

FACTORS INFLUENCING THE UPTAKE OF MEMORY COMPENSATIONS
FOLLOWING ACQUIRED BRAIN INJURY

by

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Abstract

The use of memory strategies can promote independence in people who have an acquired brain injury but people often do not take readily to using such strategies. Certain demographic variables have been associated with the use of memory strategies these variables cannot be changed through therapeutic interventions. The aim of this thesis is to explore variables that may be modifiable through rehabilitation e.g. health beliefs and perceptions of aids, to see whether they help us understand factors influencing the uptake of memory strategies.

The thesis consists of three studies. The first uses Interpretative Phenomenological Analysis to explore how people feel about using memory strategies. The second is a cross sectional questionnaire design exploring the predictive power of variables identified in the first study to predict the use of strategies together with demographic variables. The third is a single case study utilising findings from the first two studies to help an individual use a mobile phone and Google calendar as a memory aid. A key factor in the use of memory compensations is the need to 'fit' the aid to an individual's lifestyle. Consequently, there is greater optimism for those who may otherwise be regarded as unlikely to use aids.

Dedications

This thesis is dedicated to:

John, my fiancé who has supported me through the highs and lows.

My parents, Carole and Henry, who have always believed in me.

My sister, Emma, my dancing partner!

Ann and Gordon (soon to be my parents-in-law), the food packages came in very handy!

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CHAPTER 1

LITERATURE REVIEW

1.1 *Introduction: brief overview*

It has been shown that using memory compensations to aid memory problems after acquired brain injury (ABI) is associated with increased functional independence (Wilson & Watson, 1996), which has been associated with better quality of life in people following traumatic brain injury (TBI) (Kreuter, Sullivan, Dahllöf and Siösteen, 1998). In fact, memory problems per se, have been found to be associated with poor quality of life in people with stroke (Donnellan, Hickey, Hevey and O’Neill, 2010). It is therefore important that people with memory problems are introduced to, and encouraged to use memory compensations as part of their rehabilitation programme.

Unfortunately, people with memory problems do not always readily adopt memory compensations even though numerous reviews have shown that such aids and strategies are effective (Cicerone, Dahlberg, Kalmar, Langenbahn, Malec, et al., 2000; Cicerone, Dahlberg, Malec, Langenbahn, Felicetti, et al., 2005; Cicerone, Langenbahn, Braden, Malec, Kalmar et al., 2011; Sohlberg et al., 2007). In 1996, Wilson and Watson stated “there is little general agreement or understanding concerning the reasons why some memory impaired people learn to use compensations efficiently and others fail to use them” (pp.466). Thus, it is very important to establish why this is the case. To date, a small number of studies have identified certain demographic and injury related variables that are associated with the use of memory strategies (Wilson & Watson, 1996; Wright, Rogers, Hall, Wilson, Evans, Emslie & Bartram (2001a); Wright, Rogers, Hall, Wilson, Evans & Emslie, 2001b; Bajo & Fleminger, 2002; Evans, Wilson Needham &

Brentnall, 2003). However, such variables, although useful in highlighting people who might need additional encouragement to use aids, cannot be changed through therapeutic interventions. Therefore, the aim of this thesis is to explore variables that are potentially modifiable through rehabilitation such as awareness of deficit, health beliefs and perceptions of memory compensations, to see whether they explain why people do not always wish to use them and whether these more modifiable variables are able to predict the use of memory aids over and above demographic variables. In particular, by beginning with a qualitative study, it might be possible to explore the link between currently known demographic predictors and use of memory compensations.

1.2 Definitions

For the purpose of this thesis the following terms are defined:

1) Acquired Brain injury (ABI) is an overarching term to describe any damage to the brain that takes place after birth which is not related to congenital disorders, developmental disabilities, or processes that progressively damage the brain (Rees Marshall, Hartridge, Mackie & Weiser, 2007). ABI can arise from a wide variety of aetiologies such as: stroke (cerebrovascular accident); tumours; infection; anoxia, or traumatic brain injury (TBI). The latter is initially caused by an external or physical force (e.g., fall; assault; accident) that results in trauma to the brain and includes secondary complications, such as haematoma (bleeding on the brain), oedema (swelling of the brain) or cerebral hypoxia (a lack of oxygen to the brain) (Daisley, Tams & Kischka, 2009).

