up support, even if they do not consciously recall being given support post injury. It is the implicit/procedural memory that may play a central role in use of the smartphone as an external memory aid post injury. Over the last few years there have been some initial studies that have reported promising results for the use of the smartphone as a modern day memory aid.

*Early Research Findings in Smartphone Benefits*

There are a few recently published studies with small samples that indicate that smartphone applications may support memory compensation in clients with ABI (Svoboda et al., 2009, 2010; De Pompei et al., 2008). De Pompei et al., (2008) looked at the use of smartphone reminders in a small sample of teenagers with brain injury based in a school setting. Outcomes showed improved completion of pre-set tasks when prompts were provided. This improvement dropped away when the reminders were removed. It was also noted that these children reported that they found the device to be inconspicuous and easy to use. Svoboda et al (2009; 2010) conducted a similar study using smartphone prompts with two adult case studies whereby memory impairments were experienced as the result of an ABI. Findings from this study also indicated that completion of pre-set tasks was greater when prompts were provided through the smartphone, in comparison to when they were absent.

More recently, there have been two studies looking into the potential benefits of reminders provided through smartphones by Svoboda et al (2012), and MacDonald et al (2011) using larger samples. Svoboda et al (2012) applied a similar design to that used in the 2010 study in which participants were provided with a to do list of tasks over a set period, with completion rates measured using a diary log and phone call response rates. The more recent paper reported that positive gains in task completion were in evidence when 10 participants with moderate to severe brain injury received smartphone prompts in comparison to when the prompts were removed. This study made use of manual entry of reminders into the phone device, a process that can be timely and prone to error, particularly for those less familiar with navigating smartphone applications. The sample of 10 enables some generalisation of results; however, pre-set tasks were monitored by completed phone calls, and a behavioural log kept by family members. While the phone calls can be objectively recorded, they only map onto one aspect of responding to everyday prospective memory tasks. In addition, behavioural memory logs are susceptible to a number of errors as family members may forget to complete them, miss completed tasks, or provide varying levels of prompting which may confound results.

Macdonald et al., (2011) has also recently published the results of randomised controlled cross over within subjects design (RCT) comparing the use of smartphone reminders with a paper and pen diary in those with moderate brain injury (n=20). Prompts were delivered by the smartphone using a synchronised calendar system through the internet connection. Entries into the email calendar would log prompts into the participants smartphone triggering reminders at set times of the day. Findings indicated that when smartphones prompts were received, task completion rates were greater compared with the use of a paper dairy. Despite the positive outcomes when using this cutting edge technology, there are a number of considerations when interpreting these findings. While this study used a larger number of participants than that of Svoboda et al., (2012), an RCT design with this sample size may lack statistical power. In addition, the heterogeneity of ABI participants' presentation makes it difficult to have equal grouping. This raises questions around internal validity and external validity. Further considerations include the same issue levelled at Svoboda et al., (2012) whereby completed tasks were monitored using a behavioural log completed by a family member. Similar limitations mentioned previously may again apply.

Despite these limitations, Svoboda et al. (2012) and Macdonald et al. (2011) have demonstrated that research into smartphones may hold compensatory benefits. Svoboda et al (2012) also reported that the use of smartphone reminder systems may have secondary benefits in reducing care giver strain levels in those supporting people with ABI. This suggestion, coupled with the emerging technology employed by Macdonald et al (2011) may yield an interesting area of further research. It is hypothesised that smartphone reminders programmed remotely using email calendars may benefits for both the individual with ABI, as well as those who support them. Secondary benefits for care givers will now be considered.

### 2.8. Impact on Care Giver Strain in ABI

Caregiver strain is the perceived or actual demands placed on an individual who is providing emotional, physical, psychological, financial or social support to an individual who has deficits in independent daily functioning as a result of an ABI (Chwalisz, 1996). It is an area of interest within the brain injury literature due to growing evidence of the potential negative impact that this can have on the

relationship between those injured and those providing subsequent care (Sander, 2005). The extent to which the care giving role can place strain on family members, partners and friends can be influenced by a number of factors. Research findings indicate that severity of ABI, deficits in functioning, age at injury, type of relationship, pre-injury personality, emotional coping styles, and rehabilitation/emotional support post injury can all impact on caregiver strain levels (Ergh, Hanks, Rapport, & Coleman 2002; Harris, Godfrey, Partridge & Knight, 2001; Chwalisz, 1996). There is also evidence that increased caregiver strain levels can subsequently have a negative impact on functioning and prognosis of those being cared for (Vangel, Rapport & Hanks, 2011). Caregiver strain levels are predicted to be higher when demands placed on the caregiver exceed resources, or result in changes in lifestyle/relationships that existed prior to the injury (Livingston, Kennedy, Marwitz, Arango-Lasprilla, Rapport, Bushnik & Gary, 2010; Chwalisz, 1996).

Increased dependence on caregivers is reported as an important factor in the changes to lifestyle/relationship pre and post ABI. This dependence may emerge due to the difficulties incurred as a result of the injury. Reduced/limited mobility, visual-perceptual deficits, memory difficulties, executive dysfunction, language impairments, and psychological adjustment all contribute to an increased reliance on the family/friend/partner to take on a caregiving role (Livingston et al., 2010; Kreutzer Rapport, Marwitz, Harrison-Felix, Hart, Glenn & Hammond, 2009; Chwalisz, 1996). Studies have shown that the demands placed on caregivers/family/partners can increase risk of breakdown in intimate relationships (Wood, & Yurkadul, 1997), increase care giver vulnerability to depression/anxiety (Sander, 2005; Gillen et al., 1998; Kreutzer et al., 2009), and negatively impact on the rehabilitation of people whom the care is offered to (Tyerman & Barton, 2008; Ponsford & Schonberger, 2011). With consideration of the focus of this study, it may be important to explore the possible links between caregiver strain levels and prospective memory impairments in those they support.

*Caregiver Strain and Memory Impairment*

It is proposed that following ABI, caregivers are frequently relied upon to provide intensive prompting of everyday tasks to support their loved one's ability to engage in pre-morbid activities. While the loved one with ABI is supported to engage in

everyday tasks, there is also a risk that reliance develops. It is hypothesised that this may contribute to the individual with ABI feeling deskilled. This in turn can lead to perceived or actual loss of independence on both the part of the caregiver and cared for. It is often reported that the changes in this circumstance and relationship present a challenge of the integration of this new role into one's existing sense of self for all parties involved (Teasdale, Emslie, Quirk, Evans, Fish & Wilson, 2009).

Research into caregiver strain has indicated that reducing dependence within the relationship between the caregiver and ABI sufferer may lower levels of perceived or actual demands. The application of compensatory strategies in rehabilitation aims to enhance independence, which in turn may reduce dependence on others. It is hypothesised that this reduced dependence on others will lower caregiver strain and support integration of the change in functioning and roles into one's sense of self. Prospective memory difficulties are of the most common deficits post brain injury. In addition, the inability to recall and execute tasks at a given time places significant demands on caregivers and family members. With increased demands, personal resources of caregivers are stretched and it is this imbalance between resources and demands that can result in high levels of caregiver strain (Teasedale et al., 2009; Ponsford et al., 1995).

*Care Giver Strain and Reminder Devices*

A study conducted by Teasdale et al (2009) in conjunction with the NeuroPage looked at the changes in caregiver strain levels in family/partners of those using the paging reminder system. Findings indicated that the indirect prompting may have played a role in reducing the demands on the relationship, thus reducing levels of caregiver strain.

More recently, reduction in caregiver strain levels was also reported when smartphones were introduced as a prompting device (Svoboda et al., 2010). Similarly to NeuroPage, the smartphone may help in scaffolding the prospective memory difficulties experienced by ABI sufferers. Pre-set reminders reduce demands on the individual to hold in mind and recall intended tasks, whilst also reducing the need for caregiver to actively prompt throughout the day. Smartphones offer the capacity for family members to assist those with ABI to pre programme reminders into the phone,

thus reducing reliance on in-the-moment reminders and on compensation strategies that do not provide time based cues. Svoboda et al (2009; 2010) suggested that smartphone use may indirectly reduce the emotional impact of repeated prompting throughout the day. As prompts are delivered electronically and can be set to repeat at certain times on specific days, the caregiver plays a reduced role in supporting prospective memory deficits.

It is hypothesised that over time with the reduction in reliance on caregivers and non-cuing systems to help compensate for memory deficits, those with ABI may experience an increased sense of independence. There is growing literature that suggests that independence, purposeful activity and a congruent sense of self may have positive connotations for the emotional wellbeing of those with ABI (Corrigan, Bogner, Mysiw, Clinchot & Fugate, 2001). Thus, smartphone prompting may have positive outcomes for ABI sufferers and caregivers alike.

### 2.9. Gaps in the Current Literature & Study Aims

This study aims to explore the potential benefits of remotely programmed reminders that are transferred to the smartphone through the internet capabilities of the modern phone. This is done using the smartphone's calendar function. The calendar system has an easy to use interface which can be modified to support easy navigation. It can also be synchronised to an email calendar which enables remote programming of events with alarmed reminders using the internet connectivity. In simple terms, appointments and prompts can be entered into an email calendar through a computer anywhere in the world. The reminder will then be transferred into the phone calendar over the internet. Similarly, entries into the phone will transfer to the email calendar.

There is a growing body of evidence to suggest that this line of memory compensation can yield positive outcomes for those with ABI and the families that support them (Macdonald et al., 2011; Svoboda et al., 2009; 2010; 2012). This study aims to explore this premise. In addition, this study will also assess the potential impact on the clients' mood, perceived dependence on others, confidence in coping with difficulties, and ability to engage in intended daily tasks. Caregiver strain levels will also be assessed.

If successful in improving task completion, participants and caregivers will be encouraged to continue programming of the device with regular prompts for daily activities. Over time, as learning of the programming improves, the client themselves may gradually take over the setting of their own memory reminders, thus providing a stepwise approach to reduction of scaffolding.

*Aims of this Study*

Prospective memory problems after brain injury are commonplace and there have been a number of attempts by researchers to address these problems with mixed success. In recent years the focus has turned to potential benefits of electronic devices that may act as external prompts for planned activities. Research initially explored the benefits of wrist watch alarms (Van Hulle & Hux, 2006), then pager systems (Wilson, Evans, Emslie & Malinek 1997; Wilson et al., 2001; Wilson et al., 2005; Emslie et al., 2007; Fish et al., 2008), followed by use of PDA's (Kim et al., 1999; Thone-Otto et al., 2003; Gentry et al., 2006; Kirsch et al., 2004; Wright et al., 2001; DePompei et al., 2008; Dowds et al., 2011). However, very few studies have explored the potential application of advancements in smartphone technology to address these difficulties (Svoboda et al., 2009, 2010, 2012; Macdonald et al., 2011). Moreover, it is well recognised that technology to improve memory deficits will not be adopted by clients if they do not feel comfortable using it. This study aims to use a contemporary technology that is already widely used and accepted by the 'normal' population to compensate for and overcome difficulties planning and meeting goals. It also aims to evaluate the effect of this technology on the clients' well-being and on the strain loved ones often experience. The aims of this study are outlined below.

Primary Aims

- To establish whether individuals who experience prospective memory difficulties as a result of brain trauma may benefit from task reminder cues delivered by their mobile phone. Monitoring of response to these cues will help establish whether use of the phone calendar function can support completion of pre-planned activities, even in the absence of actual task recall.

- To assess whether introduction of the system encourages use of the smartphone as a compensatory strategy in day to day life.

Secondary Aims

- To assess the impact of smartphone reminders on participants' perception of engagement in everyday tasks, self-confidence, mood and dependence on others.

- To assess whether the device indirectly reduces perceived caregiver strain.

- To explore whether use of the smartphone system is maintained at a three month follow up, what the potential barriers to use may be, and consider whether participants are likely to continue with its use in the future. In addition, caregiver's perception of changes in caregiver strain levels over the intervention and follow up periods will be assessed.

## 2.10. Research Hypotheses

*Primary Hypotheses*

1. There will be increased response rates to pre-set tasks when provided with prompts from the smartphone reminder function, as compared to when using the task list only.

2. There will be a significant increase in scores on the Strategies of Smartphone Use Questionnaire between pre intervention and post intervention, as well as pre-intervention to 3 months follow up.

*Secondary Hypotheses*

3. There will be a significant increase in scores on the Feelings about My Memory Questionnaire between pre-intervention and post-intervention, as well as pre-intervention to 3 months follow up.

4. There will be a significant reduction in scores on the Memory Mistakes Questionnaire between pre-intervention and post-intervention, as well as pre-intervention to 3 months follow up.

5. There will be a significant increase in scores on the Memory Strategies Questionnaire between pre-intervention and post-intervention, as well as pre-intervention to 3 months follow up.

6. There will be a significant increase in scores on confidence in coping with memory difficulties as recorded in the Memory Mistakes Questionnaire between pre-intervention and post-intervention, as well as pre-intervention to 3 months follow up.

7. For those who have caregiver involvement, there will be a significant reduction in Modified Caregiver Strain Index scores between pre-intervention and post-intervention, as well pre-intervention to 3 months follow up.

# 3. METHOD

## 3.1. Design

The design and methodology of this study emerged from close liaison with a service user who acted as a consultant to the project. He was encouraged to contribute comments at every stage of planning of the project and assisted in the provision of a service user perspective as to the feasibility and accessibility of the design. This was achieved through participation in a pilot study and feedback sessions.

*Case Series Methodology*

This study employed an ABAB case series design. This involved looking at the effects of an intervention on individual performance on a task over a baseline period, followed by an intervention period. This was then repeated by removing the intervention (return to baseline), followed by reinstalling it (return to intervention). The premise within this design is that the effectiveness of the intervention will be compared by exploring the variation in individual scores across the four phases. Particular interest was paid to comparing the baseline with the intervention phases. It is therefore a within subjects design (Kazdin, 2011).

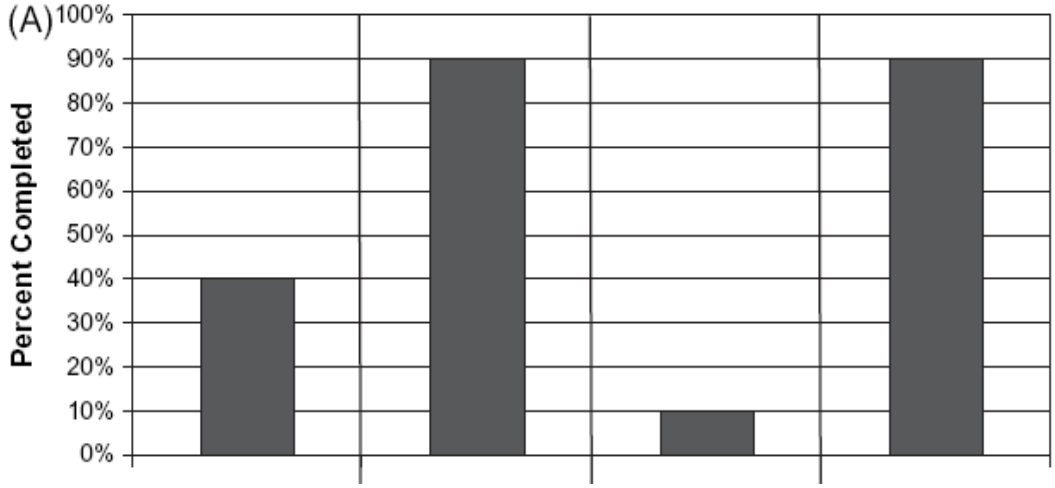


*Figure 2. Example of 4 phase task completion scores in ABAB case series design*

In conducting a multiple case series study, individual scores can be analysed in an isolated fashion, or pooled across the group. The advantages of this approach are

that those who suffer a brain injury are a heterogeneous group. To compare groups in a randomised controlled design requires large population numbers to ensure internal validity is maintained. The variation in presentation, pre-morbid functioning, age, time since injury and effects of injury makes establishing comparable groups very difficult. This design favours detailed consideration of the effect the intervention has for each individual case with their presentation and context in mind. While this may limit the ability to generalise findings to the broader brain injury population, it provides indication that the intervention may or may not be effective for some people who suffer a common deficit. In sampling people with a range of demographics, tentative interpretations regarding potential clinical use can be made (Kazdin, 2011).

*Independent & Dependent Variables*

In this study, the presence or absence of smartphone reminder prompts was the Independent Variable (IV). The Dependent Variables (DV) included:

(a) The number of pre-set tasks completed during each of the four phases of the intervention.
(b) Score changes on the Memory Mistakes Questionnaire (Troyer & Rich, 2002), Strategies of Smartphone Use Questionnaire and Memory Awareness and Strategies Scale (Svoboda, et al., 2009) pre/post intervention and at three months follow up.
(c) Score changes on the Modified-Caregiver Strain Index (Sullivan, 2008) at pre/post intervention and at three month follow up.

*Participants*

Participants were recruited from the Neurological Rehabilitation Service in Hertfordshire. In total eight participants started the study, seven of whom had caregiver/family/partner participation. Participants presented with mild to moderate ABI as determined by their Glasgow Coma Scale (GCS) score, longevity of Post Traumatic Amnesia (PTA), or in the absence of this information, presentation at pre intervention assessment (see Appendix 2). In addition, all participants reported difficulties with prospective memory. Of the eight participants, there were six men and two women. The mean age was 43 (ranging 24-60) and all were White British (see

Appendix 3 - Demographics). NHS Ethics approval was granted by the NRES Committee East of England - Cambridge South (see Appendix 4), while NHS Hertfordshire Community Trust provided Research & Development approval to recruit participants through the Hertfordshire Neurological Service (see Appendix 5). Only six participants completed the study. One participant terminated participation in the first week of the intervention due to unforeseen life events (victim of fraud) and a second terminated participation during the follow up phase due to health issues and relocation of home. Assessments and data from these participants have been excluded from the analysis.

| Participant number | Age | Gender | Ethnicity | Aetiology | Time Post Injury | Carer/Family Participation | Smartphone |
|---|---|---|---|---|---|---|---|
| **PH** | 55 | Male | White British | RTA – Diffuse Axonal Damage | 20 Months | Wife | IPhone |
| **MM** | 24 | Male | White British | Epilepsy | Life long | Father | Nokia Lumia |
| **LL** | 35 | Female | White British | Brain Tumour & Epilepsy | 48 Months | Partner | IPhone |
| **CC** | 25 | Male | White British | Hypoxic ABI- Cardiac Arrest | 19 Months | Mother | IPhone |
| **CW** | 48 | Female | White British | RTA - Right Frontal Haemorrhage | 13 Months | Husband | Samsung Galaxy |
| **DR** | 23 | Male | White British | Fall | 24 Months | N/A | IPhone |

*Figure 3. Participant Demographics*

Participants were identified by Registered Clinical Psychologists working within the Hertfordshire Neurological Service. If participants met inclusion and exclusion criteria, the Clinical Psychologist made contact to provide basic details of the study and enquire if they wished to be contacted by the researcher (see Appendix 6 – Study Flowchart). If participants gave consent to be contacted, a call was made by the researcher to arrange a face to face meeting. During this meeting, participant/caregiver information sheets (see Appendix 7) and the study flow chart were provided. In addition, a verbal explanation of the study and its requirements was provided over the course of 30 minutes. Participants were given seven days to decide if they wished to proceed, this was followed up with a phone call by the researcher. Following this break, if participants wished to continue, the information sheet and flow

chart were discussed again and consent forms (see Appendix 8) signed by the participants and the caregiver where appropriate.

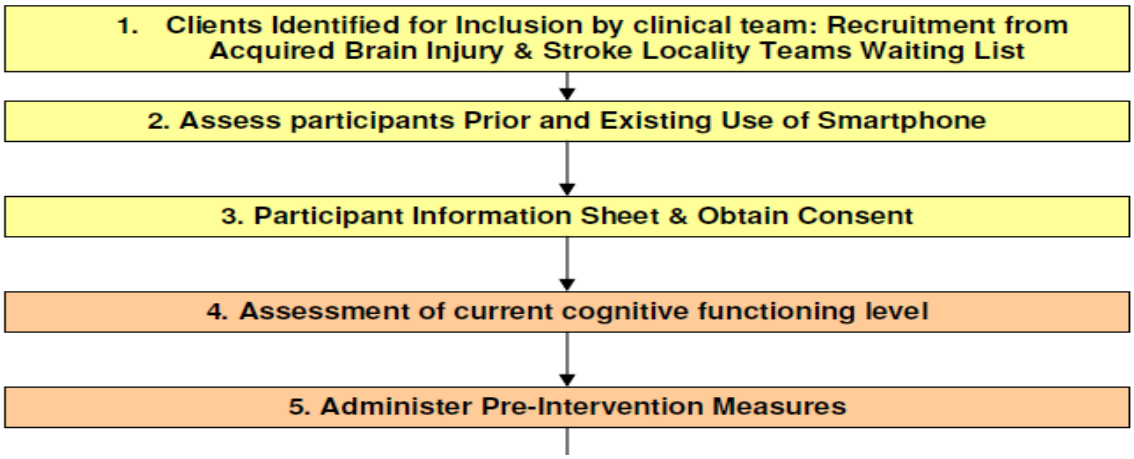


*Figure 4. Identification and Assessment of Participants Protocol*

Once consent was attained, neuropsychological assessment measures were administered to assess (a) suitability for the study, and (b) participants current functioning across cognitive domains. Participants were then assessed on their ability to (a) read and respond to smartphone calendar prompts, (b) enter events and set reminders into their smartphone, (c) enter and read calendar entries on their email calendar. This was followed by completion of pre-intervention measures including: Strategies in Smartphone Use Questionnaire, Memory Mistakes Questionnaire (Troyer & Rich, 2002) and the Memory Strategies and the Awareness Questionnaire (Svoboda et al, 2009). Caregivers were then administered the Modified Caregiver Strain Index (Sullivan, 2008) and asked to complete the caregiver section of the Strategies in Smartphone Use Questionnaire.

*Inclusion Criteria:*

- Participants were required to have owned and used a smartphone prior to their ABI.
- Participants were required to demonstrate the necessary skills in navigating the calendar function on the smartphone and on their email by the end of the two training sessions.

- Participants were to be free from any symptoms of Post Traumatic Amnesia (PTA).
- Participants were required to report day to day memory difficulties of a prospective nature.
- Participants were required to be physically able to use their smartphone device, i.e. have sufficient dexterity, visual, or auditory capability to use the smartphone. This was assessed in the training period through interview and observation.

*Exclusion Criteria*

Participants were excluded from the study if they scored within the Moderate to Severe range on either the Beck Depression Inventory II (BDI) (Beck, Steer, & Brown, 1996) or the Beck Anxiety Inventory (BAI) (Beck & Steer, 1990). Moderate to severe symptoms of anxiety or depression can impact significantly on memory performance and potentially act as a confounding variable.

*Neuropsychological Assessment Measures*

- *Demographics Questionnaire*

  The demographics questionnaire was administered to gather information relating to participant age, gender, ethnicity, date of injury/diagnosis, type of injury, involvement of caregiver and model of smartphone. This questionnaire was designed for this study (see Appendix 9).

- *Wechsler Test Adult Reading (WTAR; Wechsler, 2001)*

  This is a well validated test used to assess pre-morbid intellectual functioning level. Its administration enables comparison of current functioning with this pre-morbid estimate. The greater the difference from this marker, the greater the impact the ABI has had on cognitive functioning. This measure provides

standardised age appropriate norms to which scores can be compared with the normative population (Wechsler, 2001).

- *Repeatable Battery Assessment Neuropsychological Screen (RBANS; Randolph, 2002)*

  This measure is a screening tool that provides an indication of functioning across the domains of Memory (Visual/Verbal, Recall & Recognition), Language (Naming and Fluency), Visuo-spatial Construction (Object and Space Perception) and Attention (Working memory and Sustained Attention). This measure provides standardised age appropriate norms to which scores can be compared with the normative population (Randolph, 2002).

- *Controlled Oral Word Association Test (COWAT; Loonstra, Tarlow & Sellers, 2001).*

  This is a test that assesses language functioning (receptive and expressive). Participants are required to name as many words beginning with the letters F, A and S in one minute. They are then required to name as many animals they can think of in one minute. Scores are then assessed using standardised, age appropriate norms (Strauss, Sherman & Spreen, 2006).

- *Trail Making Test (TMT; Reitan & Wolfson, 1985; Tombaugh, 2004)*

  This test places demands on processing speed and the ability to apply flexibility and inhibit thoughts and actions. The test has two parts: Trails A and Trails B. In Trail Making Task A the participant is asked to join up sequences of numbers that are printed randomly across a page as quickly as possible (this is to assess attention, monitoring and processing speed). On the Trail Making Task B, the participant is asked to join letters and numbers alternatively following a rule. Again, these are spread across the page randomly, placing demands on cognitive flexibility in addition to attention, processing speed and monitoring. Age appropriate standardised norms are available for the TMT (Tombaugh, 2004).

- Hayling & Brixton Test of Dysexecutive Functioning (Burgess & Shallice, 1997)

  This test assesses processing speed, cognitive flexibility, inhibition, and self-monitoring. The Hayling subtest assesses participants' ability to inhibit ones dominant response following instruction to do so. Brixton subtest requires participants to identify pattern emergence and change. Both subtests provide standardised scores that allow age comparisons. The Hayling and Brixton Test is a well validated measure in the research literature (Burgess & Shallice, 1997).

- *Beck Anxiety Inventory (BAI; Beck & Steer, 1990)*

  The Beck Anxiety Inventory (BAI) is a 21-item multiple-choice self-report inventory that measures the severity of anxiety symptoms in 16-80 year olds. It has good internal consistency with a Cronbach's alpha range of .92 to .94 and a test-retest reliability of .75.

- *Beck Depression Inventory II (BDI II; Beck, Steer, & Brown, 1996)*

  The Beck Depression Inventory (BDI-II) is a 21 item multiple choice inventory that measures the severity of depression symptoms in 16-80 year olds. It has good internal consistency and test-retest reliability. Administration of a mood measure is important as research has shown that mood changes are common post injury and can have a negative impact on memory performance (Evans, 2010).

- *Prospective & Retrospective Memory Questionnaire (PRMQ; Smith, Della Sala, Logie, and Maylor, 2002; Crawford, Henry, Ward, & Blake, 2006).*

  This is a self-report questionnaire that assesses memory for past (Retrospective) and future planned (Prospective) events. Using a 4 point scale, scores can be compared with age normative data. It is well validated with good test-retest reliability (Crawford, Henry, Ward & Blake, 2006) (see Appendix 10).