2) The terms memory compensations, aids or strategies will be used to describe: external memory aids (such as written or electronic diaries, mobile phone, wall

calendar), internal memory aids (such as mnemonics, chunking, repetition) and environmental adaptation (e.g. putting things in key places).

3) The term assistive technology is also used to describe external electronic aids/devices such as electronic diaries, pagers, mobile phones, voice organizers that help people compensate for memory difficulties.

1.3 Rationale for the thesis

1.3.1 The extent of the problem

The International Brain Injury Association highlights that ABI is the world's leading cause of death and disability (International Brain Injury Organisation, 2011). In the UK over a million people each year will attend accident and emergency departments (A&E) as a result of a head injury. This figure includes injuries that do not result in damage to the brain (e.g. broken nose, fractured jaw, minor bumps to the head), as well as those injuries that are diagnosed by a medical professional that have caused direct damage to the brain such as a TBI (Daisley et al., 2009). Approximately 135, 000 people a year will be admitted to hospital due to the severity of their TBI; 130,000 people in England and Wales have a stroke each year and approximately 13,000 people a year are diagnosed with a brain tumour (Headway, 2009).

Following ABI many people have life expectancies similar to those of the general public (Lollar & Crews, 2003; Headway, 2009). In a more recent study however, McMillan, Teasdale, Weir and Stewart (2011) found that following a brain injury 40% of young people and adults had died 13 years post injury which is much higher compared to other non head injury patients (i.e. those who were hospitalised for any other injury that did not result in injury or damage to the head) and community control groups in which 28% and 19% respectively died. In addition, McMillan et al.

(2011) highlight that there was no significant relationship between injury severity and death between years two to thirteen, with those with mild brain injury experiencing a similar death rate (32.4%) to those with moderate (37.9%) and severe brain injury (32.4%). McMillan et al. (2011) suggest that differences in methodological designs, in particular limitations in the recruitment of representative samples may account for discrepancies between previous study findings. They also highlight that few studies have compared the death rate following brain injury with the death rate of the expected demographic population from which the head injured patients come (McMillan et al., 2011). McMillan et al. (2011) report that late after injury deaths following brain injury could not be explained by demographic characteristics (gender; age; deprivation) but occurred as a result of the same main causes (circulatory illness; respiratory illness; digestive illness; mental/behavioural or external cues) as for the general population. However they argue that those with ABI are at increased vulnerability and therefore further research to explain the range of causes of deaths is required. Nevertheless, Daisley, et al. (2009) and Headway (2009) estimate that in the UK, approximately 500,000 adults aged 16-74 live with long term disabilities as a result of TBI and an estimated 450,000 people in England live with severe disability as a result of a stroke (Daisley et al., 2009; Headway, 2009). Following ABI people can face a number of difficulties including motor, sensory, cognitive, emotional, behavioural and social difficulties (Wilson, 2010). Cognitive problems include difficulties with processing information, attention, concentration, executive functioning, language and memory (Wilson, 2010). However, the focus of this thesis is on memory difficulty which is one of the most common and most disabling cognitive deficits following ABI, with 36 % of people with severe ABI suffering significant and permanent memory impairments

(Wilson, 1995; Wilson, 2004). In the UK this equates to approximately 2500 people with newly acquired memory impairments each year (Wilson, 2004).