*Outcome Measures*

- *Task Completion Rates*

  This is the completion rate of pre-set tasks in the absence or presence of reminders provided through the smartphone calendar function. Tasks consisted of sending text messages or leaving voicemails to provide updates as to progress with set tasks, posting pre-addressed letters, and making entries into the smartphone calendar at set times. Over each of the four phases of the intervention, there were 35 tasks to complete, five per day. The times of these tasks varied between the hours of 7 a.m. and 8 p.m. These times were also varied across the four weeks so as to limit learning of a routine (see Appendix 11).

- *Memory Mistakes Questionnaire (MMQ; Troyer & Rich, 2002)*

  This self-report measure uses a four point scale to assess the frequency/severity of common memory mistakes (from 'Never' to 'All of the time'). It has been historically used in dementia research and more recently has been administered by Svoboda et al. (2010; 2012) in a study looking at the usefulness of smartphone reminders for adults experiencing severe memory impairments through ABI (see Appendix 12).

- *Strategies of Smartphone Use Questionnaire (SSUQ; Svoboda et al., 2009)*

  This is a self-report measure that looks to assess participants' use of their smartphone as a compensatory aid prior to and after the intervention. In addition, it looks to gather the perceptions of caregivers or close family members regarding the participants' use of the device. The measure was designed by Svoboda et al. (2009) *(see Appendix 13).*

- *Memory Awareness and Strategies Scale (MASS;* Svoboda et al., 2009)

  This is a self-report measure that consists of three parts. Each measure was used by Svoboda et al. (2009; 2010; 2012) and is currently undergoing standardisation (see Appendix 14). The MASS assesses:

  (a) Participants' feelings towards their memory difficulties using a four point rating scale ('Strongly Agree' to 'Strongly Disagree').
  (b) Participants' use of compensation strategies to help manage memory difficulties using a four point rating scale ('All of the time' to 'Never').
  (c) Participants' confidence in managing everyday memory tasks that place demands on prospective memory, using a 5 point rating scale ('Not Confident' to 'Very Confident').

- *Modified - Caregiver Strain Index (M-CSI; Sullivan, 2008)*

  This is a multidimensional measure of strain on caregivers. It is a self-report measure that requires caregivers to identify statements which best represent the impact of care-giving on daily living (the answers include 'Yes a lot', 'Yes sometimes' and 'No'). It has been used extensively in the literature with older adults, however the demands placed on brain injury caregivers are considered to be very similar. As a measure, the M-CSI has an internal reliability coefficient of .90 and a test retest reliability co-efficient of .88 *(see Appendix 15).*

- *Impact of Smartphone Reminder Cues Questionnaire - ISRCQ*

  This questionnaire aims to gather participants and their caregivers' qualitative perceptions of the impact of smartphone reminder prompts on the ability to engage in daily activities, confidence in managing memory difficulties, mood, and dependence on others. It uses seven open ended questions to do this. It is a measure designed specifically for the purpose of this study. A service user who consulted on the design of the study assisted in this questionnaire's development *(see Appendix 16).*

- *Smartphone Reminder System – 3 Month Follow Up Questionnaire (SRS-FU)*

  This questionnaire was administered to both the participant and the caregiver and aimed to assess the smartphone reminder system use three months after the intervention period had ended. Questions looked at the following:

  (a) Current use of the smartphone reminder system.
  (b) Current use of the email link with the calendar reminders.
  (c) Barriers to using the smartphone reminder system.
  (d) Barriers to using the email link up with the calendar reminders.
  (e) Support that may aid smartphone reminder usage.
  (f) Support that may aid use of the email link up with the calendar reminders.
  (g) Likelihood of continued use of the smartphone reminder system.

(h) Likelihood of continued use of the email link up with the calendar reminders (see Appendix 17).

## 3.2. Procedure

On completion of neuropsychological assessment and pre-intervention measures, participants were introduced by the researcher to the technology which would be used to provide prompts during the study. Participants were allocated an email address created for the purpose of the study (this email was either a Gmail or Hotmail account with access to the email calendar). The email calendar was then synchronised with the participants' phone calendar by the researcher. This enabled events entered in either the email or the phone calendar to be automatically copied over to the other. Participants were trained in the use of the calendar reminder function over a period of 30 minutes to one hour depending on their familiarity with the system. They were instructed by the researcher to practice entering reminders and deleting reminders over a period of seven days. On meeting the following week, participants were tested by the researcher on their ability to read, enter, modify and delete calendar reminders.

*Task List Creation*

In collaboration with participants and caregivers, the four week task list was then created. Daily, weekly, or one off events were entered into the four week period. These events were allocated times according to the task lists randomised schedule. Each day on the task list included a calendar entry, text message responses, voicemail responses, and two pre-addressed letters that were to be sent to the researcher over each week. There were five tasks in total per day. The aims of these tasks were to replicate everyday prospective memory demands and increase familiarity with the smartphone reminder functions. Across the four week intervention period, the times of pre-set tasks varied so as to prevent learning effects that may have confounded task completion rates.

*Intervention Period*

1. '*Intervention Phase 1 - No Prompting'*

The participant was provided with a list of five pre-set tasks per day (leaving voicemails, sending text messages, sending a letter, and entering activities into the smartphone calendar) that needed completing at varying times. Each participant received a typed task list for each phase of the four week intervention. Whether participants carried out the pre-set tasks was recorded by monitoring text messages, phone calls, calendar entries and letters received over each phase. Text and voicemail responses were monitored using a research smartphone and the data was then transferred to a spread sheet. The times at which tasks were carried out varied from day to day. Participants were encouraged to use pre-existing strategies to help them complete the set tasks. Caregivers were asked to provide the same level of support in prompting participants throughout the study, across different stages. A total of thirty-five tasks were set for the first phase. At the end of Phase 1, participants received a phone call from the researcher to inform them that Phase 2 would start the following day, in addition to provide them with feedback as to performance on tasks in the previous week *(see Appendix 6 & 7).*

2. '*Intervention Phase 2 - Prompting Provided'*

The participants were provided with the task list for the week as in Phase 1, however, in addition all pre-set tasks were entered into the email calendar with a prompting alarm five minutes before the set task time. This entry was then automatically entered into the smartphone calendar through the internet connection. Participants' response to the prompts was monitored in the same manner as in Phase 1. At the end of Phase 2, participants received a phone call from the researcher to inform them that Phase 3 would start the following day, in addition to provide them with feedback as to response rates to pre-set tasks for the previous week. The aim of the feedback was to replicate the emotional experience of real life forgetting or completion of planned tasks.

3. *'Intervention Phase 3 - No Prompting'*

   The participants were provided with the task list for Phase 3. There were no smartphone prompts provided in this phase and participants responded to pre-set tasks in the same manner as Phase 1 and 2. At the end of each phase, participants received a phone call from researchers to inform them that the next phase would start the following day, in addition to provide them with feedback as to performance in the previous week.

4. '*Intervention Phase 4 - Prompting Provided'*

   The participants were provided with a task list for this phase. Similarly to Phase 2, smartphone reminders were provided five minutes before set tasks. Responses to reminders took the same form as in Phases 1-3. At the end of Phase 4, participants received a phone call from the researcher to provide feedback as to performance on tasks in the previous week and to inform them that the intervention period had finished.

*Post-Intervention*

Within ten days of completing the intervention, participants were re-administered the SSUQ, the MASS, the MMQ and the Impact of Smartphone Reminder Cues Questionnaire. Caregivers were administered the M-CSI, the caregiver section of the SSUQ, and the ISRCQ. Caregivers and participants received additional training over two hour long sessions to ensure that on-going use of the email and smartphone calendar synchronisation could be maintained to plan and prompt daily activities. Participants and their caregivers were then encouraged to try and use the system on a daily basis for the next three months.

*Three Month Follow Up*

Participants and their caregivers were contacted three months after finishing the intervention phases and were administered the post intervention assessment measures for a second time. In addition, participants and caregivers were asked to complete a questionnaire (SRS-FU) assessing the perceptions as to whether they would continue to use the smartphone prompting system. This questionnaire included

questions regarding barriers to using the system and the additional support that could be offered to aid use. This was followed by a full debrief provided by the researcher and the contact details for accessing support in maintaining the smartphone calendar reminder system.

## 3.3. Statistical Analysis

Three methods of analysis were used to test out the hypotheses for this investigation: Visual Inspection Analysis, Wilcoxon Ranks Statistical Analysis and a basic Thematic Analysis.

*Visual Inspection Analysis*

The individual and collated mean data for task completion rates were analysed using Visual Inspection Analysis. This is a common method of analysis in ABAB case series design. It looks to assess change in performance between phases of the study, i.e. when smartphone prompts are present compared to when they are absent. This can be done by comparing the mean scores between phases which is commonly referred to as Mean Change Analysis. Visual inspection also enables assessment of the immediate change in task completion rates between the final day of one phase and the first day of the next. This is commonly known as Change Level Analysis (Kazdin, 2011). In this study both Mean Change Analysis and Change Level Analysis have been used to compare performance between prompt present and prompt absent phases of the ABAB design for the collated case series scores.

*Wilcoxon Ranks Statistical Analysis*

The Wilcoxon Ranks test was used to assess whether there was a statistical difference between mean scores from one phase to the next, i.e. whether there was a statistical difference between mean task completion scores on Phase 1 in comparison with Phase 2. The Wilcoxon Ranks test was also used to assess whether there was a statically significant difference on pre, post and follow up questionnaire scores. The Wilcoxon Ranks test was selected due to the non-parametric nature of the research results due to the small sample size. Calculation of effect sizes was done using Cohen's D.

*Basic Thematic Analysis*

Due to the small sample size and limitations in psychometric questionnaires, a simple thematic analysis was also conducted. This aimed to draw out themes in participants and caregivers' responses to a qualitative questionnaire looking into perceived impact of smartphone prompting on six areas of everyday functioning (Braun & Clarke, 2006). Thematic analysis is a qualitative approach that can be used to identify patterns within spoken or written responses to open questions. Its use within this study aimed to provide insight into to the qualitative experiences of the participants and caregivers in taking part in the smartphone reminder trial. The hope was that the qualitative feedback would supplement the Visual Inspection Analysis and Statistical Analysis.

# 4. RESULTS

## 4.1. Case Series - Collated Results

*Task Completion Scores*

Visual Inspection Analysis

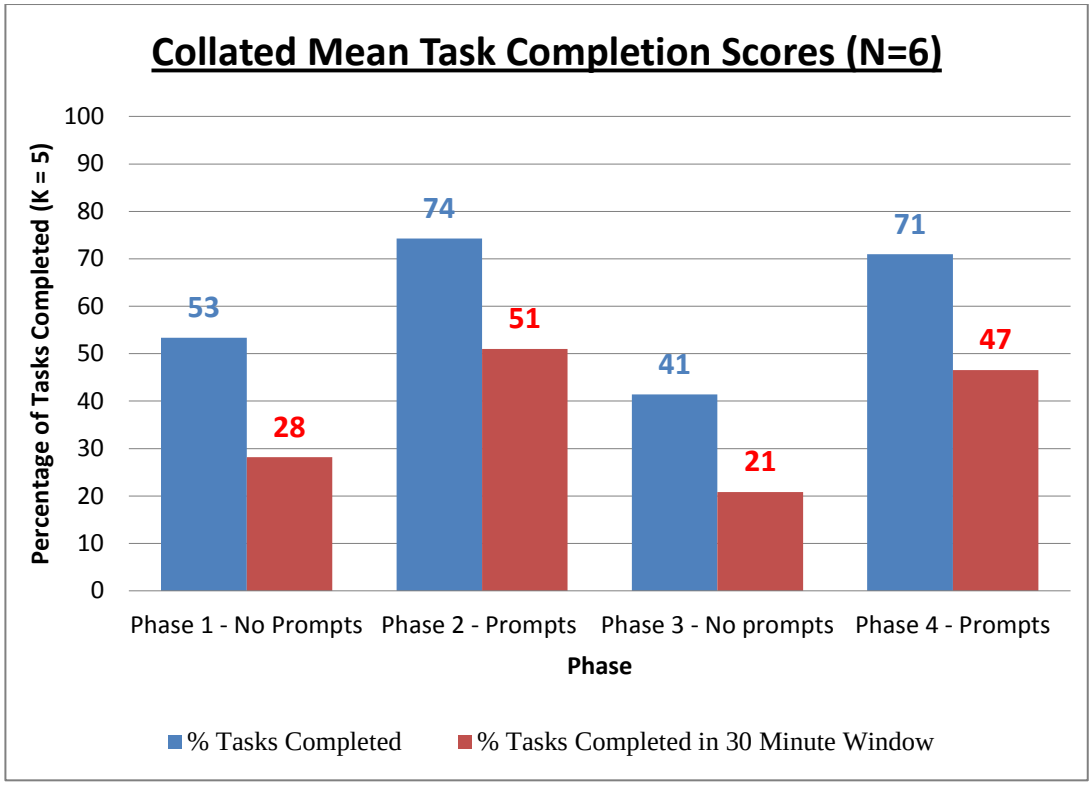


*Figure 5. Average task completion rates (Blue) and the average completion rates that occurred within 15 minutes either side of the tasks' identified time (Red).*

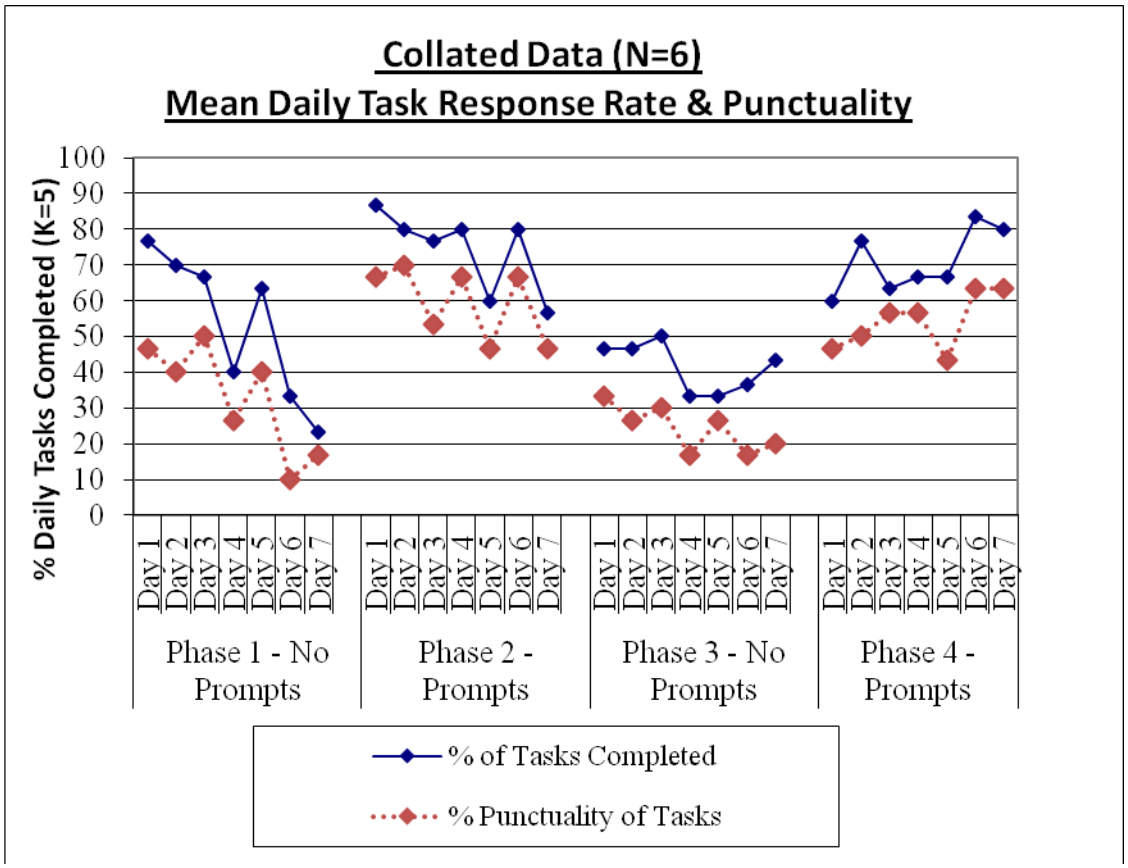


*Figure 6. Average daily task completion rates (Blue) and the average completion rates that occurred within 15 minutes either side of the identified time (Red).*

Through inspection of Figures 5 & 6 using Mean Change Analysis and Change Level Analysis, it is noticeable that participants' performance across phases showed an increase in task completion when prompts were provided. In Phase 1, task completion was relatively high; however, despite tasks being completed, they were not completed with great punctuality. In Phase 2 when prompts were available, task completion and punctuality increased. When prompts were removed, task completion scores and punctuality fell again, below the level recorded in Phase 1. With the re-introduction of prompting, the level of task completion and punctuality of task completion rose again to a similar level to that of Phase 2. Over the four phases, prompting improved task completion and the ability to complete the tasks within a 15 minutes either side of the allocated time. In order to explore the significance of these changes across phases, a series of Wilcoxon Signed Rank Tests were calculated. The results are outlined below.

Statisitical Analysis of Task Completion Scores

*Table 1. Task Completion - Mean and Standard Deviation (N=6)*

| Phase | Task Completion Mean & Std. Deviation | Task Punctuality Mean & Std. Deviation |
|---|---|---|
| Phase 1 (No prompts) | 53.33 (37.913) | 33.33 (32.957) |
| Phase 2 (Prompts) | 74.29 (28.383) | 59.05 (34.486) |
| Phase 3 (No Prompts) | 41.43 (41.764) | 24.29 (32.017) |
| Phase 4 (Prompts) | 70.95 (32.820) | 53.81 (32.002) |

The direction in the mean score changes across the four phases suggests a significant increase in task completion rates when smartphone prompts were present. The direction of mean score changes across the four phases also suggests that punctuality of task completion rates was greater when smartphone prompts were present as compared with when they were absent.

*Table 2. Task Completion Statistical Analysis - Wilcoxon Rank Test (N=6)*

| **Task Completion** | **Z Score** | **P Value (1 Tailed)** | **Effect Size** | **95% CI** |
|---|---|---|---|---|
| Phase 1 (No prompts) Vs. Phase 2 (Prompts) | -4.026 | .000 | 0.625 | -0.533, 1.784 |
| Phase 2 (Prompts) Vs. Phase 3 (No prompts) | -4.204 | .000 | 0.920 | -0.269, 2.110 |
| Phase 3 (No Prompts) Vs. Phase 4 (Prompts | -4.113 | .000 | 0.785 | -0.388, 1.960 |
| **Task Punctuality** | **Z Score** | **P Value (1 Tailed)** | **Effect Size** | **95% CI** |
| Phase 1 (No prompts) Vs. Phase 2 (Prompts) | -3.996 | .000 | 0.762 | -0.409, 1.934 |
| Phase 2 (Prompts) Vs. Phase 3 (No prompts) | -4.628 | .000 | 1.044 | -0.161, 2.250 |
| Phase 3 (No Prompts) Vs. Phase 4 (Prompts | -4.498 | .000 | 0.922 | -0.268, 2.112 |

*All 95% Confidence Intervals include zero due to the small sample size of six participants.

The Cohen's D effect size calculation on scores between phases would be classified as 'large'. This would usually suggest that there is a significant difference of task completion scores between phases when prompts are present and when they are absent. However, caution should be taken when interpreting these results due to the small sample size of the study. A limited sample is frequently an issue in a case series design and as a result, the findings may lack statistical power. It is for this reason that the statistical findings will be interpreted with the Visual Inspection Analysis in mind.

Quantitative Questionnaire Collated Results

In addition to the task completion scores, participants were also requested to complete a series of quantitative questionnaires pre-intervention, post-intervention and at follow up. The collated results can be seen in the table below (see Appendix 18 – Table of Individual Case Scores).

*Table 3. Mean collated scores - Quantitative questionnaires (N=6)*

| **Questionnaires Administered** | **Mean Pre Intervention** | **Mean Post Intervention** | **Mean 3 Month Follow Up** |
|---|---|---|---|
| Strategies In Smartphone Use<br>*0 = Low, 78 = High use* | 33 | 47 | 48 |
| Feeling About Memory<br>*0 = Negative, 78 = Positive Feelings* | 35 | 39 | 40 |
| Memory Mistakes<br>*0 = Few, 80 = Numerous Mistakes* | 47 | 44 | 49 |
| Memory Strategies<br>*0 = Few, 76 = Numerous Strategies* | 36 | 45 | 43 |
| Confidence in Coping<br>*0 = Low, 30 = High Confidence* | 21 | 23 | 27 |
| Modified Caregiver Strain Index<br>*0 = Low, 26 = High Strain* | 10 | 11 | 9 |

A series of statistical Wilcoxon Signed Ranks tests were also calculated to assess whether the score changes across pre-intervention, post intervention and follow up were significant. The results are outlined on the next page.

*Table 4. Statistical Analysis of Quantitative Questionnaires (N=6)*

| Questionnaires | Phase of Administration | Mean & Std. Deviation | Z Scores | P Values (1 Tailed) | Effect Size | 95% CI |
|---|---|---|---|---|---|---|
| **Strategies in Smartphone Use Questionnaire** | Pre-intervention – Post Intervention | 14 (11.02) | -2.201 | .028* | 0.907 | -0.280, 2.096 |
| | Pre-intervention – 3 Month Follow Up | 15 (12.78) | 2.220 | .026* | 1.062 | -0.146, 2.271 |
| | Post Intervention – 3 Month Follow Up | 1 (6) | -.843 | .399 | 0.147 | -0.985, 1.280 |
| **Feelings about My Memory Questionnaire** | Pre-intervention – Post Intervention | 4 (4.6) | -1.682 | .093 | 0.399 | -0.743, 1.542 |
| | Pre-intervention – 3 Month Follow Up | 4 (9.06) | -1.051 | .293 | 0.339 | -0.800, 1.478 |
| | Post Intervention – 3 Month Follow Up | 0 (6.6) | -2.10 | .833 | 0.012 | -1.119, 1.143 |
| **Memory Mistakes Questionnaire** | Pre-intervention – Post Intervention | -3 (3.74) | -1.761 | .078 | 0.324 | -0.814, 1.463 |
| | Pre-intervention – 3 Month Follow Up | 2 (7.47) | -.943 | .345 | 0.134 | -0.997, 1.267 |
| | Post Intervention – 3 Month Follow Up | 5 (10.50) | -.943 | .345 | 0.375 | -0.765, 1.517 |
| **Memory Awareness & Strategies Questionnaire** | Pre-intervention – Post Intervention | 8 (13.18) | -1.367 | .172 | 0.569 | -0.585, 1.723 |
| | Pre-intervention – 3 Month Follow Up | 7 (14.47) | .943 | .345 | 0.636 | -0.523, 1.795 |
| | Post Intervention – 3 Month Follow Up | -2 (8.8) | -.314 | .753 | 0.078 | -1.053, 1.210 |
| **Confidence in Coping Questionnaire** | Pre-intervention – Post Intervention | 3 (4) | -.631 | .528 | 0.306 | -0.831, 1.445 |
| | Pre-intervention – 3 Month Follow Up | 6 (5.88) | -1.78 | .074 | 1.361 | 0.105, 2.616 |
| | Post Intervention – 3 Month Follow Up | 4 (2.16) | -2.214 | .027* | 1.669 | 0.355, 2.984 |
| **Modified Care Giver Strain Questionnaire** | Pre-intervention – Post Intervention | 1.2 (3.34) | -.756 | .450 | 0.199 | -1.042, 1.442 |
| | Pre-intervention – 3 Month Follow Up | -1 (4.63) | .542 | .588 | 0.176 | -1.065, 1.418 |
| | Post Intervention – 3 Month Follow Up | -2.2 (2.94) | -1.604 | .109 | 0.520 | -0.739, 1.781 |

*All 95% Confidence Intervals include zero due to the small sample size of six participants.

Statistical Analysis of Quantitative Questionnaire Results

*Strategies in Smartphone Use Questionnaire (SSUQ) Scores*

Across participants' scores it is noticeable that there was an increased use of the smartphone as a memory aid over the course of the study. This increase is most noticeable after the intervention, but is also maintained at follow up (this is supported through statistical testing). The null hypothesis that there would be no significant change in smartphone use from pre to post-intervention, and pre-intervention to follow up may therefore be tentatively rejected. In addition, the null hypothesis that this change would not be maintained at three months follow up can also be tentatively rejected. This is supported by the 'Large' effect size calculated using Cohen's D between pre and post intervention, as well as pre intervention and follow up. The word tentatively is used due to the limited power in the statistical testing as result of a small sample size.

*Memory Mistakes Questionnaire (MMQ) Scores*

The table indicates that there was a mean decrease in memory mistakes scores over the intervention period. However, over follow up, perceived memory mistakes increased beyond the level at baseline. There was noticeable score variation between participants. The null hypothesis suggesting that there would be no significant change in perceived memory mistakes from pre to post-intervention cannot be rejected. Scores also remained relatively stable after three months.

*Feelings about My Memory Questionnaire Scores*

Despite mean score increases, the null hypothesis suggesting that there would be no significant change in participants' feelings about their memory functioning from pre to post-intervention and from pre-intervention to follow up cannot be rejected. Scores remained relatively stable from post-intervention to follow up.

*Confidence in Coping Questionnaire* Scores

The confidence in coping scores increased a little over the intervention period and then increased again over follow up. The null hypothesis that there would be no significant change from pre to post-intervention in confidence in coping cannot be rejected. However, the null hypothesis that confidence in coping would show no change from post-intervention to follow up may be tentatively rejected. This may suggest that confidence increases with time after the intervention period has been completed. This is supported by the 'Large' effect size calculated using Cohen's D.

*Memory Awareness & Strategies Scale (MASS) Scores*

On the MASS, it appears that there was mean increase in awareness and use of memory strategies over the intervention period. This dropped a little after follow up, but remained higher than baseline. The null hypothesis suggesting that there would be no significant change in strategies used to support memory from pre to post-intervention cannot be rejected. Scores remained relatively stable after three months.

*Modified Care Giver Strain Questionnaire Scores*

The table highlights that the mean caregiver strain scores increased a little over the intervention period, but then fell below baseline after follow up. The null hypothesis suggesting that there would be no significant change from pre to post-intervention in the levels of strain experienced by significant others living with participants cannot be rejected. Scores remained relatively stable after three months.

## 1.1. Individual Case Results

As well as identifying a number of interesting findings in the results collated across participants, there may also be value in taking each case individually to assess the potential benefits that the smartphone reminders system provided. This section will be broken down for each participant into the subheadings which will provide an overview of presenting difficulties, history of brain injury, cognitive functioning and performance within the study (see Appendix 19 for Neuropsychological scores). The presentation of results is supplemented by tables, graphs and figures throughout this section.