1.3.2 Quality of life and memory

Memory problems have widespread and long term consequences that significantly impact on: daily functioning, return to work and an individual's ability to live independently (Wilson & Watson, 1996). Given this, it is not surprising that ABI has an impact on quality of life/life satisfaction. Kaminski (2009) suggests that emotional functioning, social role functioning, daily life activities and the ability to participate in enjoyable activities are four key areas for assessing quality of life following brain injury. Findings concerning life satisfaction following TBI suggest that people report lower life satisfaction than those without brain injury (Tomberg, Toomela, Pulver & Tikk, 2005, Andelic, Hamergren, Bautz-Holter, Sveen, Brunborg & Roe, 2009; Jacobsson, Westerberg & Lexell, 2010). Interestingly, Jacobsson, Westerberg and Lexell (2010) note that some studies have reported that those with mild TBI report lower quality of life than those with moderate and severe TBI (Findler, Cantor, Haddad, Gordon & Ashman, 2001; Gordon, Haddad, Brown, Hibbard & Sliwinski, 2000), whilst other studies have found no relationship between quality of life and injury severity (Colantonio, Dawson & McLellan, 1998; Tomberg et al., 2005; Nestvold & Stavert, 2009). These mixed findings may be due to the different measures used as well as differences between study designs. Another possible explanation may be that as participants in Findler et al. (2001) and Gordon et al.'s (2000) studies were more recently injured, those individuals with mild TBI may have therefore been more aware of their difficulties, comparing their post-injury functioning to pre-injury ability and rating quality of life as lower. Nestvold and Stavert (2009) who reviewed quality of life

22 years post injury suggest that over time the association between quality of life and injury variables may not be as important as other variables.

Quality of life has been positively associated with employment outcomes following ABI (i.e. those employed full-time or part-time following ABI report a better quality of life than those who do not return to work) (Warren, Wrigley, Yoels and Fine, 1996; Steadman-Pare, Colantonio, Ratcliff, Chase & Vernich, 2001). In addition, people who were actively participating in leisure activities following TBI also reported better quality of life than those who were not (Corrigan, Bogner, Mysiw, Clinchot & Fugate, 2001). Individuals who have greater social support following TBI also rate quality of life as better (Steadman-Pare et al., 2001). Kreuter, et al. (1998) found that following TBI independence in activities of daily living, in particular, physical and social independence were correlated with quality of life in individuals ranging from 1 to 20 years post injury (i.e. lower scores on the sickness impact profile (SIP) indicating lower levels of physical and social dysfunction, which were associated with better quality of life). In addition, these authors report that positive mood, physical and social functioning, severity of disability and time since injury accounted for 46% of the variance in quality of life following TBI (Kreuter et al., 1998).

It has also been found that following ABI memory difficulties per se impact on quality of life. In particular, Donnellan et al. (2010) found that although at one month post stroke, people with memory difficulties rated their quality of life the same as prior to their injury (as they were less aware of their problems) those who were one year post stroke rated their quality of life significantly lower. Warren, Wrigley, Yoels and Fine (1996) found that increased life satisfaction among people with TBI was associated with memory independence, as measured by the Functional Independence Measure (FIM;

Keith, Granger, Hamilton & Sherwin, 1987). This measure assesses how much an individual relies on carers or other people to assist them in their daily living (i.e. in terms of memory how much an individual relies on others to remember information, events, details and so forth). Although it is not explicitly stated, functional independence may have been achieved through the use of memory compensations as this would reduce the need to rely on other people. Furthermore, being functionally independent following ABI has been associated with the use of six or more memory aids (Wilson, 1991; Wilson & Watson, 1996; Evans et al., 2003).

Wilson and Watson (1996) defined people as independent if they were either in paid employment, in full-time education or living alone (or any combination of these). In their 2003 study, Evans et al. modified the definition of independence to include those individuals who were living with family, but who took a significant role in running the household (e.g., taking responsibility for family finances) or caring for children. In both studies independence was associated with the increased use of memory compensations.

For the majority of people who have suffered an ABI memory functioning is unlikely to improve to any significant degree after the acute stages (Wilson & Watson, 1996) and there is little evidence that suggests that lost memory functioning can be restored following ABI (Wilson, 2009; Wilson & Kapur, 2009). Thus it is important to ensure that memory difficulties do not prevent people from maintaining independence (e.g., accessing employment or participating in leisure and social activities), by providing formal intervention in the form of cognitive rehabilitation (Wilson & Watson, 1996). Cognitive rehabilitation is a process whereby individuals are helped to achieve

their optimum physical, emotional, psychological and vocational functioning (Wilson, Gracey, Evans & Bateman, 2009).