### *1.1.1. Case PH: Road Traffic Accident*

*Brief History*

PH is a 55 years old white British man who lives with his wife. He had recently retired from work due to the cognitive and physical difficulties experienced as a result of his brain injury. A clinical history was taken using medical notes, neurologist reports and clinical interviews with PH and his wife. PH suffered his brain injury in January 2011 after being involved in a Road Traffic Accident (RTA). He had lost control of his vehicle and hit a tree. He was taken to hospital whereby scans revealed that he had suffered diffuse axonal injury and a fractured scapula. PH was in a coma for 14 days. PTA was difficult to establish due to difficulties with speech. His Glasgow Coma Scale on admission was 4/15. PH and his wife reported that following his injury he experienced difficulties with new learning, multi-tasking, sustained attention, quick thinking and cognitive fatigue. PH reported an absence of any past or present mental health difficulties and was described by his wife as being an outgoing and cheerful person.

*Neuropsychological Profile*

PH scored within the *High Average* range on a test assessing pre-morbid functioning. A summary of mild and moderate-marked impairments relative to premorbid functioning across cognitive domains is provided.

Mild Impairment

- Letter fluency and object naming
- Sustained attention

Moderate to Marked Impairment

- Immediate and delayed memory recall and recognition
- Prospective & retrospective memory
- Switching attention and cognitive flexibility
- Planning and problem solving
- Semantic category word finding
- Processing speed

The neuropsychological assessment highlighted that PH was experiencing impaired functioning in the ability to complete everyday prospective memory tasks that rely on episodic and executive functioning processes. This suggested suitability for inclusion in the study.

*Intervention Task Completion Scores*

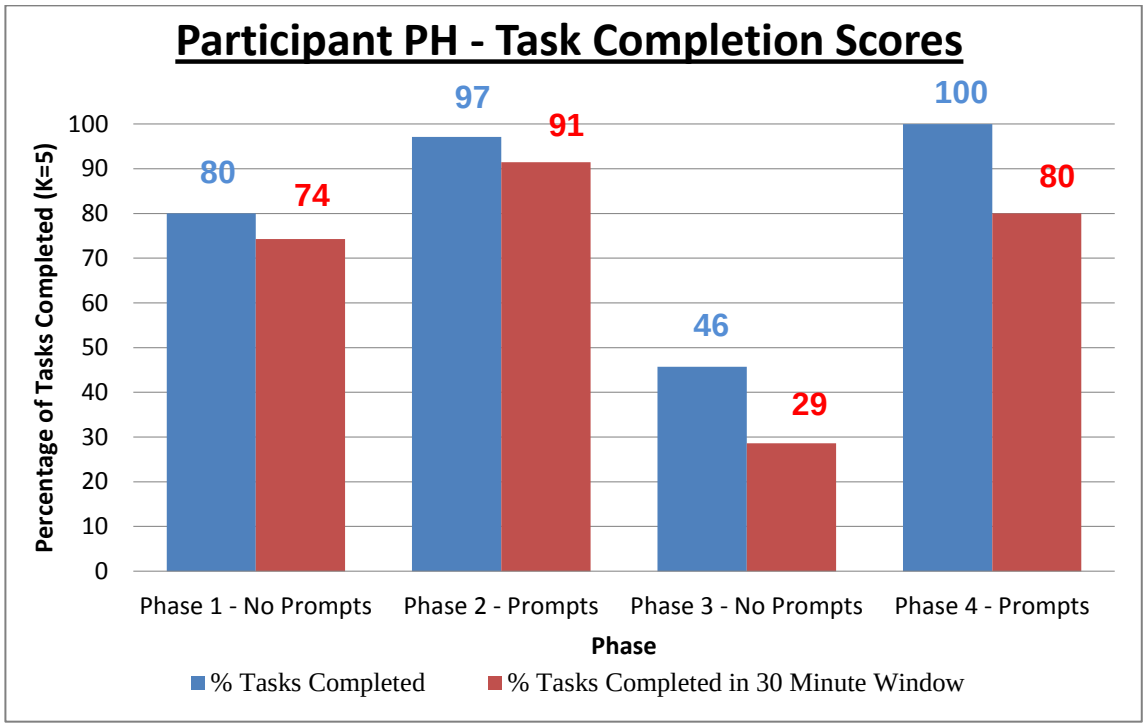


*Figure 7. Average task completion rates (Blue) and the average completion rates that occurred within 15 minutes either side of the tasks' identified time (Red).*

Using a Mean Change Analysis, it is noticeable that performance in Phases 2 and 4 when reminders were provided, task completion and the punctuality of task completion were greater than when prompts were absent in Phases 1 and 3. Also of interest was the pattern which shows that in Phase 1, average task completion and punctuality were greater than in Phase 3 despite an absence of reminders in both. It could be hypothesised that in Phase 1 scores were the result of PH's desire to perform well in the experiment in which encouraged an increased level of conscious monitoring and checking behaviour to ensure that tasks were completed with punctuality. By Phase 3, this conscious effort was no longer sustained providing a more accurate picture of functioning in the absence of smartphone prompts. Also of interest were the greater levels of task completion and punctuality in Phases 2 and 4, both of which provided time specific reminders via the smartphone device.

*Memory & Caregiver Strain Questionnaire Scores*

*Table 5. Memory & Caregiver Questionnaire Scores – Participant PH*

| **Questionnaires Administered** | **Pre Intervention** | **Post Intervention** | **3 Month Follow Up** |
|---|---|---|---|
| Strategies In Smartphone Use<br>*0 = Low use, 78 = High use* | 6 | 38 | 37 |
| Feeling About Memory<br>*0 = Negative Feelings, 78 = Positive Feelings* | 34 | 37 | 46 |
| Memory Mistakes<br>*0 = Few Mistakes, 80 = Numerous Mistakes* | 45 | 38 | 49 |
| Memory Strategies<br>*0 = Few Strategies, 76 = Numerous Strategies* | 42 | 40 | 38 |
| Confidence in Coping<br>*0 = Low Confidence, 30 = High Confidence* | 21 | 23 | 27 |
| Modified Caregiver Strain Index<br>*0 = Low Strain, 26 = High Strain* | 17 | 13 | 13 |

The scores recorded showed increased and continued use of in smartphone use over the intervention period and follow up. PH's positive feelings towards his memory functioning increased over intervention and again over follow up. However, his perception of memory mistakes initially decreased after the intervention, but decreased over three months. Of particular interest is the increase in confidence PH reported over the intervention and then again after follow up, while caregiver strain levels fell post intervention and remained stable over 3 months.

In summary, PH appeared to benefit from the presence of reminders to help with task completion and punctuality of performance. He also showed increased use of the smartphone as a memory compensation aid over the course of the study and follow up. Positive feelings towards memory and confidence in coping with memory demands increased as caregiver strain levels fell. Scores suggest that PH experienced a number of positive gains through use of the smartphone reminder system.

### *1.1.2. Case MM: Epilepsy*

*Brief History*

MM is a 24 year old white British man who lives with his father. He was employed as a part-time squash coach at the time of his participation in the smartphone study and had historically held a number of full-time employment positions from which he had been dismissed due to errors associated with cognitive difficulties. Neurological reports indicated that MM had suffered Frontal Lobe Epilepsy from the age of nine months. He experienced a number of seizures (tonic-clonic) in his first few years of life, however since being stabilised on an anti-epileptic medication, the frequency and severity of seizures had reduced. Neurological reports indicated that these seizures were thought to have had a cumulative effect on MM's memory and executive functioning capacity. MM and his family reported that MM experienced difficulties in recall and completion of pre-planned tasks. In addition, his family reported that MM had fluctuating motivation to complete daily activities and could be impulsive in his decision making at times. MM had received input from the local ABI rehabilitation team to support occupational engagement, development of memory strategies and risk management around impulsive spending. MM reported an absence of any past or present mental health difficulties.

*Neuropsychological Profile*

MM scored within the *Average* range on a test assessing pre-morbid functioning. A summary of mild and moderate-marked impairments across cognitive domains is provided.

Mild Impairment

- Letter fluency, semantic fluency and object naming
- Sustained attention

Moderate to Marked Impairment

- Immediate memory recall and recognition
- Prospective & retrospective memory
- Switching attention and cognitive flexibility

- Planning and problem solving
- Processing speed

The neuropsychological assessment highlighted that MM was experiencing impaired functioning in the ability to complete everyday prospective memory tasks that rely on episodic and executive functioning processes. This suggested suitability for inclusion/selection in the study.

*Intervention Task Completion Scores*

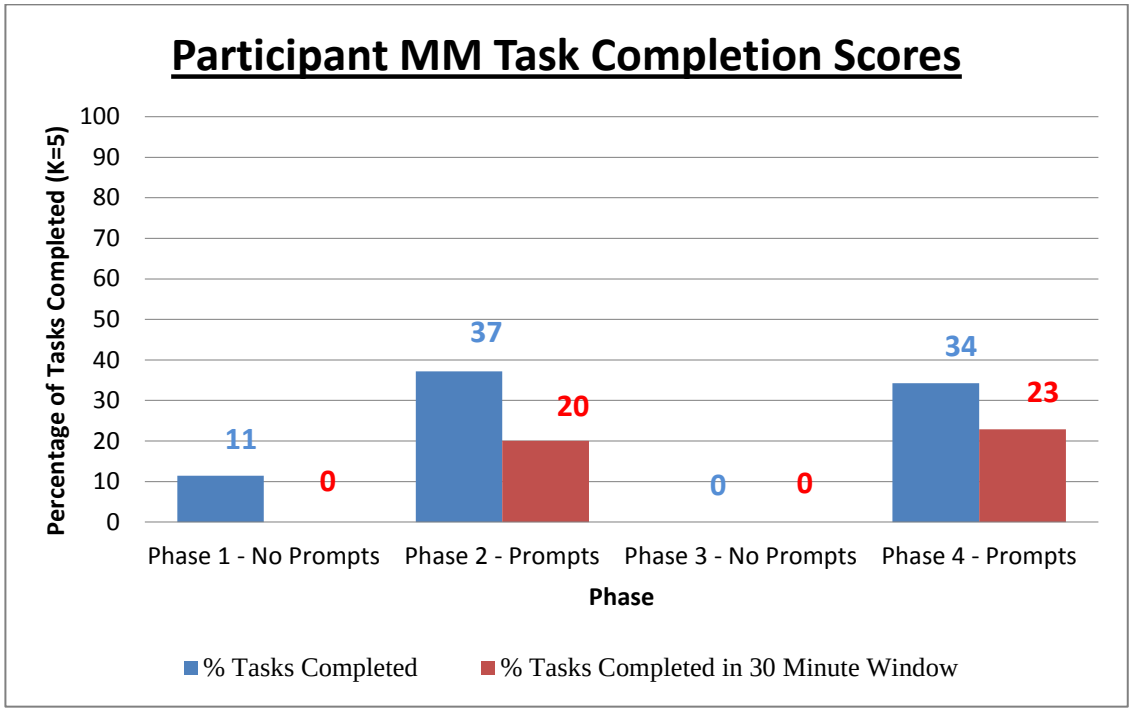


*Figure 8. Average task completion rates (Blue) and the average completion rates that occurred within 15 minutes either side of the tasks' identified time (Red).*

In summary, Mean Change Analysis suggests that MM was more likely to complete pre-set tasks when reminders were provided. Also of interest was that Phase 1 mean task completion rates and punctuality were better than in Phase 3 despite an absence of reminders in both. Across both phases MM's mean task completion rates were very low. He also found it difficult to be punctual in completing tasks at an identified time. Also of interest were the greater levels of task completion and punctuality in Phases 2 and 4, both of which provided time specific reminders via the smartphone device. This indicates that MM benefitted from the reminders to not only

complete more of the pre-set tasks, but also to complete them punctually. It must however be noted that even when reminders were provided, MM failed to complete 66% of tasks in Phases 2 and 4. This suggests that task completion is influenced by additional factors on top of time/event specific cueing difficulties.

*Memory & Caregiver Strain Questionnaires*

*Table 6. Memory & Caregiver Strain Questionnaire Scores – Participant MM*

| **Questionnaires Administered** | **Pre Intervention** | **Post Intervention** | **3 Month Follow Up** |
|---|---|---|---|
| Strategies In Smartphone Use<br>*0 = Low, 78 = High use* | 45 | 55 | 57 |
| Feeling About Memory<br>*0 = Negative, 78 = Positive Feelings* | 51 | 61 | 65 |
| Memory Mistakes<br>*0 = Few, 80 = Numerous Mistakes* | 39 | 35 | 45 |
| Memory Strategies<br>*0 = Few, 76 = Numerous Strategies* | 29 | 38 | 47 |
| Confidence in Coping<br>*0 = Low, 30 = High Confidence* | 25 | 20 | 23 |
| Modified Caregiver Strain Index<br>*0 = Low, 26 = High Strain* | 18 | 18 | 11 |

The scores recorded showed increased and continued use of smartphone over the intervention period and follow up. MM's positive feelings towards his memory functioning increased over the intervention period and again over follow up. However, his perception of memory mistakes initially decreased after the intervention, but over three months. Of particular interest is the increase in the number of strategies used to manage memory difficulties over the intervention and then again after follow up. MM's confidence in coping with memory difficulties fluctuated over the study, however caregiver strain fell over the three month follow up period.

In summary, while MM's task completion was low across phases he appeared to gain some benefit from the presence of reminders to help with task completion and punctuality of performance. He also showed increased use of the smartphone as a memory compensation aid over the course of the study and follow up. Positive

feelings towards memory, use of compensation strategies and confidence in coping with memory demands increased over the course of the study. Caregiver strain levels as reported by MM's father also fell over the follow up period. MM's scores suggest that he experienced a number of positive gains through use of the smartphone reminder system.

### *1.1.3. Case LL: Tumour & Epilepsy*

*Brief History*

LL is a 35 year old white British woman who lives with her partner and six year old son. She worked part-time in an administration role. LL presented as a gregarious outgoing character with an active home, work and social life. LL had come into contact with the local ABI service following referral from the neurologist who worked with her to manage epileptic seizures. LL's medical notes reported that she experienced a febrile convulsion in childhood and then in 2008 she experienced a number of partial and secondary generalised seizures of a tonic-clonic presentation. According to neurology reports this was thought to have emerged as a result of a superior temporal gyrus. After a number of severe seizures LL was placed on Lamotrigine (225mg daily) in an attempt to reduce their frequency and severity. On meeting with LL she reported experiencing difficulties in remembering recent conversations and tasks that she had set out to do earlier. She also said that she was easily distracted and fatigued quickly. At the time of assessment LL was not receiving any additional rehabilitation input and reported an absence of any mental health difficulties.

*Neuropsychological Profile*

LL scored within the *Average* range on a test assessing pre-morbid functioning. A summary of mild and moderate-marked impairments across cognitive domains is provided.

Moderate to Marked Impairment

- Prospective & retrospective memory

The neuropsychological assessment highlighted that on standardised testing, LL showed little impairment in functioning as compared with pre-morbid estimates. However, her reports of prospective memory difficulties that were significantly impacting on everyday functioning suggested that she was suitable for inclusion in the study. This was supported by her self-report PRMQ scores.

*Intervention Task Completion Scores*

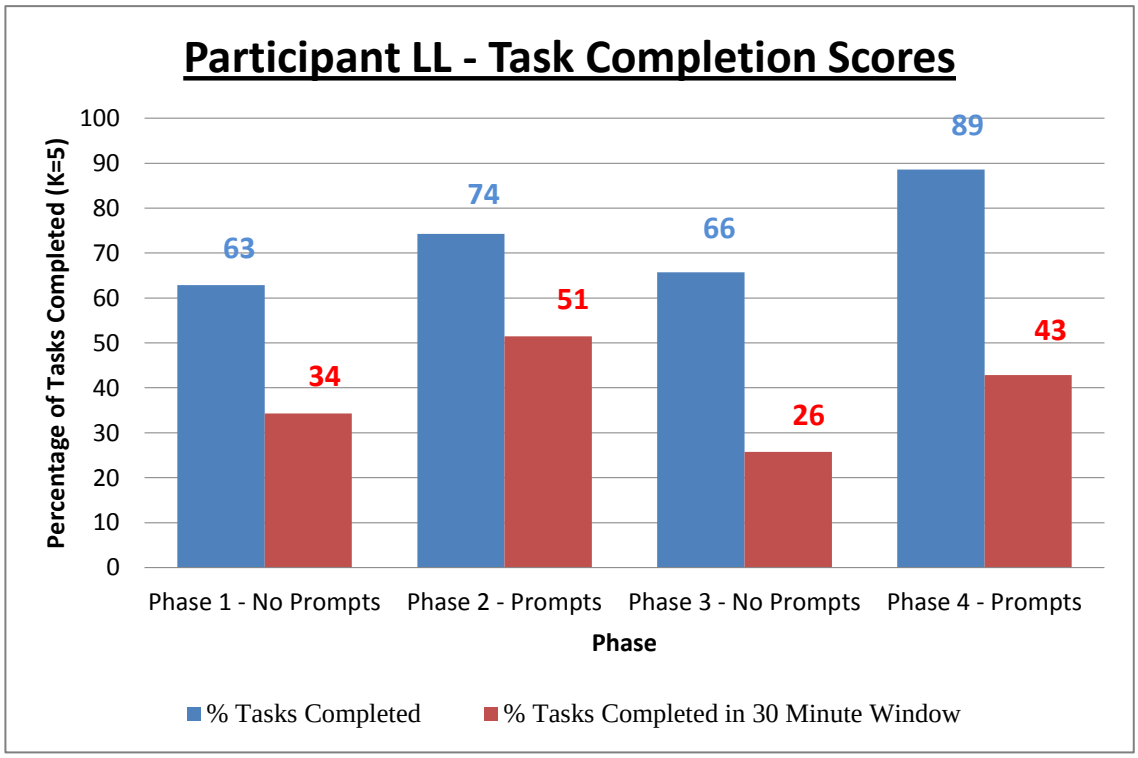


*Figure 9. Average task completion rates (Blue) and the average completion rates that occurred within 15 minutes either side of the tasks identified time (Red).*

Using a Mean Change Analysis, it was noticeable that LL showed greater task completion and punctuality of task completion when prompts were available. The scores recorded also showed an interesting pattern. In Phase 1 and Phase 3, task completion and punctuality rates were quite similar. This may indicate that LL was able to execute tasks without reminders in over half of the tasks each day. However, punctuality of this execution was only accurate in half of the tasks completed. It is interesting to note that even with reminders, there were occasions across Phases 2 and 4 in which she did not complete the task, or completed the task outside of the 30 minute window.

*Memory & Caregiver Strain Questionnaires*

*Table 7. Memory & Caregiver Strain Questionnaire Scores – Participant LL*

| **Questionnaires Administered** | **Pre Intervention** | **Post Intervention** | **3 Month Follow Up** |
|---|---|---|---|
| Strategies In Smartphone Use<br>*0 = Low use, 78 = High use* | 49 | 50 | 52 |
| Feeling About Memory<br>*0 = Negative Feelings, 78 = Positive Feelings* | 28 | 29 | 30 |
| Memory Mistakes<br>*0 = Few Mistakes, 80 = Numerous Mistakes* | 44 | 39 | 45 |
| Memory Strategies<br>*0 = Few Strategies, 76 = Numerous Strategies* | 41 | 44 | 51 |
| Confidence in Coping<br>*0 = Low Confidence, 30 = High Confidence* | 21 | 20 | 27 |
| Modified Caregiver Strain Index<br>*0 = Low Strain, 26 = High Strain* | 2 | 6 | 5 |

The scores recorded showed a small increase in smartphone use over the intervention and follow up period. Given that use was moderate prior to participation, the aim of this study was to try and optimise the benefits that this system may provide in everyday life. LL's positive feelings towards her memory functioning increased a little while perception of memory mistakes fluctuated. Use of memory strategies increased over intervention and follow up with a significant note being that confidence in coping with memory demands also increased. Care giver strain was reported to increase over intervention and then remained stable over the three month follow up period. However, carer strain levels were quite low to start and throughout.

In summary, LL appeared to benefit from smartphone reminders both with task completion and punctuality. While there was little change on smartphone use, it is hypothesised that she became more aware of its role as a compensatory aid. Confidence in coping with memory demands and strategies to manage difficulties increased. LL's scores suggest that she experienced a number of positive gains through use of the smartphone reminder system.

### *1.1.4. Case CC: Cardiac Arrest*

*Brief History*

CC is a 26 year old white British male who lived with his mother, father and younger sister. Prior to his injury, CC worked in a sports retail shop and enjoyed playing cricket to a good standard in a local league. Medical notes and clinical interview indicated that CC suffered a cardiac arrest following viral myocarditis while travelling in South East Asia in 2010. Following hypoxic brain injury, CC had a cardiac defibrillator inserted in February 2011. Due to suffering his ABI while he was in Thailand, the length of his PTA and his GCS were unknown and unreported in his medical records. However, we do know that he was unconscious for 24-36 hours and then in an induced coma for five days. On his return to the UK, CC was referred to the local ABI service for support with his cognitive, emotional and behavioural difficulties. He attended the Memory Group in which he developed compensatory strategies and started to use his smartphone as a memory aid. Over time his impulsivity and irritability subsided. CC and his family reported an absence of current or historical mental health difficulties.

In recent months CC had gained employment at the local golf club as a Greens Keeper Assistant and returned to playing cricket. At assessment he presented as a good humoured, intelligent young man. However, CC and his family reported that the injury had led to difficulties with new learning, attention, decision making, and the ability to complete tasks that he had set out to do earlier that day. Following participation in the intervention period, CC experienced a second incident during which while on holiday in Crete, his pacemaker responded to a drop in electrolytes which triggered a cardiac arrest. This resulted in hospitalisation for four days. Upon his return home, CC experienced no lasting effects of the incident and showed no signs of further cognitive impairment.

*Neuropsychological Profile*

CC scored within the *High Average* range on a test assessing pre-morbid functioning. A summary of mild and moderate-marked impairments across cognitive domains is provided.

Mild Impairment

- Visuo-spatial Construction
- Object naming

Moderate to Marked Impairment

- Immediate and delayed memory recall and recognition
- Prospective & retrospective memory
- Letter fluency, semantic fluency
- Switching attention and cognitive flexibility
- Planning and problem solving
- Processing speed

The neuropsychological assessment highlighted that CC was experiencing impaired functioning in the ability to complete everyday prospective memory tasks that rely on episodic and executive functioning processes. This suggested suitability for inclusion/selection for the study.

*Intervention Task Completion Scores*

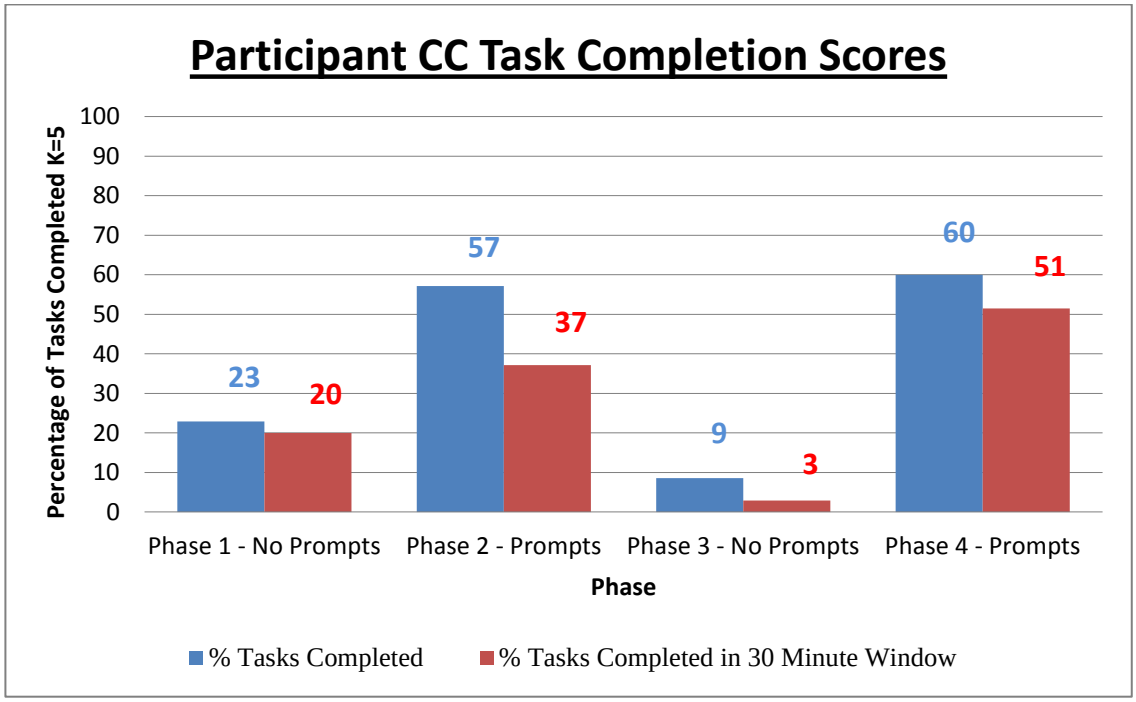


*Figure 10. Average task completion rates (Blue) and the average completion rates that occurred within 15 minutes either side of the tasks' identified time (Red).*

Mean Change Analysis of CC's performance across phases suggested that when he remembered to complete a task, he did so with relative punctuality. Task completion was however significantly better when he was aided by reminders from his smartphone.

*Memory & Caregiver Strain Questionnaires*

*Table 8. Memory & Caregiver Strain Questionnaire Scores – Participant CC*

| **Questionnaires Administered** | **Pre Intervention** | **Post Intervention** | **3 Month Follow Up** |
|---|---|---|---|
| Strategies In Smartphone Use<br>*0 = Low use, 78 = High use* | 47 | 60 | 50 |
| Feeling About Memory<br>*0 = Negative Feelings, 78 = Positive Feelings* | 29 | 35 | 26 |
| Memory Mistakes<br>*0 = Few Mistakes, 80 = Numerous Mistakes* | 37 | 40 | 24 |
| Memory Strategies<br>*0 = Few, 76 = Numerous Strategies* | 34 | 50 | 35 |
| Confidence in Coping<br>*0 = Low Confidence, 30 = High Confidence* | 13 | 21 | 28 |
| Modified Caregiver Strain Index<br>*0 = Low Strain, 26 = High Strain* | 6 | 8 | 5 |

The scores recorded showed an increase in smartphone use over the intervention which decreased a little during the follow up period. Given that smartphone use was moderate prior to participation, the aim of this study was to try and optimise the benefits that this system may provide in everyday life. CC's positive feelings towards his memory functioning fluctuated while his perception of memory mistakes decreased. The use of memory strategies also increased over intervention, yet fell back at follow up time. Of particular significance is that CC's confidence in coping with memory demands increased over the intervention and then again over follow up. On the other hand, caregiver strain increased during intervention and subsequently dropped back to the pre-intervention level.

In summary, CC appeared to benefit from smartphone reminders both with task completion and punctuality. While there was little change in smartphone use from pre-intervention to follow up, it is hypothesised that CC became more efficient in its potential use as a compensatory aid. Confidence in coping with memory demands also increased considerably. CC's scores suggest that he experienced a number of positive gains through use of the smartphone reminder system.

### *4.1.1. Case CW: Road Traffic Accident*

*Brief History*

CW is a 48 year old white British woman who lives with her husband and two teenage daughters. CW suffered her ABI when she was involved in a road traffic accident (RTA) in June 2011 whereby she was knocked from her bicycle. According to neurological reports this incident resulted in her suffering a right frontal focal haemorrhage, small contusion in right anterior frontal region and small avulsive facture of the occipital bone. Her PTA was 7 days and her GCS 11/15. She also suffered facial fractures, chest injuries and upper limb/lower limb trauma. CW received rehabilitation input at a regional rehabilitation unit for two months (August-October 2011) and made good progress in her recovery. She also received support with frequent panic attacks and was prescribed 50mg Sertraline and 0.5mg Lorazepam to help manage this anxiety. At the time of assessment for this study, CW reported a significant reduction in anxiety and scored in the Mild Range on the Beck Anxiety Index (BAI). Following her brain injury, CW returned to her role as a catering manager within a local school. On meeting with CW, she presented as being a very motivated individual with a huge desire to return to her previous active lifestyle despite her cognitive difficulties. CW and her husband reported that her main difficulties post injury were time management, sustained attention and recall of conversations and planned tasks. CW reported that she had no previous contact with mental health services. Following her ABI she had received psychological support with anxiety around using the road.

*Neuropsychological Profile*

CW scored within the *Average* range on a test assessing pre-morbid functioning. A summary of mild and moderate-marked impairments across cognitive domains is provided.

Mild Impairment

- Letter fluency, semantic fluency and object naming
- Prospective memory

The neuropsychological assessment highlighted that on standardised testing CW showed little impairment in functioning as compared with pre-morbid estimates. However, her reports of prospective memory difficulties that were significantly impacting on everyday functioning suggested that she was suitable for inclusion in the study. This was supported by her self-report PRMQ scores.

*Intervention Task Completion Scores*

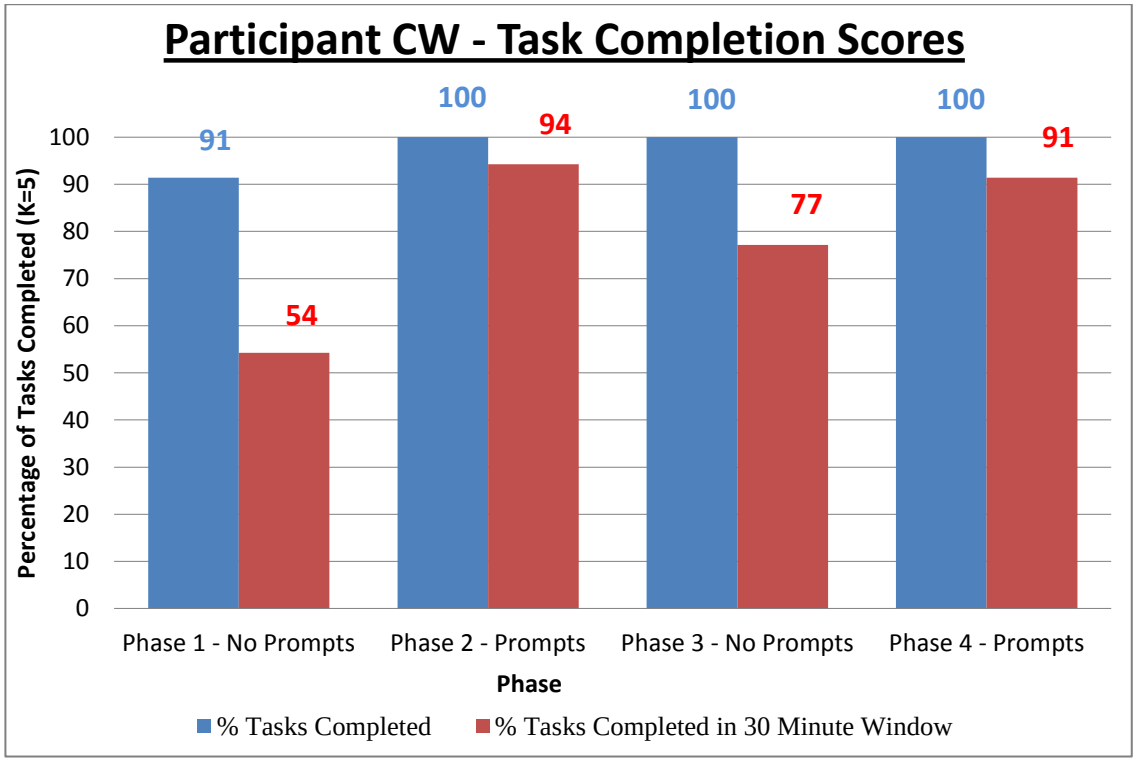


*Figure 11. Average task completion rates (Blue) and the average completion rates that occurred within 15 minutes either side of the tasks' identified time (Red).*

CW's performance across phases suggested she was able to remember to complete the majority of tasks with or without reminders provided by her smartphone. However, there were noticeable improvements in terms of punctuality of task completion when cuing from the smartphone was present in Phases 2 and 4. This may suggest that

CW's prospective memory difficulties emanate from deficits in executive functioning rather than episodic memory capacities. This is consistent with her self-reports of difficulties.

*Memory and Caregiver Strain Questionnaire Scores*

*Table 9. Memory & Caregiver Strain Questionnaire Scores – Participant CW*

| **Questionnaires Administered** | **Pre Intervention** | **Post Intervention** | **3 Month Follow Up** |
|---|---|---|---|
| Strategies In Smartphone Use<br>*0 = Low use, 78 = High use* | 37 | 44 | 49 |
| Feeling About Memory<br>*0 = Negative Feelings, 78 = Positive Feelings* | 35 | 32 | 26 |
| Memory Mistakes<br>*0 = Few Mistakes, 80 = Numerous Mistakes* | 58 | 53 | 65 |
| Memory Strategies<br>*0 = Few Strategies, 76 = Numerous Strategies* | 55 | 49 | 43 |
| Confidence in Coping<br>*0 = Low Confidence, 30 = High Confidence* | 29 | 27 | 30 |
| Modified Caregiver Strain Index<br>*0 = Low Strain, 26 = High Strain* | 7 | 11 | 11 |

The scores recorded showed an increase in smartphone use over the intervention and over follow up. CW's positive feelings towards her memory functioning fell after intervention and then follow up, perhaps due to an increased awareness of everyday memory difficulties. Her perception of memory mistakes decreased during intervention, however increased again over follow up. The use of memory strategies also fell over intervention and follow up, perhaps due to greater dependence on one strategy, rather than a range of strategies. Confidence in coping with memory demands initially fell over intervention, but then increased over follow up. Given that CW's confidence in coping was high to start, there was minimal change over the study. Caregiver strain increased during intervention and remained at the same level after follow up.

In summary, CW appeared to benefit from reminder prompts to aid punctuality of task completion. While her scores across quantitative measures fluctuated, she did report a considerable increase in use of the smartphone as a memory compensation aid. CW's scores suggest that she experienced a number of positive gains through use of the smartphone reminder system.

### *4.1.2. Case DR: Accidental Fall*

*Brief History*

DR is a 23 year old white British man who at the time of starting the study was commencing a fitness instructor training qualification. According to medical notes, DR sustained right post parietal cerebral contusions and a traumatic subarachnoid haemorrhage when he fell from a multi-storey car park in October 2011. He also suffered facial injuries, a fractured mandible, left distal diaphysis, lung contusions and a fracture of the glenoid fossa right scapula. His PTA was 24 days and his GCS score was unknown as it was not recorded in his medical notes. DR engaged in assessment at the local ABI service in 2011, but opted not to receive any rehabilitation. In July 2012 he was referred to the service to receive support with managing his cognitive difficulties with the aim of finding employment. Prior to sustaining a brain injury, DR had worked in a number of professions. On leaving school he played professional and semi-professional football both in the UK and in Europe. On meeting with DR at assessment, he presented as an active young man who was motivated to engage in employment and social activities as soon as he was in position to do so during screening for the study DR reported that he experienced difficulties in new learning, sustained attention, fatigue, and completing planned activities. DR reported an absence of any mental health difficulties prior to injury.

*Neuropsychological Profile*

DR scored on the border of the *Low Average/Average* range on a test assessing pre-morbid functioning. A summary of mild and moderate-marked impairments across cognitive domains is provided.

Mild Impairment

- Immediate memory recall and recognition
- Switching attention and cognitive flexibility
- Planning and problem solving
- Processing speed

The neuropsychological assessment highlighted that on standardised testing DR showed mild impairment in functioning as compared with pre-morbid estimates. However, reports of prospective memory difficulties significantly impacting on everyday functioning suggested that he was suitable for inclusion in the study. Despite self-reports of prospective memory difficulties, these were not captured on the PRMQ. In view of said inconsistencies in performance and self-reporting, the decision to participate was left with DR. He requested to participate in the study.

*Intervention Task Completion Scores*

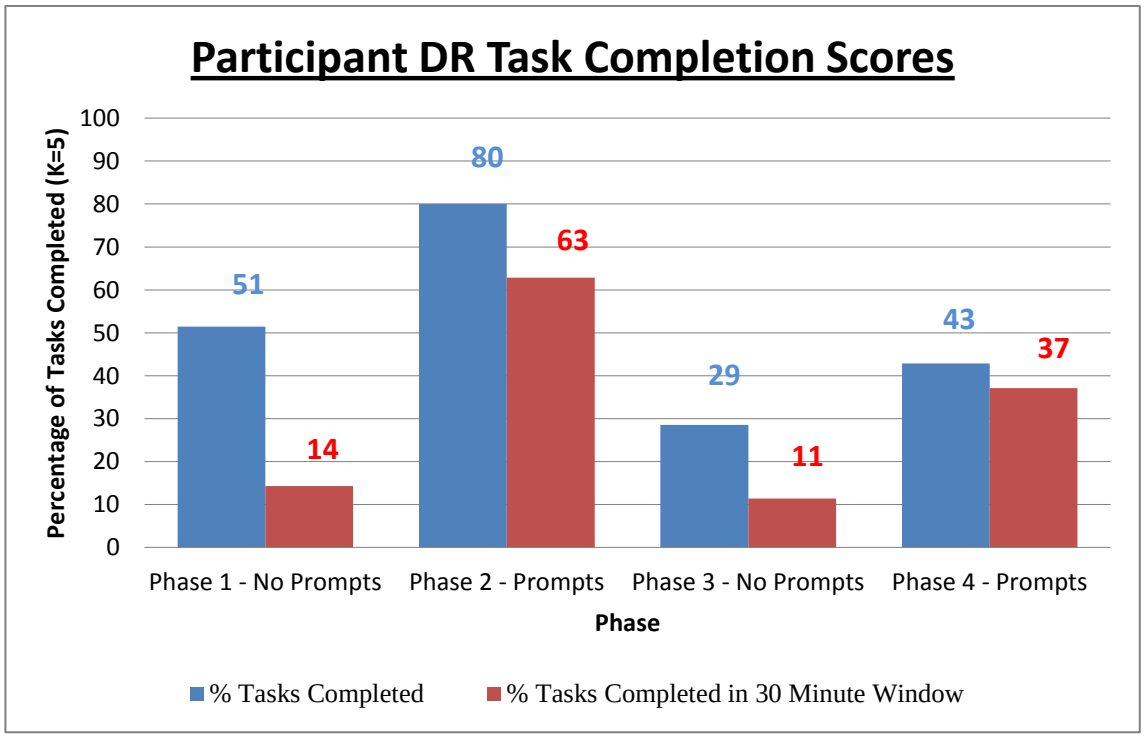


*Figure 12. Average task completion rates (Blue) and the average completion rates that occurred within 15 minutes either side of the tasks' identified time (Red).*

Mean Change Analysis suggests that when DR remembered to complete a task, he did so with relative punctuality. Task completion was however significantly better when he was aided by reminders from his smartphone. This was particularly evident in his performance in Phase 3 whereby it is likely he was no longer closely monitoring the task list as he may have done in Phase 1, due to awareness that his responses were being recorded. It is also important to note that during Phases 3 and 4, DR had

started a period of classroom based training which placed greater demands on his memory and executive processing.

*Memory & Care Giver Strain Questionnaires*

*Table 10. Memory & Caregiver Strain Questionnaire Scores – Participant DR*

| **Questionnaires Administered** | **Pre Intervention** | **Post Intervention** | **3 Month Follow Up** |
|---|---|---|---|
| Strategies In Smartphone Use<br>*0 = Low use, 78 = High use* | 11 | 32 | 42 |
| Feeling About Memory<br>*0 = Negative Feelings, 78 = Positive Feelings* | 35 | 42 | 44 |
| Memory Mistakes<br>*0 = Few Mistakes, 80 = Numerous Mistakes* | 58 | 58 | 63 |
| Memory Strategies<br>*0 = Few Strategies, 76 = Numerous Strategies* | 16 | 46 | 43 |
| Confidence in Coping<br>*0 = Low Confidence, 30 = High Confidence* | 19 | 25 | 27 |
| Modified Caregiver Strain Index<br>*0 = Low Strain, 26 = High Strain* | N/A | N/A | N/A |

The scores recorded showed a significant increase in smartphone use over the intervention and over follow up. DR's positive feelings towards his memory functioning also increased, however he was more aware of his memory mistakes. After intervention and follow up, DR was using a greater range of memory strategies and more frequently, and his confidence in coping with memory demands increased and remained high.

In summary, DR appeared to benefit from smartphone reminders to aid task completion and in particular, the punctuality of completing pre-set tasks. He reported increased use of memory strategies in general and a greater level of confidence in coping with demands on his memory. On the whole, it may be suggested that DR gained a number of benefits through use of the smartphone reminder system.

## 4.2. Impact of Smartphone System Questionnaire - Thematic Analysis

Perceptions of the impact that smartphone reminder prompts had on participants' daily lives varied, however, a number of overarching themes emerged from the responses of those who participated and their partner/relative. These have been separated into 'Global' (expressed by a number of participants and caregivers) and 'Unique' themes (expressed by a small number of participants or caregivers) (Braun & Clarke, 2006) (see Appendix 20 for Summary of Themes).

### *4.2.1. Global Themes*

'Supports Task Completion'

This theme captures the ability of participants to carry out tasks that they had previously planned when receiving smartphone reminders. Not only does it refer to completion of the pre-set task, but also to the ability to complete it at the intended time. This functional skill is important due to the secondary consequences that increased task completion can have on activity level, self-efficacy, dependence on others and goal achievement. There were 16 references by participants and five references by caregivers alluding to the smartphone system supporting task completion. Quotes included:

'*I feel I am remembering things I need to do due to receiving the prompts' (MM)*

*'I am able to do more activities because of the reminder. I can complete tasks that I need to do' (CC)*

*'I noticed that when she was reminded by the smartphone, she was able to carry out the task' (LL's partner)*

*'Promotes Independence'*

This theme captures the ability of participants to complete pre-identified tasks without the need to be reminded by family, friends, or partners around them. This sense of increased independence is closely related to a perceived reduction of reliance on others to scaffold memory functioning. References made by participants and caregivers captured the impact of the smartphone system on freeing up time for caregivers. This also encouraged participants to feel able to complete everyday tasks that place demands on the memory without the need to rely on those around them for scaffolding. There were 12 references to this increased independence in those with ABI and 16 references by caregivers highlighting that their loved one appeared more self-reliant. Quotes included:

*'I hopefully don't rely on others so much (at work), meaning that they can do their jobs. At home I put reminders into my phone and it saves others from having to let me know what to do' (CW)*

*'The phone has taken over prompting me. The strain that was placed on my wife is transferred back to me. This is important in becoming independent; it's the aim of the game' (PH)*

*'He can be left for long periods alone as I know he will mostly do what the reminders from his phone tell him' (CC's Mother)*

*'Promotes Positive Mood & Wellbeing'*

This theme captures reports that the smartphone reminders had a positive impact on participants' mood and wellbeing. This includes an increased sense or perceived contentment, a sense or appearance of being more relaxed, and a reduction in anxiety around remembering to complete pre-identified tasks. This theme also captures an increased sense or perceived happiness in those with ABI. Participants made nine references to this, while five caregivers observed improved mood and wellbeing. The support of positive mood and wellbeing can be important given the

vulnerability in the ABI population to suffer from psychological difficulties such as anxiety and depression. Quotes included:

*'I like the fact that I do not have to struggle to remember everything that I need to do. I always look at my phone calendar the day before to make sure I know what I'm doing the next day. This relaxes me as I know that I won't forget things' (LL)*

*'She is far happier now that she has her smartphone to remind her to do things she would have otherwise forgotten' (CW's husband)*

*'Increases Confidence'*

This theme captures the impact that the smartphone reminder system had on participants' increased confidence in being able to meet demands placed on their prospective memory. This increased confidence may be attributed to a perceived competency in being able to use compensatory aids to manage memory tasks. Caregivers also reported a perceived change in participants' confidence in managing their memory difficulties more independently using the smartphone reminder system. Confidence in coping with memory demands may be linked with an increased willingness to identify everyday goals, explore new situations and try out tasks that would have previously appeared too daunting. This process is integral to neuropsychological rehabilitation. Low confidence and self-esteem is a common obstacle to progress in working towards goals post ABI. There were five references to increased confidence made by participants and three references of a perceived upward shift in confidence made by caregivers. Quotes included:

*'I am more confident that I will be able to achieve or attempt a task because I know that I will have a prompt to help me' (PH)*

*'CW is far more confident in remembering everyday tasks as a result of the prompts she receives through her smartphone' (CW's husband)*

### *4.3. Unique Themes*

*'Reduces Stigma'*

This theme captures the qualities that a smartphone reminder system provides to those with prospective memory difficulties. The portable nature of smartphones, in addition to the widespread use of smartphones for multiple purposes, makes this system discrete and accessible throughout the day. These qualities enable reminders to be entered into the smartphone either directly or remotely through the internet. These reminders can then be programmed and activated as participants go about their daily lives. Stigma is a common reason for attrition of compensatory aids (Baldwin et al., 2011). This theme highlighted that some participants and caregivers believe the device is less exposed to potential stigma around using memory compensation aids. Quotes included:

*'As the smartphone is always in his pocket it means that it not only reminds him constantly but he can update it anytime that he is out. The phone also has the ability to be updated by other people through their own systems' (CC's mother)*

*'Maintains Dignity'*

This theme captures participant and caregivers feelings that the smartphone reminder system acts to maintain the dignity of those with prospective memory difficulties. The indirect manner in which reminders can be provided can reduce reliance on face to face prompting of participants by family, friends and partners. This at times can be perceived as nagging and a reminder to the participant that they are dependent on another person in order to go about their everyday life. The smartphone reminder system provides opportunity for indirect prompting, and self-prompting through self-programming of the reminders given. This may be linked with increased self-efficacy, reduced dependence on others, increased confidence in coping, and a willingness to identify and move towards rehabilitation goals.

'*In having the reminders through his smartphone is so much more dignified than having post-it notes and whiteboards everywhere' (PH's wife)*

*'Because I don't nag him so much he is more content and will respond better when I do have to ask him to remember to do something' (CC's mother)*

*'Pressure to Complete Tasks'*

This theme is in reference to the potential for smartphone reminders to be distracting and also lead to a perception of increased pressure/stress to complete pre-identified tasks. The reminders throughout the day could lead to increased demands on the participant if they felt obliged to complete the tasks prompted for. This theme was raised by one participant who made the following quotes:

*'Getting the reminders put too much pressure on me to complete tasks as I have been very busy lately' (DR)*

*'Meaningful Reminders'*

This theme captured the reference by one participant that the reminders were most helpful when they were few in number and targeted to prompt tasks regarded as important or meaningful. This links with references made by Baldwin et al. (2001) who reported that continued use of compensatory aids is influenced greatly by the ability of the device to directly meet individual needs. This theme was raised by one participant who quoted:

*'I think it is a really good idea, but only for important things, not just reminders like are you going to the gym today?' (DR)*

The themes identified provide an interesting insight into participants and caregivers' perception of how the smartphone reminder system impacted on aspects of everyday functioning. The inferences drawn from these perceptions will be considered in the discussion.

Following participation in the intervention period, participants and caregivers were shown how to programme the calendar using the email synchronisation. They were then encouraged to use their smartphone as a memory reminder system for three months without input from the research team. Some of the caregivers were interested in the use of the email synchronisation while others were not. It was left to individual cases to decide how they would take on the system into their everyday life.

### 4.4. Smartphone Study - Three Month Follow Up

The focus of the three month follow up questionnaire was to assess whether participants and caregivers were still using the smartphone system. It also explored how they were using it, what barriers they had experienced, and whether individuals were likely to sustain its use. A follow up questionnaire aimed to provide insight into smartphone use in everyday life was administered outside of experimental conditions. Given the high attrition rates associated with memory compensation strategies, it was felt that an assessment of whether the system was still in use three months post study would provide insight into the practicality and motivation to integrate this system into everyday living situations. The results were as follows:

1. All of the participants and caregivers reported that they or their loved one continued to use their smartphone to assist with memory difficulties in the follow up period. Specific use included planning and organising appointments, managing weekly social and work activities, assisting with dinner preparation, reminders to carry out house chores, remembering birthdays, reminders to take medications, and assisting recall of conversations.

2. Two out of six participants and two out of five caregivers reported that they used the smartphone calendar email link up system to support participants' memory. One participant and partner reported use of the email link up to 30 or more occasions in a month. Another participant and mother reported use of the email link up around six to ten occasions in a given month. Four participants and three caregivers did not use the email link up.

3. Participants reported a number of barriers to using their smartphone as a reminder device. These included forgetting the phone, battery charge running low, phone or internet signal being inconsistent, software compatibility issues resulting in the phone failing to notify with an alarm when the reminder activated, and initial lack of confidence that manual reminders had been entered into the phone correctly.

4. Caregivers reported a number of barriers to using the email link up with the smartphone calendar. These included poor or inconsistent phone/internet signal,

lack of confidence in reminder entry into the email calendar, entry fatigue, limited use of email system by caregivers, and software compatibility issues resulting in failure of the phone to activate the alarm at the time of a reminder.

5. Participants reported that in order to use the smartphone more effectively as a memory aid, they may benefit from receiving on-going support around use of smartphone functions having a smartphone provided by ABI services, incorporating a task list system whereby tasks reminded for can be ticked completed, or being prompted again at a later point in the day. Another participant reported that they felt training in smartphone use was essential to successful take up and continued use of the device as a reminder system.

6. Caregivers reported that in order to use the email link up with the smartphone calendar there is a need for a reliable phone/internet signal. Some participants and caregivers reported that they did not feel the need to use the email link up due to limited use of email. One participant and father reported that there is a need for on-going support to ensure that the email link up with the smartphone is on-going and adjustments can be made if there are software compatibility issues.

7. Five participants rated the likelihood of continued use of their smartphone device to be very likely, with one participant rating on-going use to be between 'Perhaps-Very Likely'. All five of the caregivers who participated reported that they felt it 'Very Likely' that that their loved one would continue to use the system.

8. Two participants and their caregivers reported that they were 'Very Likely' to continue use of the email link up. One participant and their caregiver reported use of the email link up to be 'Perhaps-Very Likely'. One participant said that they would 'Perhaps' use the email link up, while two participants and caregivers said that email link up was 'Not Likely'.

*Summary of findings*

The three months follow up questionnaire feedback suggests that participants and their caregivers perceived the system to be of use in everyday life. The general consensus was that they would continue to use aspects of the system in the future. Some participants and caregivers reported that the email link up was of benefit, whilst others reported that they felt that it was not practical due to the demands placed on understanding of IT and use of email systems. A number of barriers to use were raised and suggestions as to improvements in the set up and monitoring of the system were provided. These will be discussed in more detail.

# 5. DISCUSSION

This section will discuss the research findings in relation to each hypothesis identified at the start of this study.

## 5.1. Research Hypotheses

*Primary Hypothesis*

**Hypothesis 1: There will be increased response rates to pre-set tasks when provided with prompts from the smartphone reminder function, as compared to when using the task list only.*

The collective mean response rates were higher when reminders were provided through the smartphone device rather than when participants used the task list only. The mean results across cases also showed that punctuality of response was higher when reminders were provided. When examining individual case scores it was noticeable that all participants performed better when reminders where in place, as compared to when they were absent. An interesting finding was that some participants completed tasks to a high level even when reminders were absent. These participants (PH, CW) reported that they spent a great deal of effort monitoring the task list when reminders were not available. They also noted that this monitoring became more difficult over the weeks as fatigue set in and effort levels dropped. This may account for lower scores in Phase 3 when the reminders were absent for a second time.

Another interesting observation was that even when task completion rates were close between reminder present/absent phases due to active monitoring, the punctuality of task completion was different between phases, with task punctuality being better when reminders were present. The recall of planned tasks can be compensated by active monitoring of task lists, however, punctuality places greater demands on executive functioning. Therefore, the difference in punctuality may have been due to deficits in executive functioning. This is consistent with the prospective memory (PM)

literature that suggests PM is reliant on both episodic memory of the task and the executive functioning skills that monitor and prompt execution of the task.

**Hypothesis 2: There will be a significant increase in scores on the Strategies of Smartphone Use Questionnaire (SSUQ) from pre to post-intervention, and from pre-intervention to three months follow up.*

There was a statistically significant change in scores between pre and post-intervention, and pre-intervention to follow up. Scores remained relatively stable from post-intervention to follow up. The SSUQ is a measure that looks to assess use of the smartphone to aid retrospective and prospective memory functioning. The result of this study suggests that participation in the intervention period showed an increase in use of the device to aid memory. These benefits were maintained following everyday use for three months. The SSUQ outcomes are consistent with self-reports by participants and their relatives/carers of an increased use of the smartphone calendar system to support everyday prospective memory tasks.

This finding suggests that despite having clinically impaired prospective memory functioning, participants were able to learn how to use their smartphone device as a compensatory aid. It is proposed that the take up and sustained use of the smartphone reminders suggests that participants recognised it to be a helpful system in scaffolding everyday functioning. Moreover, the ability of participants to integrate the smartphone into everyday functioning adds support for the proposal that well learnt skills remain protected from the impact of ABI. In this study, pre-morbid competency in smartphone use was integral to the introduction of this reminder system. The skills required to navigate, programme and respond to the device appeared to have been retained through intact implicit memory processes. This study encouraged use of these well learnt skills to help individuals compensate for episodic memory and executive functioning impairments that are central to prospective memory. It may be suggested that participants with impaired prospective memory can learn new skills, and in particular make use of existing well learnt skills to compensate for impairments. This is consistent with Baddeley & Wilson's (1994) proposal that implicit memory pathways can be used to learn new skills and make use of existing well learnt knowledge to compensate for memory difficulties in everyday tasks.