1.3.3 Cognitive Rehabilitation for memory problems

Two types of cognitive rehabilitation models have been differentiated by Benedict (1989): the restorative (remedial/retraining) approach and the compensatory (adaptive) approach. The restorative approach aims to stimulate damaged neural networks or establish new networks through retraining using repetitive drills/rehearsal (Fleming, Shum, Strong & Lightbody, 2005). In contrast, the compensatory approach aims to teach people to bypass certain difficulties by employing strategies/compensations that will facilitate performance (Ben-Yishay & Diller, 1993). Zencius, Wesolowski and Burke (1990) undertook a study to see which type of approach was the most effective. They compared three strategies that they categorised as memory retraining strategies (written rehearsal, verbal rehearsal and acronym formation) with a compensatory strategy consisting of an external memory aid (memory notebook logging which consisted of participants recording information in a notebook that could be used for future reference). Six participants with TBI were trained in all four memory strategies. Participants were asked to choose two job adverts for each memory strategy (a total of eight different adverts were used per participant); participants were then asked to collect three pieces of information (employer; job title and experience/education needed) for every job advert. The objective of this study was to find out which strategy or aid enabled participants to recall the most information. Only memory notebook logging was found to be effective in increasing recall of the required information. Zencius et al. (1990) concluded that the time and effort required to implement cognitive retraining strategies exceeded the benefits, consequently it is

simpler and more efficient to train people to use memory compensations in order to improve recall of information.

The compensatory approach has been received more readily due to its nature and orientation towards the undertaking of functional activities (Ben-Yishay & Diller, 1993). Thus in clinical practice rehabilitation professionals often address memory difficulties by encouraging clients to use compensatory aids and strategies. Reviews of literature addressing cognitive rehabilitation for people with TBI or stroke also suggest that cognitive rehabilitation for memory difficulties should primarily focus on compensatory cognitive strategies/aids. Cicerone et al. (2000) and Cicerone et al. (2005) undertook a systematic literature review and concluded that the use of memory aid/strategy training (i.e. teaching people to use aids such as diaries or notebooks) should be a practice standard (as opposed to practice guidelines or practice option) for those with mild memory difficulties following ABI. In contrast, they suggest that for those with moderate or severe memory difficulties there is only probable evidence for the effectiveness of external compensations (including assistive technology). They therefore recommend that training people in the use of external compensations following moderate or severe memory difficulties should be a practice guideline. In addition, evidence also suggests that internal strategies (e.g. repetition, chunking) are ineffective for people with severe memory difficulties (Rees et al., 2007). In 2005, Cicerone et al. highlighted that there was a need for future research to address whether assistive technology was effective in aiding people with severe memory difficulties following ABI and that this should be investigated through the use of controlled studies. Rohling, Faust, Beverly and Demakis (2009) conducted a meta-analytic re-examination of Cicerone et al.'s (2000; 2005) systematic reviews. They report that there was a small

but significant treatment effect after controlling for improvements within non-treatment control groups, suggesting that there is only modest quantitative support for Cicerone et al. (2005) statement that “There is now a substantial body of evidence demonstrating that patients with TBI or stroke benefit from cognitive rehabilitation” (p. 1689). In addition, Rohling et al. (2009) highlight a modest improvement in cognitive performance for those participants who did not receive cognitive treatment, suggesting that this may have been due to natural recovery, motivational improvements, a placebo effect due to increased attention received by participation with the studies or practice effects on the test themselves. Rohling et al.’s (2009) meta-analysis revealed a medium-to-large effect for visuospatial treatment for stroke groups and a small-to-medium effect for language treatment for aphasia, thus providing further support in line with Cicerone et al.’s (2000; 2005) findings. However, Rohling et al. (2009) did not find evidence to support Cicerone et al. (2005) statement that there is substantial evidence to support the efficacy of memory, attention and language (functional communication) rehabilitation for individuals following TBI. They highlight that for memory rehabilitation their findings are mixed and weak, even though a medium-to-large effect for memory training emerged. This is because 61% of the evidence in support of memory rehabilitation came from single group pre and post (SGPP) design studies in which there were no control groups (Rohling et al., 2009). The differing findings may be due to methodological differences (Cicerone et al., 2011) for example Rohling et al. (2009) were not able to partial out the influence of severity of TBI on memory interventions, thus memory rehabilitation benefits for those with mild TBI may have been obscured by data collected from those with severe memory deficits (Rohling et al., 2009). In an update of their reviews and in response to Rohling et al.’s (2009) meta-analytic review,