*Secondary Hypotheses*

**Hypothesis 3: There will be a significant increase in scores on the Feelings about My Memory Questionnaire (FMMQ) post intervention and at three months follow up in comparison with pre-intervention.*

This study found an absence of any statistically significant change in scores on the FMMQ. This measure was administered to assess whether introduction of the smartphone reminder system would have an impact on participants' perception of their memory performance. These results are unsurprising given that introduction of the smartphone is unlikely to change perception of memory itself, but rather the ability that one has to manage the memory difficulties they experience. This would not be captured on the FMMQ. On the other hand, the thematic analysis findings may show support for this in that participants and caregivers felt that they were more confident and more able to cope with everyday prospective memory demands due to their use of the smartphone system.

**Hypothesis 4: There will be a significant reduction in scores on the Memory Mistakes Questionnaire (MMQ) post intervention and at three months follow up in comparison with pre-intervention.*

The results of this study did not show a statistically significant change across pre, post-intervention and follow up scores on the Memory Mistakes Questionnaire (MMQ). This may be accounted for by the variation in perceived changes in memory mistakes across participants. Some reported that they had noticed an increase in everyday memory mistakes from pre to post-intervention and then at follow up. Other participants however reported a slight reduction in memory mistakes over the course of the study. It is hypothesised that the perceived increases in memory mistakes may be accounted for by participation in a study whereby participants were loaded with additional tasks to complete each day. Feedback on task completion rates was provided each week and at the end of the trial. One may therefore expect that the increase in everyday tasks and regular feedback may have increased perception of memory mistakes during this period. Others participating in the study may have felt that smartphone reminders actually reduced everyday errors. This is supported by

the thematic analysis in which some participants reported a sense that they were able to complete planned tasks with greater accuracy and punctuality than they had prior to the study.

**Hypothesis 5: There will be a significant increase in scores on the Memory Awareness & Strategies Scale (MASS) at post intervention and at three months follow up in comparison with pre-intervention.*

The results from this study found there to be an absence of any statistically significant change in scores on the MASS pre, post-intervention and at follow up. Some participants reported that they increased the frequency and range of strategies used to aid everyday memory functions. Other participants reported that introduction of the smartphone system led to a reduction in the range of strategies used as participants increasingly relied on the functions that the smartphone provided. This is consistent with themes reported by participants and caregivers. Participants reported that they increasingly used their smartphone to support a range of memory functions. Some participants found that use of the smartphone increased awareness of possible memory aids available and therefore encouraged uptake.

**Hypothesis 6: There will be a significant increase in scores on confidence in coping with memory difficulties as recorded in the Memory Mistakes Questionnaire (MMQ) at three months follow up in comparison with post-intervention.*

There was a significant increase in confidence reported between post-intervention and three months follow up scores. There was an absence of statistically significant changes in scores in confidence in coping with memory difficulties between pre and post-intervention, and between pre-intervention and three months follow up. However, it is hypothesised that participation in the study may have increased confidence in coping in some participants and reduced it in others. On the other hand, following completion of the intervention period, everyday use of the smartphone system led to significant increases in confidence. This is supported by the overwhelming feedback that emerged from the thematic analysis in which both participants and caregivers reported that the introduction of the smartphone system had led to a greater belief that participants could manage a range of situations placing demands on prospective memory functioning. It was reported that the

knowledge that the reminders could be pre-programmed or manually entered throughout the day reduced the level of pressure to recall activities or events. It is also proposed that the confidence measure used in this study may have suffered from a limited number of questions that looked to assess the scope of confidence in coping across multiple situations. This therefore may have restricted the study's ability to capture the full extent of participants' confidence change over the course of the investigation.

**Hypothesis 7: For those who have caregiver involvement, there will be a significant reduction in Modified Caregiver Strain Index (M-CSI) scores at three months follow up in comparison with pre-intervention.*

The results from this study showed an absence of any statistically significant changes in caregiver strain scores on the M-CSI. One may have predicted that caregiver strain scores reduced over time following the introduction of the smartphone reminder system. This premise was based on the theory behind caregiver strain. Teasdale et al. (2009) described caregiver strain in ABI to be linked with increased demands placed on caregivers following their loved one experiencing an ABI. In particular, prospective memory difficulties place demands on the caregiver to act as a compensatory aid for people with ABI, offering prompting and reminders throughout the day. Limited score change on the M-CSI index may be indicative of limited impact of the smartphone system on reducing demands placed on the caregiver. This hypothesis appears unlikely given the overwhelming reports by participants and caregivers of reduced dependency within the relationship in the thematic analysis. It may also be hypothesised that a lack of score change is due to the complex nature of caregiver strain in caregivers of people with ABI. Caregiver strain can increase with time as the caregiver develops their insight into the needs and dependency levels of those with ABI and realise that their loved one is unlikely to completely return to their functioning level prior to injury. Therefore, the introduction of the smartphone may have reduced dependency in some domains; however, this clashes with the increasing awareness on the caregivers' part that a level of support may be required for life.

It may also be hypothesised that a lack of score change was due to the relatively short time-scale of the study, and the limited range of questions within the M-CSI

questionnaire itself. It could be hypothesised that caregiver strain may gradually reduce over time if the smartphone is a constant in the participant's life. It may also be the case that the M-CSI fails to capture the complexity of caregiver strain and therefore small changes in dependency experienced on the caregivers' part may not be captured on the measure. It is proposed that the thematic analysis results may indicate that the introduction of the smartphone reminders system, with or without email link up, may actively reduce dependency of the participant on the caregiver. Over time this may have secondary implications on both participants and caregivers' lives as the individual with ABI starts to take on more responsibility for organising and managing everyday tasks, planning of events and independently re-engaging in occupational activities. This may have a positive impact on mood levels, which in turn may also reduce emotional demands placed on the caregiver. It would be of interest to assess caregiver strain levels over a prolonged period of time. If the smartphone reminder system can bring about primary and secondary benefits, one may expect to see longer term reductions in caregiver strain.

The results of this study showed that implementation of the smartphone technology significantly increased response rates to pre-set tasks. With the exception of the results from the SSUQ and the Confidence in Coping with Memory Difficulties Questionnaire, the quantitative results of the questionnaires from this study show no significant changes between pre-intervention, post-intervention and follow up scores. However, the thematic analysis provided a qualitative exploration of the perceived impact that the smartphone reminder system had on participants' everyday lives. Some of the key themes have been touched upon already, however, further consideration of how these themes may impact on participants and their caregivers' lives may add to our understanding of the potential benefits and limitations of the smartphone reminder system.

## 5.2. Themes Identified

*'Supports Task Completion'*

The most significant finding of this study was that task rate completion increased when participants were prompted using the smartphone technology. It was commonly reported that reminders enabled participants to complete pre-identified tasks on the task list. Considering this on a wider everyday level, the ability to enter reminders for tasks into ones' smartphone calendar may empower participants to engage in occupational and social activities (Svoboda et al., 2009; 2010; 2012).

*'Promotes Independence'*

It was noted that in feeling more able to complete everyday tasks without relying on caregivers, participants experienced a greater sense of independence. The ability to programme and receive reminders through the smartphone reduced reliance of caregivers to provide prompting. In the knowledge that prompts were stored and available at the times required, participants reported that they felt able to rely on this external aid to a greater degree. This turn placed fewer demands on caregivers. It is hypothesised that long term use of this system could act to reduce the demands on caregivers, potentially reducing the level of perceived burden. In addition, participants' increased sense of independence may have positive implications for self-esteem, act as a protective factor against psychological distress and reduce the potential for family system breakdown (Ponsford et al., 1995). As independent functioning is crucial in rehabilitation, this increased sense of having the ability to manage one's own difficulties could facilitate goal setting which is seen as integral in the adjustment process post ABI.

*'Promotes Mood & Wellbeing'*

Participants and caregivers reported a sense that the introduction of the smartphone reminder system had a positive impact on the mood of those with ABI. More specifically, the knowledge that the smartphone contained information and the capability to prompt task completion at a set time left people feeling more relaxed and

content. While one participant reported that reminders lead to increased levels of perceived pressure and therefore was stressful at times, the majority reported feeling a reduction in the demands placed on their memory system. It has been well documented that anxiety and stress (particularly rumination) can occupy a significant portion of one's attention. In the case of those with impaired attention (i.e. the participants involved in this study), this drain on limited resources may have played a role in further inhibiting prospective memory functioning (Evans, 2010). If the smartphone reminder system can reduce the demands placed on attention and memory processes, it is theoretically feasible that the ability to remember and execute pre-identified tasks not specifically programmed into the calendar could be improved. At the very least, a reduction in rumination around potential memory errors may have positive implications for the emotional wellbeing of participants, and perhaps the caregivers they live with.

As noted earlier, the ability to independently engage with everyday tasks coupled with lower anxiety/stress around forgetting may play a significant role in protecting those with prospective memory difficulties from developing a sense of hopelessness around their future prospects. This may be of great significance in reducing risk of prolonged low mood or anxiety.

*'Increases Confidence'*

Participants reported feeling more confident in their ability to use tools and strategies at their disposal to get the task done, rather than entering a state of learned hopelessness or anxiety when faced with tasks placing demands on prospective memory. This theme of confidence appeared to be linked with an increased sense of control and resourcefulness. It might be helpful to consider how this links with lower levels of stress and anxiety given that control and perceived resources to cope with demands are thought to mediate the experience of these emotions. It could be suggested that the smartphone acts to both compensate for the prospective memory difficulty itself and to provide secondary gains in placing this tool at the disposal of the person with ABI, which in turn increases perceived resourcefulness in managing everyday difficulties without the need for others help. In the long term, it is hypothesised that this may encourage participants to set new goals that extend their current skill and functioning level, thus supporting the rehabilitation process.

There has been increasing interest in memory compensation literature around the issue of what supports uptake and prolonged use of memory aids in the ABI population. Baldwin et al. (2011) reported on a number of factors that encourage or discourage memory aid longevity. One such finding was that of device portability. This was a theme that interestingly emerged in our qualitative questionnaires. Participants and caregivers reported that they found the smartphone to be easy to carry and use at any time. Due to the multiple functions that a smartphone provides, it is an electronic accessory that is carried at all times in modern culture. The internet capability also makes it possible for the smartphone calendar to be updated remotely at any time through 3G connectivity.

*'Reduction Stigma'*

In the thematic analysis there were two positive references to the portability of the smartphone reminder system. Both caregivers stated that the device was easy to carry at all times, easy to programme on the move, and the duel function of a phone reduced stigma placed on their loved one as smartphone is an everyday gadget that the general population carry around. In a qualitative study published by Baldwin et al. (2011), it was reported that compensatory aids were more likely to be taken up and maintained if they were perceived to be non-stigmatising, easy to use, and easy to integrate into one's lifestyle, affordable and clearly evidencing that the benefits of use outweigh the costs of implementation. This issue of smartphones being portable may well map onto these themes. As a reminder device it is familiar, used for a multiple purposes in everyday life and most importantly portable as highlighted by those participating in the study. This portability may play a big role in long-term use in comparison with alternative aids such as notebooks, sticky notes, calendars and dairies. As noted by the caregivers of two participants, the multiple functions of the smartphone increases the likelihood that people will have it with them at all times, thus optimising the reminder function's effect. While portability and the non-stigmatising properties of the smartphone reminder system were raised as positive attributes, it was also noted that this system felt like a more dignified way of being prompted than alternative strategies such as verbal reminders from caregivers.

*'Maintains Dignity'*

A number of caregivers commented on the way the smartphone is a dignified means of prompting their loved ones. A common issue within ABI rehabilitation is the increased reliance by those who have been affected on their family and friends (Ponsford et al., 1995; Teasdale et al., 2011; Sander et al., 2005). This may place strain on caregivers and encourage a process whereby prompting is perceived as a nagging by both the caregiver and the individual with memory difficulties. It is hypothesised that this repeated prompting by loved ones may leave those with prospective memory difficulties feeling de-skilled and create tensions in the family system. The indirect programming and prompting function of the smartphone may reduce these family tensions and provide the scaffolding required for everyday functioning in a dignified way. This in turn may have positive secondary implications on self-esteem, independence, caregiver strain, and confidence in coping with memory difficulties.

*'Meaningful Reminders'*

One participant made reference to the need for reminders to be meaningful to the individual who receives them. The prospective memory literature suggests that in order for people to successfully recall and execute pre-planned tasks, there must be motivation to do so (Ellis and Kvavilashvili, 2001). Participant DR highlighted that the prompts were only effective if he deemed the prompted task to be meaningful or important. The smartphone provides the memory cue at the time wanted; however, there must be a desire to complete the action being prompted. It may therefore be hypothesised that effective integration of this system is not about programming multiple reminders for all varieties of everyday tasks, but rather identifying which tasks people have motivation to complete and prompting these only. Without meaningful reminders the system becomes redundant because the execution of the task fails due to an individual's motivation rather than their memory, self-monitoring, or cueing deficits.

In summary, the smartphone reminder system offered a number of positive outcomes for participants and their caregivers. These included perceived improvements in the ability to complete pre-identified tasks, increased independence, increased

confidence, improved mood and wellbeing, reductions in perceived stigma, and a sense that participants' dignity was maintained when reminders were provided. These outcomes suggest that this system is perceived to be of great benefit for those with prospective memory difficulties. However, an additional consideration when using this system is the need to ensure that reminders are meaningful and do not place additional stress on the participant receiving them. Perhaps this may best be addressed through personalising the nature and frequency of prompts to the individual using the system. This approach is supported by the flexible and easy to access programming through the handset itself or the email link up.

### 5.3. Follow-Up Questionnaire Feedback

The thematic analysis highlighted a number of positive outcomes perceived by both participants and their caregivers. As highlighted by Baldwin et al. (2011), it is not uncommon for new compensatory aids to be introduced and used for a short period, only to fall away after a couple of months due to issues of cost, stigma, portability, perceived effectiveness and so on. In order to assess whether the smartphone reminder system with email link up would suffer from attrition, participants were asked to continue everyday use of the device as they saw fit. A follow up questionnaire was then administered to assess whether the system was still in use after three months, what it was used for and whether on-going use was likely.

The results from the follow up questionnaire suggested that participants continued to use the device in everyday life. This is perhaps due to the system's capacity to meet the needs of the user in a socially accepted, discrete, easy to use, and portable manner. Not only that, the device is familiar and used in everyday life for a number of other functions, i.e. phone calls, emails, texts, internet browsing. Specific usages focused on prompting of everyday tasks, planning social and work activities. With regards to the email link up, some caregivers of participants involved in the study reported that the ability to programme and view their loved ones' calendar reduced demands on face to face reminding which can often be seen as nagging. However, not all participants' caregivers made use of this system. Some of the reasons for this included limited use of email in everyday life and limited caregiver IT knowledge. It may also be hypothesised that the time needed to programme the email calendar

further added to the demands placed on caregivers. Without a period of testing out of the system, it may have been difficult for caregivers to see the cost-benefit gains of this activity over time.

A number of barriers to using the smartphone reminder system and the email link up were raised within this questionnaire. It was reported that the email link up at times failed to result in a notification alarm sounding when the planned event was activated in the phone calendar. On later inspection, this was the result of software incompatibility with a specific email provider. This has since been resolved; however, it raised an interesting and important issue around the need for on-going technical support that may be required in order for the system to run effectively. Another participant raised the issue of there being a need for more prolonged training in the smartphone and email functions in order to encourage everyday use due to lack of confidence in programming events at the start of the follow up period.

The follow up questionnaire highlighted that all but one of the participants and their caregivers were 'Very Likely' to continue use or encourage to use the smartphone reminder system. One participant stated they were just below 'Very Likely' on a 1-5 rating scale, rating themselves at 4. This is a positive indication of the impact that participants and caregivers perceived the system to have on their everyday lives and the lives of their loved ones. With regards the email link up system, this was used frequently and with good effect by two participants and their caregivers. The other participants in the study felt that the manual input in the smartphone was sufficient.

A positive learning outcome gathered from the follow up feedback was the importance of assessing each person individually as to the suitability of introducing the smartphone reminder system. In doing so, introduction of the email link up can be considered, the degree of training in smartphone calendar functions moderated, and the need for on-going system support collaboratively agreed. Each individual's ABI is different, families and relationships can vary, and the impact that the injury has on one's ability to engage in everyday tasks will be unique to that person. This provides a dilemma to clinicians. In an NHS climate whereby time to conduct assessment is limited at present, the additional time needed to conduct a smartphone assessment may be difficult. However, there are potential rehabilitation benefits if this assessment is conducted. By ascertaining the cognitive needs of clients and matching these with

smartphone technology functions, everyday gains can be achieved. The question then posed is how may this technology, training and support be delivered with rehabilitation services and by whom.

With the conclusions from the thematic analysis and follow up questionnaire in mind, it is important to consider how the results from this study may contribute to the growing body of literature in the area of prospective memory compensation in ABI.

### 5.4. Contribution of Findings to Existing Research

The findings reported in this study provide further support for outcomes shown in Svoboda et al. (2009, 2010, 2012) and MacDonald et al. (2011). Task completion increased when reminder prompts were provided by the smartphone, while there is also suggestion through the qualitative feedback that lower levels of dependence/reliance were placed on caregivers. Previous research has focused on moderate to severe memory impairments, whereas this study shows similar benefits of smartphone reminders for those with mild to moderate ABI. Given the difficulties with running studies using large samples within ABI population, this case series adds to the growing literature that suggests that people with similar prospective memory difficulties may benefit from using the smartphone as a discrete reminder device.

The qualitative and quantitative elements of this study aimed to improve our understanding of the perception of participants and caregivers who use this system. While we are unable to say that smartphone reminders brought about a significant reduction on caregiver strain within this study, it was reported that relationships between participants and caregivers were less dependent and therefore less strained. Independence and reduced demands on the caregiver have been linked with reduction in risk of strain and burnout (Teasdale et al., 2011; Sander et al., 2005; Ponsford et al., 1995). Also of interest within this study was the qualitative and quantitative reporting that confidence in coping with memory difficulties increased from post-intervention to three months follow up. This supports the findings reported by Svoboda et al. (2012) and encourages further investigation of the links between confidence in coping and quality of life in future research projects.

These findings also contribute to Baldwin et al's (2011) conclusions that in order for compensatory devices to be effective they needed to take account the following: cost, stigma, ease of use, motivation factors and flexibility. The outcome of this investigation adds support for the on-going use of smartphone technology to scaffold prospective memory (PM) functioning in a way that is congruent with these influencing factors. The smartphone is increasingly affordable, stigma is minimised due to the widespread use of this device within the general population and smartphone interfaces are increasingly intuitive and adaptable to fit the preferences of the user. Motivation to use the device can be developed through positive results through trial periods of use, while the flexibility of use allows individuals to determine how they want to be reminded, when, through what form and who by.

## 5.5. Study Limitations

Despite the positive extent to which this investigation builds upon the existing research findings in this area, it is important to also reflect on the limitations of this design when drawing conclusions from this study. The main limitations identified in the methodology are outlined for consideration.

*Questionnaires Selected*

The quantitative questionnaires used within this study were selected based on their use in similar studies published by Svoboda et al. (2010; 2012). However, in conducting this study it may be suggested that some of the measures selected lacked sensitivity to change over a short period of time (e.g. Modified Caregiver Strain Index). Others such as the Memory Mistakes Questionnaire and the Memory Awareness & Strategies Scale lacked standardisation, making it difficult to compare scores to the general population. There is also the issue that by using questionnaires, there is an implicit assumption that participants are able to recall how they have experienced life over the last two weeks in order to answer the questions asked. This task in itself presented a challenge to the participants taking part. Despite the criticisms of the questionnaires used, it must be held in mind that standardised questionnaires assessing these aspects of memory and everyday functioning are

limited in this field due to the heterogeneous nature of the ABI population. A common challenge to ABI research is that interventions aim to improve non-specific but important factors in everyday life. These consist of increased participation in daily living, occupational and social activities, improved wellbeing, sense of identity and so forth. These factors are difficult to measure, yet play a central role in neuropsychological rehabilitation.

In an attempt to compensate for the limitations in the quantitative questionnaires used, a self-report qualitative measure was also constructed to capture themes of participants and caregivers' perceived impact of the smartphone system over the course of the intervention period. These questions were open ended and drawn up based on common areas of impairment or change post-ABI (Ponsford et al., 1995; King and Tyerman, 2008). A potential critique of the construction of the questionnaire may centre on the use of focused open ended questions rather than non-focused questions about the experience of the smartphone reminder system and its effects. The rationale for selecting questions that looked to explore dependence, mood, task completion and confidence was due the frequency with which these are reportedly affected within the brain injury literature. In addition, these areas of change were highlighted in the pilot study and the service user who collaborated in developing this design felt that having questions around these areas would offer participants the opportunity to think about the smartphone effects. The pilot study also raised that open ended questions can be a little ambiguous and challenging for those with mild to moderate cognitive difficulties post ABI. There are therefore strengths and potential weaknesses in the qualitative questionnaire used.

*Duration of Intervention Period*

Two challenges that presented themselves when designing this study centred on the length of intervention period and the number of tasks to be completed each day. In principle, the longer the intervention periods and the greater number of tasks, the increased likelihood of gaining an accurate picture of reminder prompting effects on task completion. However, it was predicted that a longer intervention period with more tasks may have also increased risk of attrition. Feedback during the pilot prior to the study suggested that more than a month of daily task completion as part of the

study may have led people to feel fatigued or unmotivated to give their optimal performance. It was also suggested that more than five tasks a day may have placed excessive demands on participants while fewer than five would have limited the ability to record a consistent response rate over each phase of the intervention period. Qualitative reports from participants after the intervention period were consistent with the view from the pilot study. Participants on the whole expressed a feeling that the task number and length of trial were most suitable. In addition to the duration period, there was also a limitation in the ability to control the frequency and intensity of prompting by caregivers. In an effort to minimise this effect, all caregivers were asked to provide as few prompts as possible and try to maintain consistent over the four phases.

*Inclusion Criteria*

A potential critique of this study is the inclusion criteria that stated that participants were required to currently own and have pre-morbid experience in using a smartphone. This pre-morbid use was deemed important based on theoretical models of memory which indicate that well learnt skills are more robust to the effects of ABI (Baddeley and Wilson, 1994). The nature of the study looked to tap into these well learnt skills to support one's ability to complete everyday tasks. It was considered that some potential participants could have previously owned a smartphone, but no longer had access to one at the time of the study. Unfortunately, due to the small research budget for this study, there was limited opportunity to provide the device for the period of the intervention and follow up. A recommendation emerging from the outcomes of this study may be that services could be encouraged to consider offering clients a trial period using a loaned smartphone to explore potential benefits of this system. This would provide opportunity for that individual to consider whether investment in the technology itself may be beneficial. However, given the current financial climate within NHS services, this may present a challenge. With these limitations in mind, services should be encouraged to consider how they may support clients to trial the use of smartphone technology. Any financial costs may offset against the potential savings it may bring about in relation to demands from clients and caregivers to support memory compensation, emotional well-being

and independent functioning. Further investigation may be an option to explore in order to confirm this.

This study also focused on individuals who had mild to moderate ABI rather than severe ABI. The severely impaired population have been studied in research recently published by Svoboda et al. (2010; 2012). It was felt that repeating a similar design to Svoboda (2010; 2012) with the same population would add little to the growing research in this area. In addition, with severe ABI, an extended period of intense training is required in order to train or adjust clients' use of the smartphone. The timescale for the scope of this study made this intense training period problematic. It was therefore deemed unfeasible in the scope of this study, but as previously highlighted, research evidence published by Svoboda et al. (2010; 2012) had previously shown positive outcomes for introducing a smartphone based reminder system in those with severe memory difficulties.

### 5.6. Clinical Implications

Holding the limitations of this investigation in mind, it may be beneficial to consider what the clinical implications may be for the findings reported in this study. The findings reported may indicate that participants perceived an increased task completion, improved sense of confidence in coping with memory difficulties and reduced reliance on others around them when smartphone reminders were available. This may suggest that smartphone reminders support progress towards primary goals such as everyday task completion, while also protecting against secondary challenges posed to psychological wellbeing for individuals with ABI. Neuro-rehabilitation services have increasingly sought to address both everyday functional difficulties through the introduction of compensatory aids and delivery of memory groups and to promote adjustment and maximise independent functioning through the provision of psychological support. Given the ever increasing ownership and use of smartphones, it may be hypothesised that in the coming years there will be an increasing number of clients who require rehabilitation support and have pre-existing well learned knowledge of smartphone device functions.

The smartphone reminder system can be set up within an hour and monitored remotely. There is scope for family, friends and even professionals to input into a client's calendar remotely (with consent naturally), which in turn may support the rehabilitation process through memory scaffolding. The frequency and intensity of support can be withdrawn gradually as the individual becomes more confident in managing the system themselves. It is proposed that this system can be set up in a group setting where training is provided to introduce how the system works and the potential benefits and drawback that it may bring. Individual set up of the system based on their needs could be then delivered over a few one to one intervention sessions. The caregiver would be involved in this process where appropriate.

To deliver this compensatory aid in this format is theoretically grounded, cost-effective and increasingly evidence based. A limitation to introducing this system into rehabilitation settings may be the requirement for psychologists and rehabilitation staff to understand smartphone technology and feel confident to set it up and monitor its effectiveness with the individual and their family. In addition, there are start-up costs in terms of professionals' time, smartphone purchase and running costs, and long term monitoring and technical support. Given the current NHS climate of increased caseloads and fewer resources, careful consideration of how this intervention programme can be delivered is required. Nevertheless it is worth considering because health professionals are also being asked to 'transform' care, by using new and innovative ideas which improve efficiency and effectiveness. With these challenges in mind, it is proposed that this intervention is offered in the following ways. Firstly, staff would require training in assessment, set up and monitoring of the smartphone reminder system. Perhaps this training could be supervised by Clinical Psychology, but implemented by Rehabilitation Assistants. Clients' suitability for this programme could be integrated into the initial assessments of their rehabilitation needs. The intervention itself could be set up as part of a Memory Group Programme and followed up through individual sessions. There are also options of including service users who have had success with the system in delivery of training to future interested clients.

It is also possible that this intervention could be supported through a 'buddy' system whereby an experienced user of the system assists new users maximise the user of Smartphone promoting. This would tap into peer support approaches which the NHS

is encouraging due to its empowering benefits for the clients and cost-effective because it requires less and less staff input.

While the research evidence base is limited at present, it would be interesting to monitor the use of this system to build a larger sample of outcome data. In addition, the use of the smartphone reminder system may also provide secondary benefits as alluded to in the themes reported for this investigation around caregiver reliance and client confidence. Given the demands on services to support clients' psychological, physical and functional wellbeing, the smartphone reminder system may provide secondary reductions in psychological distress experienced by those using the service. At present this is hypothetical; however future research may seek to explore this potential correlation further. Additional future directions for research are discussed below.

### 5.7. Future Directions for Research

A number of research investigations could be initiated to follow on from these findings. As noted above, it would be beneficial to explore whether similar results would be reported with a larger sample for a longer intervention period. This may add power to the statistical and clinical significance of findings reported. Inclusion of carer strain indices and a quality of life index may provide further understanding as to the long term benefits of smartphone reminders for both clients and their caregivers/family. This could be implemented by introducing the smartphone system as part of a Memory Group for all clients who enter the neurological service. By monitoring task completion rates and assessing the areas addressed in this study, a larger sample of data could be collected over a period of 6-12 months.

In the short-term, a 12 month follow up using the same measures and the follow up questionnaire could be administered to this case series sample to assess whether (a) pre and post-smartphone introduction gains are maintained, (b) whether people are still using the device and its reminder functions regularly. It may also be interesting to develop software for the smartphone that has an interactive function with regards to the reminders. If reminders are presented, the individual may wish to dismiss or 'snooze' this task until later. Collecting data as to whether dismissed items or 'snoozed' items are completed when prompted later would give a more accurate

reflection as to how individuals respond to prompting in real life situations. If engaged in a task, any additional tasks that are cued at this time may not be responded to and later forgotten. If a cue is then repeated at a later time, it is more likely that the task will still get executed. The ability to recycle cueing dependent on whether the task can be carried out immediately would increase the likelihood that a greater proportion of pre-programmed tasks would be completed. There are emerging smartphone applications that can perform this function available to download across the majority of smartphone devices.

The developments in smartphone application programmes and increasing use of this technology in everyday life presents an exciting and promising future for its potential use as compensatory aids in brain injury rehabilitation. Technology companies are interested in working with health professionals to think about these issues and cross-disciplinary research of this type should be encouraged. Moreover, there is a government drive to turn research findings into clinical reality (for example CLARHC).

## 6. CONCLUSION

The results from this investigation suggest that the introduction of smartphone based reminder prompts can bring about positive gains in the ability to complete pre-set tasks and to complete them punctually. The quantitative measures administered also suggest that introduction of the smartphone reminders increases use of the phone as a compensatory aid for everyday prospective and retrospective memory based tasks. This change in behaviour is also maintained after a three months follow up. Prolonged use of the smartphone system appears to increase confidence in coping with prospective memory tasks; however this gain is only evident on quantitative measures after a three months follow up. Qualitative reports from participants and their caregivers do however suggest that confidence gains are perceived within one month of use. The benefit of using qualitative as well as quantitative measures is that feedback from participants and caregivers post-intervention gives a more detailed insight as to the perceived benefits that the system has had on participants and caregivers' lives.

The thematic analysis also indicated that introduction of the smartphone system reduced participant reliance/dependence on caregivers and encouraged more independent management of everyday activities. This in turn had a positive impact on participants' mood with individuals reporting that they felt less anxious/stressed about memory functions and happier in themselves. The three month follow up showed that participants continued to use the reminder system when the intervention period was over. On the other hand, this investigation demonstrated that the email link up with the smartphone calendar only suited some individuals. Factors that dictated this centred on IT literacy of caregivers and the frequency of email use among those taking part. Participants who used the email system reported a strong likelihood that they would continue to use it in the future. Those participants who preferred to programme the smartphone directly also reported that they would continue to use this system going forwards in their life.

The outcomes of this investigation add to growing literature in this area and raise questions as to how the potential benefits of this smartphone reminder system (with and without email link up) can be delivered to people with prospective memory difficulties in a clinical setting. Training of neuro-rehab professionals in the assessment, set up and maintenance of this system will play a key role in this process. While there may be initial start-up demands on services, the potential long term benefits could be significant; particularly given the increasing role that smartphone technology may play in transforming the way in which healthcare is delivered.

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## 8. APPENDICES

## Appendix 1 – Literature Review Search Terms

Memory Aids AND brain injury

Memory Aids AND prospective memory

Prospective memory AND brain injury

Memory difficulties AND brain injury

Memory compensation AND brain injury OR prospective memory

Reminders AND memory difficulties OR brain injury

Reminder cues AND memory difficulties OR brain injury

Smartphone AND brain injury OR memory difficulties OR reminder cues OR compensation strategies

PDA's AND memory difficulties OR reminder cues OR brain injury

Compensation strategies AND memory

Phone AND brain injury

Phone AND compensation strategies OR memory difficulties OR reminder cues

Caregiver OR caregiver strain AND brain injury

Assistive technology AND memory difficulties OR memory compensation OR memory strategies

Brain injury AND quality of life OR independence

Memory difficulties AND quality of life OR independence

Brain injury AND emotional wellbeing OR psychological wellbeing

Memory difficulties AND emotional wellbeing OR psychological wellbeing

Care giver AND emotional wellbeing OR psychological wellbeing

## Appendix 2 – ABI Classification

Table showing Post Traumatic Amnesia (PTA) & Glasgow Coma Scale in Relation to Brain Injury Severity Classification

| **Severity** | **GCS** | **PTA** |
|---|---|---|
| Mild | 13-15 | <1 hour |
| Moderate | 9-12 | 1-24 Hours |
| Severe | 3-8 | 1-7 Days |
| Very Severe | N/A | 1-4 Weeks |
| Extremely Severe | N/A | >4 Weeks |

King & Tyreman (2008)

## Appendix 3 – Participant Demographics

*Table showing Participant Demographics*

| Participant number | Age | Gender | Ethnicity | Aetiology | Time Post Injury | Carer/Family Participation | Smartphone |
|---|---|---|---|---|---|---|---|
| **PH** | 55 | Male | White British | RTA – Diffuse Axonal Damage | 20 Months | Wife | IPhone |
| **MM** | 24 | Male | White British | Epilepsy | *** | Father | Nokia Lumia |
| **LL** | 35 | Female | White British | Brain Tumour & Epilepsy | 48 Months | Partner | IPhone |
| **CC** | 25 | Male | White British | Hypoxic Brain Injury Cardiac Arrest | 19 Months | Mother | IPhone |
| ***KS** | 51 | Male | White British | RTA – Bi-frontal Contusions | 38 Months | Wife | Samsung Galaxy |
| ***WM** | 60 | Male | White British | CVA Right Parietal & Occipital Haemorrhage | 9 Months | Wife | IPhone |
| **CW** | 48 | Female | White British | RTA - Right Frontal Focal Haemorrhage | 13 Months | Husband | Samsung Galaxy |
| **DR** | 24 | Male | White British | Fall | 24 Months | N/A | IPhone |

*Withdrew from the study

RTA = Road Traffic Accident, CVA= Cerebrovasuclar Accident

## Appendix 4 – Ethics Approval & Amendments

Ethics Approval - NRES Committee East of England - Cambridge South

NHS
Health Research Authority
NRES Committee East of England - Cambridge South
Victoria House
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Cambridge
CB21 5XB

Telephone: 01223 597656
Facsimile: 01223 597645

15 May 2012

Mr Scott Ferguson
Trainee Clinical Psychologist
Cambridge & Peterborough NHS Foundation Trust
Dclinpsy Department
College Lane Campus
University of Hertfordshire
AL10 9AB

Dear Mr Ferguson

| | |
|---|---|
| **Study title:** | **Smartphone Technology: Gentle reminders for everyday tasks in those with prospective memory difficulties following brain injury'** |
| **REC reference:** | **12/EE/0125** |
| **Protocol number:** | **TBC** |

Thank you for your letter of 16 April 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair in consultation with another member.

**Confirmation of ethical opinion**

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

**Ethical review of research sites**

NHS sites

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

**Conditions of the favourable opinion**

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

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

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

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

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

*Sponsors are not required to notify the Committee of approvals from host organisations*

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

**Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

| *Document* | *Version* | *Date* |
|---|---|---|
| Covering Letter | | 27 February 2012 |
| Evidence of insurance or indemnity | Zurich Municipal | 02 August 2011 |
| GP/Consultant Information Sheets | 1 | 22 March 2012 |
| Investigator CV | Mr Scott Ferguson | 05 February 2012 |
| Letter from Sponsor | Prof John Senior | 27 February 2012 |
| Other: Academic Supervisor CV | Emma Berry | 23 February 2012 |
| Other: Key Investigator CV | Mr Daniel Friedland | 01 February 2012 |
| Other: Wechsler test of adult reading | | 12 April 2012 |
| Other: The Hayling and Brixton Tests | | |
| Other: Trail - Making Tests - From the MOCA: Montreal Cognitive Assessment | | |
| Other: UK Adaptation Record Form A | RBANS | |
| Other: BDI - II | 0154018390 | |
| Other: BAI | Product Number 0154018422 | |
| Other: Verbal Fluency Pages 499 - 502 | | |
| Participant Consent Form: Carer | Version 2 | 12 April 2012 |
| Participant Consent Form: Participant | Version 2 | 12 April 2012 |
| Participant Information Sheet: Research Study Information Sheet - Participant | Version 2 | 12 April 2012 |
| Participant Information Sheet: Research Study Information Sheet - Carer/Friend/Relative | Version 2 | 12 April 2012 |
| Protocol | 1 | 22 March 2012 |

| | | |
|---|---|---|
| Questionnaire: Demographics | 1 | 22 March 2012 |
| Questionnaire: Impact of Smartphone Reminder Cues Questionnaire | 1 | 22 March 2012 |
| Questionnaire: Impact of Smartphone Reminder Cues Questionnaire - Carer | 1 | 22 March 2012 |
| Questionnaire: Memory Mistakes Questiionnaire | | |
| Questionnaire: Managing Memory Difficulties | | |
| Questionnaire: Memory Mistakes | | |
| Questionnaire: Memory Strategies | | |
| Questionnaire: Modifies Caregiver Strain Index | | |
| Questionnaire: Demographics Questionnaire | Version 2 | 12 April 2012 |
| Questionnaire: Smartphone Use Questionnaire | Version 2 | 12 April 2012 |
| Questionnaire: Prospective & Retrospective Memory Questionnaire | Crawford, Henry, Ward & Blake (2006) | |
| REC application - Submission Code 96946/297501/1/531 | | |
| Referees or other scientific critique report | Nick wood - Proposal Feedback | 17 February 2012 |
| Response to Request for Further Information | From Scott Ferguson and Mr Frieland | 16 April 2012 |
| Summary/Synopsis | Flowchart, 1 | 22 March 2012 |

**Statement of compliance**

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

**After ethical review**

Reporting requirements

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

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

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

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

| 12/EE/0125 | Please quote this number on all correspondence |
|---|---|

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

Yours sincerely

**Dr Leslie Gelling**
**Chair**

Email: april.saunders@eoe.nhs.uk

*Enclosures:* "After ethical review – guidance for researchers" *[SL-AR2]*

*Copy to:* *John Senior, University of Hertfordshire*
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*Dr Mark Whiting, Hertfordshire Community Trust*
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19 June 2012

Mr Scott Ferguson
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Dear Mr Ferguson

| | |
|---|---|
| **Study title:** | **Smartphone Technology: Gentle reminders for everyday tasks in those with prospective memory difficulties following brain injury'** |
| **REC reference:** | **12/EE/0125** |
| **Protocol number:** | **TBC** |
| **Amendment number:** | **Amendment #1 (minor)** |
| **Amendment date:** | **15 June 2012** |
| **Amendment detail:** | **A minor amendment has been made to the wording of question 4 of the documents 'Impact of smartphone reminder cues questionnaire' and 'Impact of smartphone reminder cues questionnaire (carer)'** |

Thank you for your letter of 15 June 2012, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

**Documents received**

The documents received were as follows:

| Document | Version | Date | |
|---|---|---|---|
| Notification of a Minor Amendment | Amendment #1 (minor) | 15 June 2012 | |
| Questionnaire: Impact of smartphone reminder cues questionnaire (carer) | 2 | 14 June 2012 | |
| Questionnaire: Impact of smartphone reminder cues questionnaire | 2 | 14 June 2012 | |
| Questionnaire: Impact of smartphone reminder cues questionnnaire (carer) | 1 | 22 March 2012 | |
| Questionnaire: impact of smartphone reminder cues questionnaire | 1 | 22 March 2012 | |

**Statement of compliance**

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

**12/EE/0125: Please quote this number on all correspondence**

Yours sincerely

**Peter Drew**
**Committee Co-ordinator**

E-mail: peter.drew@eoe.nhs.uk

*Copy to:* *Dr Mark Whiting, Hertfordshire Community Trust*
*John Senior, University of Hertfordshire*

Health Research Authority
**NRES Committee East of England - Cambridge South**

Victoria House
Capital Park
Fulbourn
Cambridge
CB21 5XB

Tel: 01223 596907
Fax: 01223 597645

24 September 2012

Scott Ferguson
Trainee Clinical Psychologist
Hertfordshire Community Trust
Acquired Brain Injury Team
Hertfordshire Neurological Unit
Jacketts Field
Abbots Langley
Hertfordshire WD5 0PA

Dear Scott

| | |
|---|---|
| **Study title:** | **Smartphone Technology: Gentle reminders for everyday tasks in those with prospective memory difficulties following brain injury'** |
| **REC reference:** | **12/EE/0125** |
| **Protocol number:** | **TBC** |
| **Amendment number:** | **Amendment #2 (minor)** |
| **Amendment date:** | **10 August 2012** |
| **Amendment detail:** | **(1) The intervention period is reduced to 4 weeks for administrative reasons (2) As a result of positive recruitment uptake and the reduced intervention period we would like to carry out a three month follow-up post intervention** |

Thank you for your letter of 10 August 2012, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

**Documents received**

The documents received were as follows:

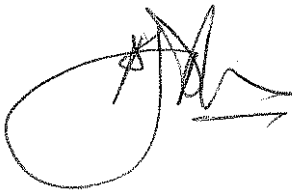
| Document | Version | Date | |
|---|---|---|---|
| Notification of a Minor Amendment | Amendment #2 (minor) | 10 August 2012 | |
| Participant Consent Form: Carer consent form | 3 | 10 August 2012 | |
| Participant Consent Form: Participants consent form | 3 | 10 August 2012 | |
| Participant Information Sheet: Carer/friend/relative | 3 | 10 August 2012 | |
| Participant Information Sheet: Participant | 3 | 10 August 2012 | |
| Research protocol flowchart | 2 | 10 August 2012 | |

**Statement of compliance**

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

**12/EE/0125: Please quote this number on all correspondence**

Yours sincerely



**Peter Drew**
**REC Assistant**

E-mail: peter.drew@eoe.nhs.uk

Health Research Authority
**NRES Committee East of England - Cambridge South**

Victoria House
Capital Park
Fulbourn
Cambridge
CB21 5XB

Tel: 01223 596907
Fax: 01223 597645

31 October 2012

Mr Scott Ferguson
Trainee Clinical Psychologist
Cambridge & Peterborough NHS Foundation Trust
Psychology Department
College Lane Campus
University of Hertfordshire
AL10 9AB

Dear Mr Ferguson

| | |
|---|---|
| **Study title:** | **Smartphone Technology: Gentle reminders for everyday tasks in those with prospective memory difficulties following brain injury'** |
| **REC reference:** | **12/EE/0125** |
| **Protocol number:** | **TBC** |
| **Amendment number:** | **Amendment #3 (minor)** |
| **Amendment date:** | **30 October 2012** |
| **Amendment detail:** | **The two impact of smartphone use questionnaire documents (for participants and for carers) have been replaced with two similar but new and renamed documents that have been altered to focus on whether the smartphone continues to be in use as a reminder device** |

Thank you for your letter of 30 October 2012, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

**Documents received**

The documents received were as follows:

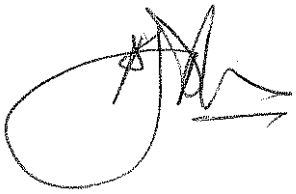
| Document | Version | Date | |
|---|---|---|---|
| Notification of a Minor Amendment | Amendment #3 (minor) | 30 October 2012 | |
| Protocol flow chart | 2 | 10 August 2012 | |
| Questionnaire: Impact of smartphone reminder cues questionnaire | 2 | 14 June 2012 | |
| Questionnaire: Impact smartphone reminder cues questionnaire (carer) | 2 | 14 June 2012 | |
| Questionnaire: Smartphone reminder system participant (3 month follow-up questionnaire) | 1 | 28 October 2012 | |
| Questionnaire: Smartphone reminder system partner/relative (3 month follow-up questionnaire) | 1 | 28 October 2012 | |

**Statement of compliance**

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

**12/EE/0125: Please quote this number on all correspondence**

Yours sincerely



**Peter Drew**
**REC Assistant**

E-mail: peter.drew@eoe.nhs.uk

## Appendix 5 – R&D Approval

NHS Hertfordshire Community Trust provided Research & Development Approval

**Peace Children's Centre**
Peace Prospect
Watford
Herts
WD17 3EW

Tel: 01923 470662
Fax: 01923 470618

mark.whiting@hchs.nhs.uk

**Date:** Monday 28th May 2012

**To:** Scott Ferguson,
13A Catherine Street,
St Albans,
Hertfordshire,
AL3 5BJ.

Dear Scott,

Re: **Smartphone technology: the applications of synchronised calendar functions in cueing event completion.**

Further to my letter of January 25th, I am now able to confirm receipt of the following:

- Formal confirmation from Leslie Gelling, Chair of NRES East of England, of a favourable ethical opinion to your proposed study (REC Reference 12/EE/0125 – letter dated 15th May 2012).
- Email correspondence from Jill Hazan, Professional Lead Clinical Psychology, confirming her formal support of your proposal on behalf of the Hertfordshire Neurological Service. Jill has also confirmed that there will be no additional costs to Hertfordshire Community Trust arising from your study.

As part of this approval to proceed, you will be required to:

- Provide information to HCT, as and when requested, as part of the Trust annual research monitoring process;
- Provide HCT with a summary of the research once it is completed;
- Inform HCT about all publications relating to the research; and
- Acknowledge HCT in all publication relating to the research.

Hertfordshire Community NHS Trust looks forward to working with you on this research project.

Please do not hesitate to contact me if you require any further information.

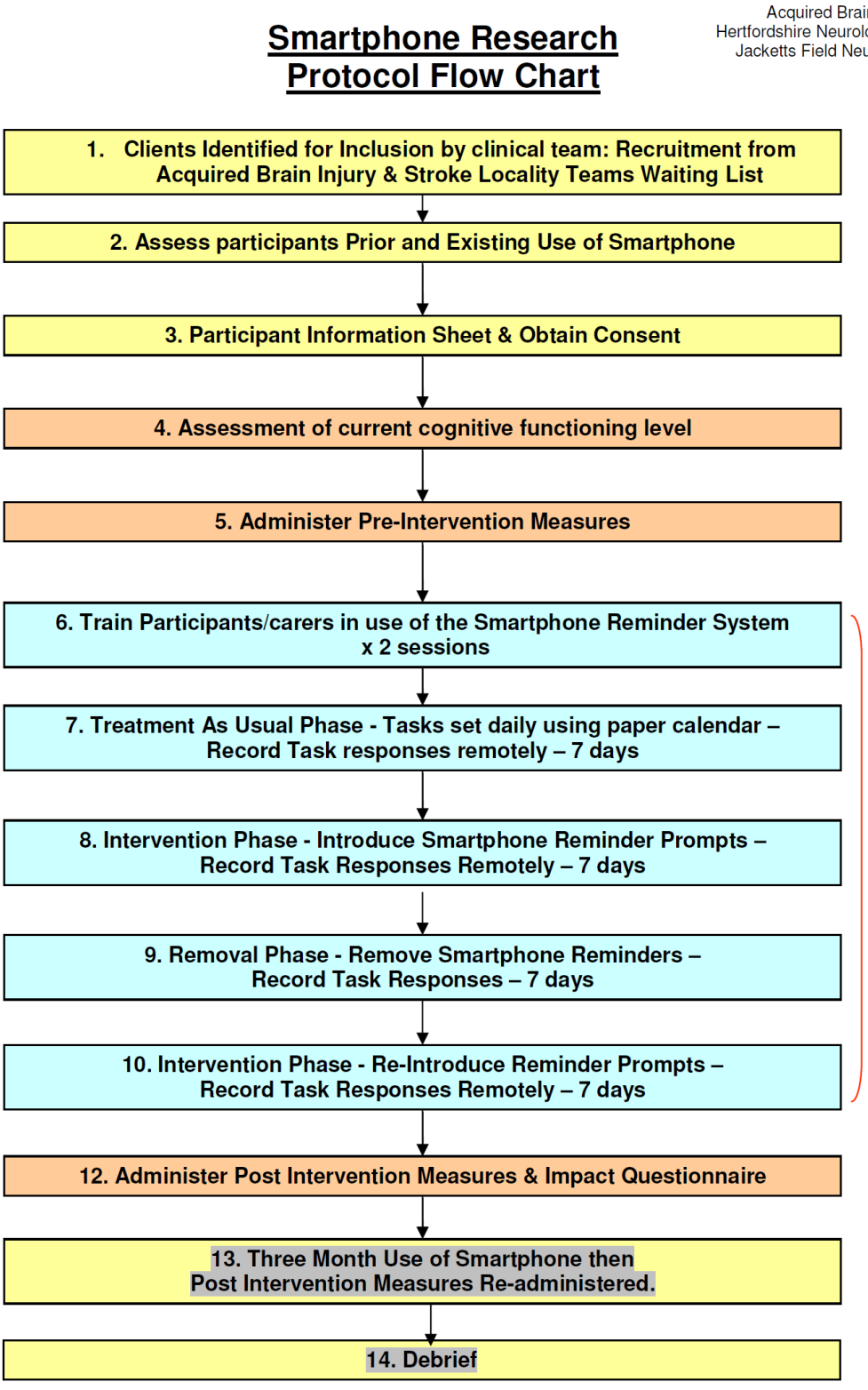
Kind regards,

**Mark Whiting,Consultant Nurse,Children's Community and Specialist Nursing**

c.c. Hemal Desai, Medical Director, Hertfordshire Community NHS Trust.
Jill Hazan, Professional Lead Clinical Psychology, Hertfordshire Neurological Service.

## Appendix 6 - Study Flowchart

Acquired Brain Injury Team
Hertfordshire Neurological Service
Jacketts Field Neurological Unit
Hertfordshire
WD5 0PA




Page **1** of **1**

## Appendix 7 – Participant/Caregiver Information Sheet

*Smartphone Reminders Study: Version 3* *Date: 10.08.12*

Hertfordshire Community NHS
NHS Trust

Acquired Brain Injury Team
Hertfordshire Neurological Service
Jacketts Field Neurological Unit
Jacketts Field
Abbots Langley
Hertfordshire
WD5 0PA
Tel: 01923 299100
Fax: 01923 299101

## Research Study Information Sheet – Carer/Friend/Relative

**Title**:

*'Smartphone Technology: Gentle reminders for everyday tasks in those with prospective memory difficulties following brain injury'*

**Introduction**

I am a Trainee Clinical Psychologist conducting research as part of my Doctoral Qualification at the University of Hertfordshire. This is an information sheet outlining a research study I am hoping to conduct with people who have suffered memory difficulties as a result of a brain trauma. As part of this research, I am hoping to involve individuals who provide a caring role to those close to them who have recently sustained a brain injury.

**Invitation paragraph**

You are being invited to take part in a research study due to the supporting role you play in your friend/relative who has sustained a brain injury. Before you decide whether you wish to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your friend/relative who has sustained the brain injury. Please ask us if there is anything that is not clear to you after reading this information sheet. Thank you for reading this.

**What is the purpose of the study?**

This is a study which will look at whether reminder prompts provided through a Smartphone will help people who have sustained a brain injury to remember to complete pre-set tasks. Prompts will be entered into the participant's phone calendar using an email calendar on the PC. The details will be transferred to the phone using the internet. Completion of set tasks will be compared between when the reminders are given, and when they are not. Set tasks will include making phone calls, sending text messages, or sending a letter. This will record the response rate to prompts given. The study will also look at whether using these reminders reduces the demands placed on family/friends or carers of those with brain injury.

**Why have I been invited to take part?**

You have been chosen for this study as you provide support and care for a relative or friend who experiences memory difficulties as a result of their brain injury. There will

be up to 7 other participants (and carers) with similar difficulties who may take part in this study.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you receive.

**What will happen to me if I take part?**

In the role of support/carer you would be asked to complete a two short questionnaire at the start and three questionnaires at the end of the study. These questionnaires will explore the impact taking on this supportive/caring role has had on your wellbeing. In addition, one of the questionnaires at the end of the study will look to assess the impact you think the Smartphone intervention has had on your friend/relatives wellbeing, independency, and confidence in coping with their difficulties. This would take approximately 30-60 minutes.

The intervention

1. In the first phase of the study your friend/relative would be asked to complete 5 pre-set tasks each day without reminders for around 7 days. These tasks would involve sending a message, making a phone call, or sending a letter. Your friend/relative would be given these tasks on a written sheet at the start of the phase and asked to use their usual strategies to help them complete the tasks.
2. In the second phase your friend/relative would receive another set of tasks on a sheet for the next 7 days. In this phase, your friend/relative would also receive reminders on their phone throughout the week to help them complete the tasks.
3. In the third phase (7 days) the reminders would be removed again, but they would still have a list of tasks for each day. In the fourth phase (7 days), the reminders would be given again to prompt completion of the set tasks.
4. Your friend/relative would then be set up with the Smartphone reminder system so that they could input events independently. They would not be expected to send any additional texts, letters, or voicemails in this period. After three months post completion of the intervention your friend/relative, and yourself would be asked to complete the post intervention questionnaires once more.

The set tasks would take approximately 1 minute to complete. Your friend/relative would be advised that **if they are required to complete a task at a time when their safety or the safety of others may be put at risk, they encouraged to delay their response until it is safe to proceed. An example might include when they are driving, or if they are using the stove.**

You and your friend would receive a phone call each week from the researcher to inform them of which stage of the intervention they are in. This would also be an

opportunity to check that you are both happy to continue and understand what is expected of you.

**What are the alternatives for treatment?**

If you or your friend/relative do not wish to take part, they will continue to receive treatment that would usually be part of their rehabilitation.

**What are the potential disadvantages of taking part?**

The disadvantages of taking part would involve the time commitment that is required to complete the pre and post study questionnaires. These however only take 30 minutes to complete, and you are expected to complete them on two occasions. Disadvantages for your friend/relative may include the intrusion of receiving reminder prompts 4-5 times a day, and then being required to act upon them. As part of the study, they will also have a period in which the prompts would be withdrawn, even if they feel that they have been helpful. The time for which they would be withdrawn would be minimised. Participating in this study may cause mild distress as the assessment and prompting programme may present evidence that your friend/relatives memory functioning is not at the level your previously believed it to be at. It may also raise awareness of the impact their brain injury has had on your life.