Cicerone et al. (2011), state that there is now sufficient evidence that external aids, in particular assistive technology, are beneficial for those with moderate to severe memory difficulties following TBI or stroke. However, Cicerone et al. (2011) state that “the presence of significant executive dysfunction appears to limit the effectiveness of these interventions for people with severe memory deficits” (p.525). They therefore continue to recommend that training in the use of external compensations, including assistive technology should be a practice guideline in cognitive rehabilitation for those with moderate to severe memory difficulties. A number of other reviews since 2005 have further highlighted the effectiveness of memory aid training for people following ABI, suggesting that the use of external memory compensations should be encouraged and routinely taught (Rees et al., 2007; Sohlberg et al., 2007). Sohlberg et al. (2007) reviewed 21 studies that looked at the use of external memory compensations following ABI and found that the most common external aid to be used were written aids in the form of a memory notebook or daily planner (diary). Sohlberg et al. (2007) therefore also suggest that the use of external memory aids like these should be a ‘Practice Guideline’ as a method of improving day-to-day functioning for people with memory difficulties following ABI.

In summary, memory problems are common following ABI and have a significant impact upon an individual’s ability to function independently. This in turn has been found to impact on quality of life. Research has suggested that compensatory approaches are the most appropriate form of cognitive rehabilitation for memory problems following ABI as they can help maintain day-to-day independence (Cicerone et al., 2000; Cicerone et al., 2005; Cicerone et al., 2011). As memory problems impact on quality of life, there is a need to ensure that people use memory compensations in

order to maintain independence, thus it is important to understand: what factors are associated with the use of memory compensations following ABI, how people view the use of memory aids and strategies after ABI and their reasons for choosing to use or not to use them.

1.4 *Studies carried out in this thesis*

This research is composed of three studies each building upon the work of the previous study. The first two studies explore why individuals with brain injury choose to use (or not use) memory compensations to compensate for memory difficulties. The aim of the third study is to use all of the principles and findings from the first two studies to help an individual who was initially unwilling to use memory compensations, integrate an aid into their daily routine, thus improving recall of prospective information.

It is hoped that the information collected in these studies will shed further light on factors that are associated with the use of memory compensations following ABI and also highlight the implications these have for clinicians when teaching and encouraging people to use memory compensations.

1.5 *Overview of thesis*

1.5.1 Chapter 1

In the remainder of Chapter 1, the literature search strategies for the three studies in this thesis are described. Detailed discussion of the actual literature is located in each individual chapter.

1.5.2 Chapter 2

Chapter 2 is the first empirical study in this thesis and is a qualitative study using Interpretative Phenomenological Analysis to explore individuals' experiences of

using memory compensations following ABI and their motivation to use (or not use) them. This chapter is in five sections. Section 2.1 consists of a literature review that looks at factors that have been found to be associated with the use of memory compensations in people with brain injury. As the literature on ABI and the use of memory compensations is sparse, this section also discusses factors that are associated with the use of compensations in other populations. Section 2.2 provides information on the methodology used in the study. Section 2.3 covers the analysis of the transcripts, revealing six master themes. In section 2.4, there is a discussion about these findings and how they relate to previous research as well as study limitations. Section 2.5 discusses clinical implications of these findings and section 2.6 provides a summary of the chapter.

1.5.3 Chapter 3

Chapter 3 describes a cross sectional questionnaire based study that explores whether beliefs about memory aids predict the uptake of memory strategies together with: control beliefs, awareness, demographic and injury related variables. In order to measure beliefs about memory aids a new measure was developed (the Beliefs about Memory Aids Questionnaire: BMQ) based upon the themes identified in the qualitative study. In section 3.1, the main findings from Chapter 2 are revisited; however, more detail about relevant research is examined. In section 3.2, the study method is described, including the development of the BMQ. Section 3.3 consists of the data analysis and results. In section 3.4, there is a discussion about the results as well as study limitations and in section 3.5 clinical implications are examined. A summary of the chapter is provided in section 3.6.