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

Participation in this study could provide the opportunity to test out whether reminder prompts provided through your friend/relatives phone may help them feel more confident in managing their memory difficulties. This in turn may help them engage with activities that they would not otherwise be able to. It may enhance their psychological wellbeing, and sense of independence in managing the difficulties you are experiencing.

In addition, this consequently may reduce the demands placed on your care and support. This in turn may promote your positive wellbeing. This is a study that may compliment rather than impede your friend/relatives rehabilitation, while reducing their dependency on yourself. We hope that the intervention will help you and your friend/relative. However, this cannot be guaranteed. The information we get from this study may help us to support people who have sustained and cared for individuals with a brain injury.

**What if new information becomes available?**

Sometimes during the course of a research project, new information becomes available about the intervention that is being studied. If this happens, your researcher will tell you about it and discuss with you whether you want to continue in the study. If you decide to withdraw your researcher will make arrangements for your care to continue. If you decide to continue in the study you will be asked to sign an updated consent form. Also, on receiving new information your researcher might consider it to be in your best interests to withdraw you from the study. He/she will explain the reasons and arrange for your friend/relatives care to continue.'

**What happens when the research study stops?**
On completing the study, the clinicians working with your friend/relative as part of their rehabilitation will look to support them in continuing to implement the intervention should it prove helpful. They would also continue to receive treatment as usual should their rehabilitation be ongoing.

**What if something goes wrong in the study?**
It is unlikely that yourself or your friend/relative will experience negative repercussions as a result of taking part. If you or they were harmed by taking part in this research project, there are no specific compensation arrangements. If you or they are harmed due to someone's negligence, then you may have grounds for a legal action, but you may have to pay for legal support. Regardless of this, if you wish to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms will be available to you both. If you wish to access further support, or complain about your care as a result of participation in this study you may contact the Patient & Liaison Service (PALS) on 08000 116 113 or pals.hchs@nhs.net.

**Will my taking part in this study be kept confidential?**
Personal information which is collected about you or your friend/relative during the course of the research will be kept strictly confidential and accessed by the researchers only. As part of the study, you may provide feedback on your experiences which may be used in publication of the study. If this was the case, any details that may identify you would be removed or pseudonyms would be used.

**What will happen to the results of the research study?**
The results of the study will be published as part of a Doctoral Level Thesis in Clinical Psychology. It may also be published in a peer reviewed Clinical Journal, and presented at research conferences. You will receive a written summary of the research findings. You will also be able to access the final thesis publication, and any journal publication through correspondence with the researcher. Any publications will contain only anonymous data from the study, Due to the small number of participants, there is a chance that quotes could identifiable, and therefore prior to publication, their inclusion would be checked with you.

**Who is organising and funding the research?**
The research will be funded by Cambridge and Peterborough NHS Foundation Trust as part of a Doctoral Qualification in Clinical Psychology.

**Who has reviewed the study?**
This study proposal has been reviewed by the East of England – Cambridge South REC, and the Lead for Research and Development in Hertfordshire NHS Community Trust.

*Smartphone Reminders Study: Version 3* *Date: 10.08.12*

**Contacts for Further Information**

Please don't hesitate to contact the researcher for any further information:

Email: s.ferguson2@herts.ac.uk or skot_ferguson@hotmail.com
Telephone: 07841457367
Address: DClinPsy Department, University of Hertfordshire, College lane, HA10 9AB

**Thank you for your time in reading this.**

**Scott Ferguson**
*Trainee Clinical Psychologist*

*Supervised by Dr. Emma Berry & Mr. Daniel Friedland*

*Smartphone Reminders Study: Version 3* *Date: 10.08.12*

Hertfordshire Community NHS
NHS Trust

Acquired Brain Injury Team
Hertfordshire Neurological Service
Jacketts Field Neurological Unit
Jacketts Field
Abbots Langley
Hertfordshire
WD5 0PA
Tel: 01923 299100
Fax: 01923 299101

## Research Study Information Sheet - Participant

**Title**

*'Smartphone Technology: Gentle reminders for everyday tasks in those with prospective memory difficulties following brain injury'*

**Introduction**

I am a Trainee Clinical Psychologist conducting research as part of my Doctoral Qualification at the University of Hertfordshire. This is an information sheet outlining a research study I am hoping to conduct with people who have suffered memory difficulties as a result of a brain injury. An audio copy of this sheet is available should you find it helpful to hear a recording of the information provided.

**Invitation paragraph**

You are being invited to take part in a research study. Before you decide whether you wish to participate it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Please feel free to ask us if there is anything that is not clear after reading this information sheet.

Thank you for reading this.

**What is the purpose of the study?**

This is a study which will look at whether reminder prompts provided through a Smartphone will help participants who have suffered a brain injury to remember to complete pre-set tasks. Prompts will be entered into the phone calendar using the internet link with your phone. Completion of set tasks will be compared between when the reminders are given, and when they are not. Set tasks will include making phone calls, sending text messages, and sending letters at preset times. The study will also look at whether using these reminders reduces the demands placed on family/friends, or carers who may support you with your memory.

**Why have I been invited?**

You have been invited to participate in this study as you have reported memory difficulties following your brain injury. There will be up to 7 other people with similar difficulties who may take part in this study.

**Exclusion Criteria**

It is important to note that should potential participants present with moderate or severe symptoms of depression as measured on the Beck Depression Inventory, they will be excluded from the study.

*Smartphone Reminders Study: Version 3* *Date: 10.08.12*

**Do I have to take part?**
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you receive.

**What will happen if I take part?**
You would be asked to complete a set of short paper and pen tasks before starting the study. This would take approximately 1 hour. These tasks will assess the type of difficulties you are experiencing at the moment. These tasks are often given to people who enter the service as part of the assessment process. In addition to the short tasks, you would be asked to complete 5 short questionnaires before and after the study looking at different aspects of your memory functioning. This would take approximately 30-60 minutes. If you have a family member, or partner who is supporting you, they may be asked to complete a questionnaire looking at the impact your brain injury has had on their day to day life.

At the end of the study an additional short informal questionnaire will assess whether you feel that the prompting system has had an impact on your ability to cope with your memory difficulties, your wellbeing, and the extent of the support you may need from others. This would take approximately 30 minutes.

1. In the first phase of the study you would be asked to complete 5 pre-set tasks each day without reminders for around 7 days. These tasks would involve sending a text, making a phone call, or sending a letter. You would be given these tasks on a written sheet at the start of the phase and asked to use your usual strategies to help you complete the tasks.
2. In the second phase you would receive another set of tasks on a sheet for the next 7 days. In this phase, you would also receive reminders on your phone throughout the week to help you complete the tasks.
3. In the third phase (7 days) the reminders would be removed again, but you would still have a list of tasks for each day.
4. In the fourth phase (7 days), the reminders would be given again to help you remember the set tasks. After the fourth phase, we would ask you to complete the questionnaires again.
5. You and your family/friend/carer would then be set up with the Smartphone reminder system so that you could input events independently. You would not be expected to send any additional texts, letters, or voicemails in this period. After three months post completion of the intervention you would be asked to complete the post intervention questionnaires once more.

**Safety Notice:** ***If you are required to complete a task at a time when your safety or the safety of others may be put at risk, you are asked to delay your response until it is safe to proceed. An example might include when you are driving, or if you a using the stove.***

You would receive a phone call each week from the researcher to inform you of which stage of the intervention you are in. This would also be an opportunity to check that you are happy to continue and understand what is expected of you.

**What are the alternatives for treatment?**
Taking part in this study may incur small costs to your mobile phone bill depending on the type of phone contract you have. An expenses payment will be made to you on a sliding scale from £5 to £20 depending on how much your phone contract covers the internet, text messages and phone calls

that would be required in taking part. This can be discussed in further detail with the chief investigator.

**What are the alternatives for treatment?**
If you do not wish to take part, you will receive treatment that would usually be part of your rehabilitation.

**What are the potential disadvantages of taking part?**
The disadvantages of taking part would involve the time commitment that is required to complete the pre study questionnaires. These take 30-60 minutes to complete, before and after the study. Additional disadvantages may include receiving reminder prompts 4-5 times a day which may be a little intrusive. As part of the study, you would also have a period in which the phone prompts would be removed, even if you feel that they have been helpful. This needs to be done, however the length of time they are removed for would be kept as short as possible. Participating in this study may cause mild distress as the assessment and prompting programme may present evidence that your memory functioning is not at the level your previously believed it to be at.

**What are the possible benefits of taking part?**
Participation in this study could provide the opportunity to test out whether phone reminder prompts can you manage your memory difficulties. This in turn may help you engage with activities that you would not otherwise be able to. It may enhance your psychological wellbeing, and sense of independence in managing the difficulties you experience. In addition, it may also be shown to have a positive effect on reducing the demands placed on people who may support you in day to day life at the moment. We hope that both the intervention will help you. However, this cannot be guaranteed. The information we get from this study may help us to support future patients with similar memory difficulties.

**What if new information becomes available?**
Sometimes during the course of a research project, new information becomes available about the intervention that is being studied. If this happens, your researcher will tell you about it and discuss with you whether you want to continue in the study. If you decide to withdraw your researcher will make arrangements for your care to continue.

**What happens when the research study stops?**
On completing the study, the clinicians working with you as part of your rehabilitation will look to support you in continuing to use the intervention should it prove helpful. You would also continue to receive treatment as usual should your rehabilitation be ongoing.

**What if something goes wrong in the study?**
It is unlikely that you will experience negative repercussions as a result of taking part. If you are harmed by taking part in this research project, there are no specific compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action, but you may have to pay for legal support. Regardless of this, if you wish to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms will be available to you. If you wish to access further support, or complain about your care as a result of participation in this study you may contact the Patient & Liaison Service (PALS) on 08000 116 113 or pals.hchs@nhs.net.

**Will my taking part in this study be kept confidential?**

*Smartphone Reminders Study: Version 3* *Date: 10.08.12*

Personal information which is collected about you during the course of the research will be kept strictly confidential and accessed by the researchers only. Any information about you which leaves the research site will be anonymised. As part of the study, you may provide feedback on your experiences which may be used in publication of the study in the form of quotes. These quotes may feature in the thesis, and a published journal. However, the author of these quotes would be anonymous. Due to the small number of participants, there is a chance that these quotes could identifiable, and therefore prior to publication, their inclusion would be checked with you. Your GP will be notified that you are participating in this study as the intervention may form part of your on-going rehabilitative support. This will be done in the form of a brief letter at the start of the study, and a summary of findings and recommendations at the end.

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

The results of the study will be published as part of a Doctoral Level Thesis in Clinical Psychology. It may also be published in a peer reviewed Clinical Journal, and presented at research conferences. You will receive a written summary of the research findings. You will also be able to access the final thesis publication, and any journal publication through correspondence with the researcher. Any publications will contain only anonymous data from the study,

**Who is organising and funding the research?**

The research will be funded by Cambridge and Peterborough NHS Foundation Trust as part of a Doctoral Qualification in Clinical Psychology.

**Who has reviewed the study?**

This study proposal has been reviewed by the East of England – Cambridge South REC, and the Lead for Research and Development in Hertfordshire NHS Community Trust.

**Contacts for Further Information**

Please don't hesitate to contact the researcher for any further information:

Email: s.ferguson2@herts.ac.uk or skot_ferguson@hotmail.com
Telephone: 07841457367
Address: DClinPsy Department, University of Hertfordshire, College lane, HA10 9AB

**Thank you for your time in reading this.**

**Scott Ferguson**
*Trainee Clinical Psychologist*

*Supervised by: Dr Emma Berry (Clinical Psychologist)*
*Mr. Daniel Friedland (Consultant Clinical Psychologist)*

## Appendix 8 – Consent Forms

*Smartphone Reminders Study: Version 3* *Date: 10.08.12*

Hertfordshire Community NHS
NHS Trust

Acquired Brain Injury Team
Hertfordshire Neurological Service
Jacketts Field Neurological Unit
Jacketts Field
Abbots Langley
Hertfordshire
WD5 0PA

Tel: 01923 299100
Fax: 01923 299101

**CARER CONSENT FORM**

**Title of Project:** '*Smartphone Technology: Gentle reminders for everyday tasks in those with prospective memory difficulties following brain injury*'

**Name of Researcher:** Scott Ferguson

**Please initial box**

1 I confirm that I have read and understand the Carer Information Sheet Version 2 dated 12.04.12 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2 I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. I understand that data collected during the study may be looked at by the researcher where it is relevant to my taking part in this research. This information may also be accessed by the NHS Trust as part of routine data collection and audit practices conducted by regulatory authorities. I give permission for these individuals to have access to this data. ☐

3 I agree to take part in the above study. ☐

| | | |
|---|---|---|
| Name of Carer | Date | Signature |
| Name of Person taking consent (if different from researcher) | Date | Signature |
| Researcher | Date | Signature |

Page 1 of 1

*Smartphone Reminders Study: Version 3* *Date: 10.08.12*

Hertfordshire Community NHS
NHS Trust

Acquired Brain Injury Team
Hertfordshire Neurological Service
Jacketts Field Neurological Unit
Jacketts Field
Abbots Langley
Hertfordshire
WD5 0PA

Tel: 01923 299100
Fax: 01923 299101

## PARTICPANTS CONSENT FORM

**Title of Project:** '*Smartphone Technology: Gentle reminders for everyday tasks in those with prospective memory difficulties following brain injury*'

**Name of Researcher:** Scott Ferguson

| | | **Please initial box** |
|---|---|---|
| 1 | I confirm that I have read and understand the Participant Information Sheet Version 2 dated 12.04.12 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | ☐ |
| 2 | I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. | ☐ |
| 3 | I understand that relevant sections of my medical notes and data collected during the study may be looked at by the researcher where it is relevant to my taking part in this research. This information may also be accessed by the NHS Trust as part of routine data collection and audit practices conducted by regulatory authorities. I give permission for these individuals to have access to my records. | ☐ |
| 4 | I agree to my GP being informed of my participation in the study. | ☐ |
| 5 | I agree to take part in the above study. | ☐ |

| | | |
|---|---|---|
| _____ | _____ | _____ |
| Name of Patient | Date | Signature |
| _____ | _____ | _____ |
| Name of Person taking consent (if different from researcher) | Date | Signature |
| _____ | _____ | _____ |
| Researcher | Date | Signature |

Page **1** of **1**

## Appendix 9 - Demographics Questionnaire

Smartphone Reminder Study – Version 2 Date: 12.04.12

Hertfordshire Community NHS
NHS Trust

Acquired Brain Injury Team
Hertfordshire Neurological Service
Jacketts Field Neurological Unit
Jacketts Field
Abbots Langley
Hertfordshire
WD5 0PA

Tel: 01923 299100
Fax: 01923 299101

Referrals: 01923 299106
Fax: 01923 299107

**Demographics Questionnaire**

The questions below aim to gather information on the sample of people who are taking part in the study. These demographics would not include identifiable information. Please circle and complete the blanks.

1. Participant Number: ……..
2. Age: 18-26 26-35 36-45 46-55 56-65 66-75 76+
3. Gender: Male Female
4. Ethnicity: ……..
5. Type of Brain Injury: ……..
6. Date of Injury: ……
7. Carer/Friend/Relative participation in the study: Yes No
8. Model of Smartphone: ……

If you have any questions relating to this questionnaire, please don't hesitate to ask the researcher.

**Scott Ferguson**
**Trainee Clinical Psychologist**
**University of Hertfordshire**

## Appendix 10 - Prospective & Retrospective Memory Questionnaire

**REMEMBERING TO DO THINGS**

The following questions are about minor memory mistakes that everyone makes from time to time, but some of them happen more often than others. We would like you to tell us how often these things happen to you. Please indicate this by ticking the appropriate box. Please make sure you answer all of the questions on both sides of the sheet, even if they do not seem entirely applicable to your situation.

| | Very Often | Quite Often | Sometimes | Rarely | Never |
|---|---|---|---|---|---|
| 1. Do you decide to do something in a few minutes' time and then forget to do it? | ☐ | ☐ | ☐ | ☐ | ☐ |
| 2. Do you fail to recognise a place you have visited before? | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3. Do you fail to do something you were supposed to do a few minutes later even though it's there in front of you, like take a pill or turn off the kettle? | ☐ | ☐ | ☐ | ☐ | ☐ |
| 4. Do you forget something that you were told a few minutes before? | ☐ | ☐ | ☐ | ☐ | ☐ |
| 5. Do you forget appointments if you are not prompted by someone else or by a reminder such as a calendar or diary? | ☐ | ☐ | ☐ | ☐ | ☐ |
| 6. Do you fail to recognise a character in a radio or television show from scene to scene? | ☐ | ☐ | ☐ | ☐ | ☐ |
| 7. Do you forget to buy something you planned to buy, like a birthday card, even when you see the shop? | ☐ | ☐ | ☐ | ☐ | ☐ |
| 8. Do you fail to recall things that have happened to you in the last few days? | ☐ | ☐ | ☐ | ☐ | ☐ |

Please Turn Over

| | Very Often | Quite Often | Sometimes | Rarely | Never |
|---|---|---|---|---|---|
| 9. Do you repeat the same story to the same person on different occasions? | ☐ | ☐ | ☐ | ☐ | ☐ |
| 10. Do you intend to take something with you, before leaving a room or going out, but minutes later leave it behind even though it's there in front of you? | ☐ | ☐ | ☐ | ☐ | ☐ |
| 11. Do you mislay something, that you have just put down, like a magazine or glasses? | ☐ | ☐ | ☐ | ☐ | ☐ |
| 12. Do you fail to mention or give something to a visitor that you were asked to pass on? | ☐ | ☐ | ☐ | ☐ | ☐ |
| 13. Do you look at something without realising you have seen it moments before? | ☐ | ☐ | ☐ | ☐ | ☐ |
| 14. If you tried to contact a friend or relative who was out, would you forget to try again later? | ☐ | ☐ | ☐ | ☐ | ☐ |
| 15. Do you forget what you watched on television the previous day? | ☐ | ☐ | ☐ | ☐ | ☐ |
| 16. Do you forget to tell someone something you had meant to mention a few minutes ago? | ☐ | ☐ | ☐ | ☐ | ☐ |

## Appendix 11 – Example of Task List Schedule

### Task List – Phase 1 – No prompts Provided

| Day 1 – Date: 06.08.12 | Task |
|---|---|
| 9.00 | Prepare picnic Lunch – Leave Scott voicemail when starting |
| 10.30 | Get ready for x Exercise – Text Scott when starting |
| 13.30 | Enter into Phone Calendar what you're doing now |
| 15.00 | Time to rest – Text Scott when starting |
| 17.30 | Contact x to arrange evening Walk – Text Scott when starting |
| **Day 2 – Date: 07.08.12** | **Task** |
| 9.30 | Wish x Happy Birthday – Text Scott when starting |
| 11.00 | Enter into phone calendar what you are doing now |
| 13.00 | Routine Exercise Time – leave voicemail for Scott when starting |
| 15.30 | Going Out? Or Reading a Book? Text Scott what you're up to. |
| 17.00 | Prepare ingredients for dinner – Text Scott what your making |
| **Day 3 – Date: 08.08.12** | **Task** |
| 9.00 | Send Pre Addressed Letter 1 |
| 10.30 | Get ready for x or x – Text Scott when getting ready |
| 14.00 | Time to rest – Voicemail Scott when resting |
| 15.00 | Word Puzzles – text Scott on Starting |
| 17.30 | Enter into phone Calendar what you're up to now |
| **Day 4 – Date: 09.08.12** | **Task** |
| 10.00 | Routine exercise – Text Scott on starting |
| 11.30 | Enter into phone calendar what you're up to now |
| 14.00 | Visit x – Take Keys – Voicemail Scott when starting |
| 16.30 | Send Pre-Addressed Letter 2 |
| 19.00 | Evening Walk? – Text Scott where you're going. |
| **Day 5 – Date: 10.08.12** | **Task** |
| 9.30 | Walk? – Voicemail Scott when getting ready |
| 11.00 | Prepare lunch with x – text Scott what your having |
| 13.00 | Enter into phone Calendar what you're up to now |
| 15.30 | Time to rest - text Scott when starting |
| 17.00 | Watch TV Quiz or Olympics – Text Scott what you're watching |
| **Day 6 – Date:** | **Task** |
| 11.00 | Make Brunch – text Scott what your making |
| 13.30 | Gardening with x – Text Scott when starting |
| 15.00 | Time for rest – Voicemail Scott when starting |
| 16.30 | Afternoon Tea – Text when starting |
| 18.00 | Enter into Phone Calendar what you're up to now |
| **Day 7 – Date:** | **Task** |
| 10.30 | Ready for swimming – Voicemail Scott when starting |
| 12.30 | Go to x – text Scott when starting |
| 14.00 | Enter into Phone Calendar what you're up to now |
| 16.30 | Shower (skin protect) – text Scott when starting |
| 19.00 | What you watching on TV – Text Scott |

## Task List – Phase 2 –Prompts Provided

| Day 1 – Date: | Task |
|---|---|
| 9.45 | Vacuum & Dust downstairs – text Scott on starting |
| 10.30 | Get ready for x – Text Scott when starting |
| 13.45 | Clear up after lunch – Voicemail Scott when starting |
| 16.15 | Enter into phone calendar what you're up to now |
| 18.00 | What you cooking for dinner? –Text Scott |
| **Day 2 – Date:** | **Task** |
| 9.15 | Routine exercises – Voicemail Scott on starting |
| 10.45 | Walk x – Text when getting ready |
| 13.15 | Enter in to phone Calendar what you're up to now |
| 15.45 | Crossword in 'i' – Text Scott when starting |
| 18.30 | What are you making for dinner with spud? Text Scott |
| **Day 3 – Date:** | **Task** |
| 10.00 | Pack items for day out – text Scott when starting |
| 11.30 | Ready for x – Text Scott when ready |
| 14.00 | What's for lunch – voicemail Scott |
| 16.30 | Send pre addressed Letter 3 |
| 19.00 | Enter into phone Calendar what you're doing now |
| **Day 4 – Date:** | **Task** |
| 9.45 | Routine Exercises – voicemail Scott on starting |
| 11.15 | Finalise notes for speech – Text Scott on starting |
| 13.45 | Enter into phone calendar what you are doing now |
| 16.15 | Return from local walk – text Scott, how was it |
| 18.00 | Wii Bowling/Archery – Text Scott when starting |
| **Day 5 – Date:** | **Task** |
| 9.15 | Send pre-addressed Letter 4 |
| 10.45 | Enter into phone Calendar what you're doing now |
| 13.15 | Read paper – Voicemail Scott when starting |
| 15.45 | Polish black shoes for wedding – text Scott when starting |
| 18.30 | Prepare ingredients for dinner – Text Scott menu |
| **Day 6 – Date:** | **Task** |
| 10.15 | Routine exercises – Voicemail scott on starting |
| 11.45 | Vacuum and dust downstairs – text scott on starting |
| 13.45 | Enter into phone Calendar what you're doing now |
| 16.15 | Meet x in x - text Scott when Leaving |
| 18.00 | Shopping at Tesco – Text Scott |
| **Day 7 – Date:** | **Task** |
| 10.45 | Ready for swimming – text scott when starting |
| 12.00 | Enter into phone Calendar what you have been doing |
| 13.30 | See friends at x – Voicemail Scott when starting |
| 15.45 | Time to rest – Text Scott when starting |
| 18.30 | Clear up after dinner –Text Scott when starting |

## Task List – Phase 3 –No Prompts Provided

| Day 1 – Date: 20.08.12 | Task |
|---|---|
| 9.15 | Clear up breakfast – voicemail Scott on starting |
| 10.45 | Get ready for x – Text Scott when starting |
| 13.15 | Enter into phone Calendar what your up to now. |
| 15.45 | Time for rest – text when starting |
| 18.30 | Local Walk – text when starting |
| **Day 2 – Date: 21.08.12** | **Task** |
| 9.45 | Ready for walk – text Scott on starting |
| 11.15 | Enter into phone Calendar what you are up to |
| 13.45 | Newspaper/crossword – voicemail Scott what you plan to do |
| 16.15 | Routine Exercise – text Scott on starting |
| 18.00 | What's for dinner? – Text Scott |
| **Day 3 – Date:22.08.12** | **Task** |
| 9.45 | Barbers – Extra Apt – Voicemail Scott when starting |
| 11.15 | Walk in x – text Scott on starting |
| 13.45 | Clear up after lunch Text Scott when starting |
| 16.15 | Visit mum in law – Text when starting |
| 18.00 | Enter into phone Calendar what you're doing now |
| **Day 4 – Date: 23.08.12** | **Task** |
| 9.15 | Send pre addressed Letter 5 |
| 10.45 | Enter into phone Calendar what you're doing now |
| 13.15 | Lunch out with x – text Scott location |
| 15.45 | Time for rest – Text Scott on starting |
| 18.30 | Local Walk –Text Scott where your off too |
| **Day 5 – Date:24.08.12** | **Task** |
| 9.45 | Copy of speech ready – Text when checked |
| 11.15 | On route to x – Text Scott |
| 13.45 | How's the wedding? Leave Scott voicemail |
| 16.15 | Time to Rest – Text Scott on starting |
| 18.00 | Enter into phone Calendar what you're doing now |
| **Day 6 – Date: 25.08.12** | **Task** |
| 10.45 | Pack bags for home – Text Scott on starting |
| 12.00 | Enter into phone Calendar what you're doing now |
| 13.30 | Lunch with x – Voicemail Scott location |
| 15.45 | Send pre-addressed Letter 6 |
| 18.30 | Goodbye x- Text Scott when done |
| **Day 7 – Date: 26.08.12** | **Task** |
| 10.15 | Pack swim bag – Voicemail Scott on starting |
| 11.45 | How was swimming – Text scott |
| 13.45 | Enter into phone Calendar what you're doing now |
| 16.15 | Start dinner preparation? Text Scott |
| 18.30 | How was dinner? Text Scott |

## Task List – Phase 4 - Prompts Provided

| Day 1 – Date: | Task |
|---|---|
| 9.15 | Call |
| 10.45 | Self |
| 13.15 | Enter into phone Calendar what you're doing now |
| 15.45 | Self |
| 18.30 | Text |
| **Day 2 – Date:** | **Task** |
| 9.45 | Self - text |
| 11.15 | Enter into phone Calendar what you're doing now |
| 13.45 | Call - check |
| 16.15 | Self - text |
| 18.00 | Text |
| **Day 3 – Date:** | **Task** |
| 9.45 | Call |
| 11.15 | Self text |
| 13.45 | Text |
| 16.15 | Self text |
| 18.00 | Enter into phone Calendar what you're doing now |
| **Day 4 – Date:** | **Task** |
| 9.15 | Letter |
| 10.45 | Enter into phone Calendar what you're doing now |
| 13.15 | Call |
| 15.45 | Self - text |
| 18.30 | Text |
| **Day 5 – Date:** | **Task** |
| 9.45 | Self - text |
| 11.15 | Text |
| 13.45 | Call |
| 16.15 | Letter |
| 18.00 | Enter into phone Calendar what you're doing now |
| **Day 6 – Date:** | **Task** |
| 10.45 | Self - text |
| 12.00 | Enter into phone Calendar what you're doing now |
| 13.30 | Call |
| 15.45 | Self Text |
| 18.30 | Text |
| **Day 7 – Date:** | **Task** |
| 10.15 | Call |
| 11.45 | Self - text |
| 13.45 | Enter into phone Calendar what you're doing now |
| 16.15 | Self - text |
| 18.00 | Text |

## Appendix 12 - Memory Mistakes Questionnaire

Name: _____ Date: _____

### How I feel about my memory

Below are statements about feelings that people may have about their memory. Read each statement and decide whether you agree. Think about how you have been feeling over the past *two weeks*. Then, place a check in the appropriate column.

| | Strongly agree | Agree | Undecided | Disagree | Strongly disagree |
|---|---|---|---|---|---|
| 1 I am generally pleased with my memory ability. | | | | | |
| 2 There is something seriously wrong with my memory. | | | | | |
| 3 If something is important, I will probably remember it. | | | | | |
| 4 When I forget something, I fear that I may have a serious memory problem, like Alzheimer's disease. | | | | | |
| 5 My memory is worse than most other people my age. | | | | | |
| 6 I have confidence in my ability to remember things. | | | | | |
| 7 I feel unhappy when I think about my memory ability. | | | | | |
| 8 I worry that others will notice that my memory is not very good. | | | | | |
| 9 When I have trouble remembering something, I'm not too hard on myself. | | | | | |
| 10 I am concerned about my memory. | | | | | |
| 11 My memory is really going downhill lately. | | | | | |
| 12 I am generally satisfied with my memory ability. | | | | | |
| 13 I don't get upset when I have trouble remembering something. | | | | | |
| 14 I worry that I will forget something important. | | | | | |
| 15 I am embarrassed about my memory ability. | | | | | |
| 16 I get annoyed or irritated with myself when I am forgetful. | | | | | |
| 17 My memory is good for my age. | | | | | |
| 18 I worry about my memory ability. | | | | | |

Name: _____ Date: _____

# Memory Mistakes

Below is a list of common memory mistakes that people make. Decide how often you have done each one in the *last two weeks,* then place a check mark in the appropriate column.

| | All the time | Often | Sometimes | Rarely | Never |
|---|---|---|---|---|---|
| 1 Forget to pay a bill on time. | | | | | |
| 2 Misplace something you use daily, like your keys or glasses. | | | | | |
| 3 Have trouble remembering a telephone number you just looked up. | | | | | |
| 4 Not recall the name of someone you just met. | | | | | |
| 5 Leave something behind when you meant to bring it with you. | | | | | |
| 6 Forget an appointment. | | | | | |
| 7 Forget what you were just about to do; for example, walk into a room and forget what you went there to do. | | | | | |
| 8 Forget to run an errand. | | | | | |
| 9 In conversation, have difficulty coming up with a specific word that you want. | | | | | |
| 10 Have trouble remembering details from a newspaper or magazine article you read earlier that day. | | | | | |
| 11 Forget to take medication. | | | | | |
| 12 Not recall the name of someone you have known for some time. | | | | | |
| 13 Forget to pass on a message. | | | | | |
| 14 Forget what you were going to say in conversation. | | | | | |
| 15 Forget a birthday or anniversary that you used to know well. | | | | | |
| 16 Forget a telephone number you use frequently. | | | | | |
| 17 Retell a story or joke to the same person because you forgot that you had already told him or her. | | | | | |
| 18 Misplace something that you put away a few days ago. | | | | | |
| 19 Forget to buy something you intended to buy. | | | | | |
| 20 Forget details about a recent conversation. | | | | | |

## Managing Memory Difficulties

*For the following situations, please circle the appropriate number from 1 (not confident) to 5 (very confident) that best describes how confident you feel about managing the memory demands when….*

| | Not Confident | | | | Very Confident |
|---|---|---|---|---|---|
| The receptionist phones and changes your dentist appointment? | 1 | 2 | 3 | 4 | 5 |
| You are alone and think of something that you want to do but can't do until the next day? | 1 | 2 | 3 | 4 | 5 |
| You are going to see your doctor and you need to remember what was spoken about in the previous visit? | 1 | 2 | 3 | 4 | 5 |
| You are sitting with a group of people and making arrangements to meet next week? | 1 | 2 | 3 | 4 | 5 |
| You have a number of things to do in a day and want to stay on time and not miss activities? | 1 | 2 | 3 | 4 | 5 |
| You must find your way to and from new places? | 1 | 2 | 3 | 4 | 5 |

## Appendix 13 - Strategies of Smartphone Use Questionnaire

Smartphone Use Questionnaire - Version 2 Date: 12.04.12

# Strategies Of Smartphone Use Questionnaire (Svoboda et al 2010)

(NB: PDA is an abbreviation for a Personal Digital Assistant, a term used to describe the earlier versions of the Smartphone).

Have you ever used a PDA or smartphone before? Yes ☐ No ☐

If the above response is **YES** please complete the following questions regarding your smartphone use.

When did you first begin using the smartphone? (dd/mm/year)_____

How many months/years of experience *in total* do you have using a PDA/smartphone?_____
(please answer even if you have not used it recently)

| | Never | Seldom | Sometimes | Often | Always |
|---|---|---|---|---|---|
| How often did you use it before? | | | | | |

| | Not Confident | Not that confident | Somewhat Confident | Confident | Very confident |
|---|---|---|---|---|---|
| How would you rate your confidence in using the PDA/smartphone? | | | | | |

| Please answer the following questions regarding your PDA/smartphone use. Several strategies are listed below. Please decide how often you used each one **in the last two weeks**. Then, place a check mark (✓) in the appropriate column. | Never | Seldom | Sometimes | Often | Always |
|---|---|---|---|---|---|
| **Smartphone use for remembering information from the past:** | | | | | |
| Remembering names of people. | | | | | |
| Recognising people (their face). | | | | | |
| Remembering who someone is (recording and accessing information about a person). | | | | | |
| Remembering that a particular event happened in the past week. | | | | | |
| Figuring out when/where something happened in the past (more than a week ago). | | | | | |
| Remembering important information that you were told (e.g., at a Doctor's appointment, meeting). | | | | | |

Smartphone Use Questionnaire - Version 2 Date: 12.04.12

| | Never | Seldom | Sometimes | Often | Always |
|---|---|---|---|---|---|
| **Smartphone use for remembering to do things in the future:** | | | | | |
| Remembering to do a planned activity (appointments, social events). | | | | | |
| Using the smartphone for directions to get from point A to point B. | | | | | |
| Adapting to a new routine (change in schedule or appointment time). | | | | | |
| Remembering to take important things with you that are needed for an appointment or meeting. | | | | | |
| Remembering to pass on a message or relay important information (e.g., to a family member or a healthcare professional). | | | | | |
| Planning your week ahead of time and knowing what you are doing/where you are going next. | | | | | |
| *The questions below should be answered only by the family member (if available) or by the client if s/he lives alone.* | | | | | |
| **How often does your family member [do you]…** | | | | | |
| Spontaneously use his/her smartphone when planning a future activity together (without needing reminding to use the smartphone)? | | | | | |
| Schedule events in his/her smartphone without technical assistance (e.g., entering the event, setting the alarm, attaching a note if relevant)? | | | | | |
| Respond to the alarm sound by checking his/her smartphone (without assistance)? | | | | | |
| Carry out the scheduled task after responding to the alarm sound of the smartphone (without requiring further reminding)? | | | | | |
| Successfully complete tasks you or someone else has asked him/her to do when you/other person are out or not in the same room (e.g., household maintenance, meeting you/someone some place, making a phone call)? | | | | | |

**Please describe any problems with everyday functioning that your family member [you] continues to have with smartphone use that you wish could be addressed by the memory intervention programme.**

_____

_____

_____

If you have any further questions relation to this questionnaire, please don't hesitate to ask.

**Scott Ferguson**

**Trainee Clinical Psychologist**

Page **2** of **2**

## Appendix 14 - Memory Awareness and Strategies Scale

Name: _____ Date: _____

### Memory Strategies

People often use different tricks or strategies to help them remember things. Several strategies are listed below. Decide how often you used each one in the *last two weeks*. Then, place a check mark in the appropriate column.

| | All the time | Often | Sometimes | Rarely | Never |
|---|---|---|---|---|---|
| 1 Use a timer or alarm to remind you when to do something. | | | | | |
| 2 Ask someone to help you remember something or to remind you to do something. | | | | | |
| 3 Create a rhyme out of what you want to remember. | | | | | |
| 4 In your mind, create a visual image of something you want to remember, like a name and a face. | | | | | |
| 5 Write things on a calendar, such as appointments or things you need to do. | | | | | |
| 6 Go through the alphabet one letter at a time to see if it sparks a memory for a name or word. | | | | | |
| 7 Organize information you want to remember; for example, organize your grocery list according to food groups. | | | | | |
| 8 Say something out loud in order to remember it, such as a telephone number you just looked up. | | | | | |
| 9 Use a routine to remember important things, like checking that you have your wallet and keys when you leave home. | | | | | |
| 10 Make a list, such as a grocery list or a list of things to do. | | | | | |
| 11 Mentally elaborate on something you want to remember; for example, focus on a lot of the details. | | | | | |
| 12 Put something in a prominent place to remind you to do something, like putting your umbrella by the front door so that you will remember to take it with you. | | | | | |
| 13 Repeat something to yourself at increasingly longer and longer intervals so that you will remember it. | | | | | |
| 14 Create a story to link together information you want to remember. | | | | | |
| 15 Write down in a notebook things that you want to remember. | | | | | |
| 16 Create an acronym out of the first letters in a list of things to remember, such as carrots, apples, and bread (cab). | | | | | |
| 17 Intentionally concentrate hard on something so that you will remember it. | | | | | |
| 18 Write a note or reminder for yourself (other than on a calendar or in a notebook). | | | | | |
| 19 Mentally retrace your steps in order to remember something, such as the location of a misplaced item. | | | | | |

## Appendix 15 - Modified - Caregiver Strain Index

# Modified Caregiver Strain Index

**Directions:** Here is a list of things that other caregivers have found to be difficult. Please put a checkmark in the columns that apply to you. We have included some examples that are common caregiver experiences to help you think about each item. Your situation may be slightly different, but the item could still apply.

| | Yes, On a Regular Basis=2 | Yes, Sometimes =1 | No=0 |
|---|---|---|---|
| **My sleep is disturbed** (For example: the person I care for is in and out of bed or wanders around at night) | | | |
| **Caregiving is inconvenient** (For example: helping takes so much time or it's a long drive over to help) | | | |
| **Caregiving is a physical strain** (For example: lifting in or out of a chair; effort or concentration is required) | | | |
| **Caregiving is confining** (For example: helping restricts free time or I cannot go visiting) | | | |
| **There have been family adjustments** (For example: helping has disrupted my routine; there is no privacy) | | | |
| **There have been changes in personal plans** (For example: I had to turn down a job; I could not go on vacation) | | | |
| **There have been other demands on my time** (For example: other family members need me) | | | |
| **There have been emotional adjustments** (For example: severe arguments about caregiving) | | | |
| **Some behavior is upsetting** (For example: incontinence; the person cared for has trouble remembering things; or the person I care for accuses people of taking things) | | | |
| **It is upsetting to find the person I care for has changed so much from his/her former self** (For example: he/she is a different person than he/she used to be) | | | |
| **There have been work adjustments** (For example: I have to take time off for caregiving duties) | | | |
| **Caregiving is a financial strain** | | | |
| **I feel completely overwhelmed** (For example: I worry about the person I care for; I have concerns about how I will manage) | | | |

[Sum responses for "Yes, on a regular basis" (2 pts each) and "yes, sometimes" (1 pt each)]

**Total Score =**

Thornton, M., & Travis, S.S. (2003). Analysis of the reliability of the Modified Caregiver Strain Index. *The Journal of Gerontology, Series B, Psychological Sciences and Social Sciences, 58*(2), p. S129. Copyright © The Gerontological Society of America. Reproduced by permission of the publisher.

## Appendix 16 – Smartphone Impact Questionnaire

Smartphone Reminder Study – Version 2 Date: 14.06.12

Hertfordshire Community NHS
NHS Trust

Acquired Brain Injury Team
Hertfordshire Neurological Service
Jacketts Field Neurological Unit
Jacketts Field
Abbots Langley
Hertfordshire
WD5 0PA

Tel: 01923 299100
Fax: 01923 299101

Referrals: 01923 299106
Fax: 01923 299107

### Impact of Smartphone Reminder Cues Questionnaire - Carer

1). Do you feel any there has been any change in your friend/relative's ability to engage in tasks or activities as a result of receiving reminder prompts through their Smartphone?

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

2). Do you feel there is any change in your friend/relatives confidence in managing their memory difficulties as a result of receiving prompts through their Smartphone?

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

3). Do you think there is anything that your friend/relative is able to do now that they were unable to do prior to receiving reminder prompts through their Smartphone?

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4). Do you think that using their Smartphone as a reminder device has had any impact on your friend/relative's mood?

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Smartphone Reminder Study – Version 2 Date: 14.06.12

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5). Do you think using their Smartphone as a reminder device has had any impact on your friend/relatives reliance/dependence on yourself or others for support with their memory difficulties?

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6). Do you think that using their Smartphone as a reminder device has had any other impact on your friend/relative that you have not already noted?

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If you have any questions relating to this questionnaire, please don't hesitate to ask.

Thank you

***Scott Ferguson***
***Trainee Clinical Psychologist***

Smartphone Reminder Study – Version 2 Date: 14.06.12

Hertfordshire Community NHS
NHS Trust

Acquired Brain Injury Team
Hertfordshire Neurological Service
Jacketts Field Neurological Unit
Jacketts Field
Abbots Langley
Hertfordshire
WD5 0PA

Tel: 01923 299100
Fax: 01923 299101

Referrals: 01923 299106
Fax: 01923 299107

## Impact of Smartphone Reminder Cues Questionnaire

1). Do you feel any change in your ability to engage in tasks or activities as a result of receiving reminder prompts through your Smartphone?

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2). Do you feel there is any change in your confidence in managing your memory difficulties as a result of receiving prompts through your Smartphone?

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3). Do you think there is anything that you are able to do now that you were unable to do prior to receiving reminder prompts through you Smartphone?

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4). Do you think that using your Smartphone as a reminder device has had any impact on your mood?

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Smartphone Reminder Study – Version 2 Date: 14.06.12

5). Do you think using your Smartphone as a reminder device has had any impact on your reliance/dependence on others for support with your memory difficulties?

6). Do you think that using your Smartphone as a reminder device has had any other impact that you have not already noted?

If you have any questions relating to this questionnaire, please don't hesitate to ask.

Thank you

***Scott Ferguson***
***Trainee Clinical Psychologist***

## Appendix 17 – Three Months Follow Up Questionnaire

Smartphone Reminder Study – Version 1 Date: 28.10.12

Hertfordshire Community NHS
NHS Trust

Acquired Brain Injury Team
Hertfordshire Neurological Service
Jacketts Field Neurological Unit
Jacketts Field
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Tel: 01923 299100
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Referrals: 01923 299106
Fax: 01923 299107

**Smartphone Reminder System**
**Partner/relative - 3 Month Follow up Questionnaire**

1. **Is your relative/partner using their Smartphone calendar function to assist with their memory difficulties? If yes, what are they using it to help remember? (Please Circle your responses)**

   (a) Smartphone Use: Yes/No

   (b) Uses:
   .....
   .....
   .....

2. **Have you used the email link up with the Smartphone calendar to help your relative with their memory difficulties? If so how frequently in an average month? (Please circle your responses)**

   (a) Email link up: Yes/No

   (b) Frequency of Use (month period):

   0 1-5 6-10 11-15 16-20 21-25 26-30 30+

3. **Have you noticed any barriers to your relative/partner's use of their Smartphone to assist with their memory? (Please circle your response)**

   (a) Barriers to Use: Yes/No

   (b) If yes, what have they been?
   .....
   .....

4. **Have you noticed any barriers to using the email link up system to programme the calendar remotely? (Please circle your response)**

   (a) Barriers to Use: Yes/No

(b) If yes, what have they been?

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

5. **Do you think there is anything that would support your relative/partner in using the Smartphone reminder system more effectively?**

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

6. **Do you think there is anything that would support you in using the email link up with your partner/relatives Smartphone calendar more effectively?**

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

7. **How likely do you think it is that your partner/relative will continue to use their Smartphone calendar as an on-going support for your memory difficulties? (Please circle your response)**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Not Likely | | Perhaps | | Very Likely |

8. **How likely are you to use the email link up with your Smartphone calendar as an on-going support for your memory difficulties? (Please circle your response)**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Not Likely | | Perhaps | | Very Likely |

*Thank you for completing this questionnaire. If you have any queries relating to this the questions asked, please don't hesitate to contact the Chief Investigator, Scott Ferguson.*

***Scott Ferguson***
***Trainee Clinical Psychologist***

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*07841457367*

Smartphone Reminder Study – Version 1 Date: 28.10.12

Hertfordshire Community NHS
NHS Trust

Acquired Brain Injury Team
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Fax: 01923 299107

## Smartphone Reminder System
## Participant - 3 Month Follow up Questionnaire

1. **Are you still using the Smartphone calendar function to assist with you memory difficulties? If yes, what are you using it to help you remember? (Please Circle your responses)**

   (a) Smartphone Use: Yes/No

   (b) For what uses:
   .....
   .....
   .....

2. **Is your relative/partner using the email link up with the Smartphone calendar to help remind you of task you need to do? If so how frequently in an average month? (Please circle your responses)**

   (a) Email link up: Yes/No

   (b) Frequency of Use (month period):

   0 1-5 6-10 11-15 16-20 21-25 26-30 30+

3. **Have you noticed any barriers to using your Smartphone to assist you with your memory difficulties? (Please circle your response)**

   (a) Barriers to Use: Yes/No

   (b) If yes, what have they been?
   .....
   .....

4. **Have you noticed any barriers preventing your relative/partner from using the email link up system to programme your calendar remotely? (Please circle your response)**

   (a) Barriers to Use: Yes/No

(b) If yes, what have they been?

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

5. **Do you think there is anything that would support you or your relative/partner in using the Smartphone reminder system more effectively?**

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

6. **Do you think there is anything that would support you or your relative/partner in using the email link up with your Smartphone calendar more effectively?**

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

7. **How likely are you to use your Smartphone calendar as an on-going support for your memory difficulties? (Please circle your response)**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Not Likely | | Perhaps | | Very Likely |

8. **How likely is it that your partner/relative will use the email link up to your Smartphone calendar as an on-going support for your memory difficulties? (Please circle your response)**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Not Likely | | Perhaps | | Very Likely |

*Thank you for completing this questionnaire. If you have any queries relating to this the questions asked, please don't hesitate to contact the Chief Investigator, Scott Ferguson.*

***Scott Ferguson***
***Trainee Clinical Psychologist***

*skot_ferguson@hotmail.com*
*07841457367*

## Appendix 18 – Questionnaire Scores for Individual Cases

| Pre and Post Questionnaires | PH | | | MM | | | LL | | | CC | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Pre | Post | 3 Months | Pre | Post | 3 Months | Pre | Post | 3 Months | Pre | Post | 3 Months |
| **Strategies In Smartphone Use Questionnaire** | 6/78 | 38/78 | 37/78 | 45/78 | 55/78 | 57/78 | 49/78 | 50/78 | 52/78 | 47/78 | 60/78 | 50/78 |
| **Feeling About Memory Questionnaire** | 34/72 | 37/72 | 46/72 | 51/72 | 61/72 | 65/72 | 28/72 | 29/72 | 30/72 | 29/72 | 35/72 | 26/72 |
| **Memory Mistakes Questionnaire** | 45/80 | 38/80 | 49/80 | 39/80 | 35/80 | 45/80 | 44/80 | 39/80 | 45/80 | 37/80 | 40/80 | 24/80 |
| **Memory Strategies Questionnaire** | 42/76 | 40/76 | 38/76 | 29/76 | 38/76 | 47/76 | 41/76 | 44/76 | 51/76 | 34/76 | 50/76 | 35/76 |
| **Confidence in Coping Questionnaire** | 21/30 | 23/30 | 27/30 | 25/30 | 20/30 | 23/30 | 21/30 | 20/30 | 27/30 | 13/30 | 21/30 | 28/30 |
| **Modified Carer Strain Index** | 17/26 | 13/26 | 13/26 | 18/26 | 18/26 | 11/26 | 2/26 | 6/26 | 5/26 | 6/26 | 8/26 | 5/26 |
| | | | | | | | | | | | | |

| Pre and Post Questionnaires | CW | | | DR | | |
|---|---|---|---|---|---|---|
| | Pre | Post | 3 Months | Pre | Post | 3 Months |
| **Strategies In Smartphone Use Questionnaire** | 37/78 | 44/78 | 49/78 | 11/78 | 32/78 | 42/78 |
| **Feeling About Memory Questionnaire** | 35/72 | 32/72 | 26/72 | 35/72 | 42/72 | 44/72 |
| **Memory Mistakes Questionnaire** | 58/80 | 53/80 | 65/80 | 58/80 | 58/80 | 63/80 |
| **Memory Strategies Questionnaire** | 55/76 | 49/76 | 43/76 | 16/76 | 46/76 | 43/76 |
| **Confidence in Coping Questionnaire** | 29/30 | 27/30 | 30/30 | 19/30 | 25/30 | 27/30 |
| **Modified Carer Strain Index** | 7/26 | 11/26 | 11/26 | N/A | N/A | N/A |
| | | | | | | |

## Appendix 19 – Neuropsychological Assessment Scores

| Neuropsychological Tests | PH | MM | LL | CC | CW | DR |
|---|---|---|---|---|---|---|
| ***Wechsler Test Adult Reading (WTAR)*** | 115(HA) | 102 (Av) | 99 (Av) | 112 (HA) | 100 (Av) | 89 (LA/Av) |
| **Repeatable Battery Assessment Neuropsychological Screen (RBANS)** | | | | | | |
| *Immediate Memory* | *69** (ExL)* | 69**(ExL) | 94 (Av) | 69**(ExL) | 94 (Av) | 76*(Bd) |
| *Visuo-spatial Construction* | *126 (S)* | 102 (Av) | 96 (Av) | 109 (Av) | 102 (Av) | 109 (Av) |
| *Language* | *90*(Av)* | 85*(L A) | 96 (Av) | 92 (Av) | 97 (Av) | 85(LA) |
| *Attention* | *97* (Av)* | 68**(ExL) | 112 (HA) | 88**(LA) | 109 (Av) | 82(LA) |
| *Delayed Memory* | *64** (ExL)* | 91 (Av) | 99 (Av) | 79**(Bd) | 107 (Av) | 88 (LA) |
| ***COWAT - Verbal and Category Fluency*** | | | | | | |
| *FAS* | *47*(Av)* | *34*(LA)* | *49 (Av)* | *25**(ExL)* | *28* (LA)* | *60 (Av)* |
| *Animals* | *13** (ExL)* | *19*(LA)* | *30 (S)* | *16**(LA)* | *16* (LA)* | *22(Av)* |
| ***Trail Making Test (TMT)*** | | | | | | |
| *Trails A* | 46**(LA) | 40**(ExL) | 21 (Av) | 38**(ExL) | 39 (Av) | 42*(Bd) |
| *Trails B* | 106**(ExL) | 71**(ExL) | 50 (Av) | 117**(ExL) | 75 (Av) | 95*(Bd) |
| ***Hayling & Brixton Test*** | | | | | | |
| *Hayling* | 18*(Av) | 6 (Av) | 6 (Av) | 6 (Av) | 7 (HA) | 8 (Gd) |
| *Brixton* | 4**(LA) | 6 (Av) | 8 (Gd) | 5**(MdA) | 6 (Av) | 4 (LA) |
| ***Mood*** | | | | | | |
| *Beck Anxiety Inventory (BAI)* | 3 (Min) | 1 (Min) | 1 (Min) | 5 (Min) | 6 (Min) | 1 (Min) |
| *Beck Depression Inventory (BDI)* | 8 (Min) | 0 (Abs) | 7 (Min) | 14*(Mild) | 7 (Min) | 5 (Min) |
| ***Prospective & Retrospective Memory Questionnaire (PRMQ)*** | | | | | | |
| *Retrospective* | 20**(LA) | 24**(Bd) | 19 (Av) | 30**(ExL) | 17 (Av) | 19 (Av) |
| *Prospective* | 24**(LA) | 27**(Bd) | 26**(Bd) | 33**(ExL) | 23*(LA) | 14 (Av) |

**Psychometric Test Key**: S=Superior Range, HA= High Average Range, Av=Average Range, LA=Low Average Range, Bd=Borderline Range, ExL=Extremely Low Range, MdA=Moderate Average, BAv=Below Average, Gd=Good.

**Mood Key**: Mild= Mild, Min=Minimal, Abs=Absent.

**Scores with *** = Scores Fall at least 1 Standard Deviation Below the Pre-morbid Range Score.

**Scores with **** = Scores fall two Standard Deviations or more below Pre-morbid Range Score.

## Appendix 20 – Summary of Themes Table

**Participant Themes**

| | Promotes Independence | Supports Task Completion | Positive Impact on Mood & Wellbeing | Confidence in Coping | Pressure to Complete Tasks | Meaningful Reminders |
|---|---|---|---|---|---|---|
| **PH** | X | X | X | X | | |
| **MM** | X | X | | | | |
| **LL** | X | X | X | | | |
| **CC** | X | X | X | X | | |
| **CW** | X | X | X | X | | |
| **DR** | X | X | | | X | X |

***Caregiver Themes***

| | Promotes Independence | Completion of Tasks | Promotes mood and wellbeing | Confidence in Coping | Maintains Dignity | Reduced Stigma | No Changes Noticed |
|---|---|---|---|---|---|---|---|
| **PH** | X | | X | X | X | X | |
| **MM** | | | | | | | X |
| **LL** | X | X | X | | | | |
| **CC** | X | X | | | X | X | |
| **CW** | X | X | X | X | | | |
| **DR** | N/A | N/A | N/A | N/A | N/A | N/A | N/A |

**Figures & Tables Appendix**

Figures



Tables