1.5.4 Chapter 4

Chapter 4 consists of a single case study in which the principals and findings from Chapter 2 and Chapter 3 are used to help an individual (TK) successfully implement a memory aid to compensate for prospective memory difficulties. In section 4.1, an overview of the literature relating to electronic devices is provided. Advantages and limitations of these devices are also discussed. In section 4.2, a description of the client (TK) is provided along with information about his memory difficulties and his preferences for the memory aid. The study design, outcome measures, procedure, information about the memory aid (Google Calendar text alerts and a mobile phone) and training sessions are also provided in Section 4.2. Section 4.3, discusses the method used to analyse the data (non overlap of all pairs (NAP) analysis) and the results. In section 4.4, the study findings and limitations are discussed and in section 4.5 clinical implications explored. Section 4.6 provides a summary of the chapter.

1.5.5 Chapter 5

Chapter 5 provides a general summary of all three studies as well as an overview of the methodology used within this thesis. Implications for future research are also discussed.

1.6 Literature Review Chapter 2 and Chapter 3

In this section the search strategies and retrieved literature is presented. Detailed description and discussion of the literature is reserved for the introductory sections of each study.

1.6.1 Chapter 2 and Chapter 3 Literature review strategy

In order to address the main research aims it was important to identify relevant literature and to establish the degree to which there is a gap in the area. The main focus

of this thesis is the factors associated with why people choose to use or avoid using memory compensations following ABI. The two main research aims for the qualitative study (Chapter 2) were:

- 1) To gain a better understanding about people's perspectives and experiences of using memory aids and why they chose to use or to not use them following ABI.
- 2) To expand upon current research addressing this issue.

For the quantitative study (Chapter 3) there were three research questions:

- 1) What other modifiable variables predict the uptake of memory compensations: personal control beliefs; treatment control beliefs; lifestyle fit; threat appraisals; inappropriate beliefs or awareness of difficulties?
- 2) Do any of the modifiable variables add to the predictive value of demographic and injury related variables?
- 3) Do inappropriate beliefs about memory and memory compensations mediate the relationship between personal control beliefs and memory compensation use?

The rationale for the literature search for Chapters 2 and 3 stems from Wilson and Watson's (1996) statement that despite the effectiveness of using memory aids it is sometimes difficult to encourage people with memory difficulties to use them. It is therefore important to understand: why people do not use memory compensations, to consider whether demographic and injury related variables are important and, in addition, to look at the role of psychological or social factors that may influence their use. In particular, it has been noted that stigma and stigmatizing behaviour may be important. Stigma or stigmatizing behaviour is a process in which a negative social meaning is attached to an individual or their behaviours (Goffman, 1963). Stigma has

been found to impact on an individual's decision whether to disclose information about themselves, how much information to give if they provide any at all or to whom they disclose this information (Joachim & Acorn, 2000). It is therefore important to understand how stigma impacts on individuals who have survived ABI, and whether this has implications on their decision to use memory compensations.

1.6.2 Methodology

A systematic literature search was undertaken in order to identify relevant articles. Research in brain injury and non-brain injury populations (predominantly literature relating to people with physical and congenital disability and older adults) was searched in order to gain as much insight as possible into the research questions.

1.6.3 Search terms

For Chapters 2 and 3 a literature search was conducted initially in 2008/09, 2010 and again in 2011 using the following databases: PsycINFO, EMBASE, MEDLINE, CINAHL, Web of Science and EThOS. Published papers were selected for further inspection if their titles or abstracts included any of the key areas: 'brain injury', 'demographics', 'health beliefs', 'stigma', 'impaired self-awareness, and 'memory compensations'. Table 1.1 provides a comprehensive list of relevant terms that were selected from key articles. These were then searched as part of the main key terms. Wider use of search terms was captured by truncating some words using '*' or '\$', for example 'compensatory behav*' captured behaviour, behaviours and also the American spelling behavior. In addition, the use of 'OR' or 'AND' permitted search terms to be combined for a wider search. For example: Brain injur* OR traumatic brain injur* OR cerebrovascular accidents/ or cerebral haemorrhage/ or cerebral ischemia AND memory

aid* OR memory strateg* OR compensatory behav* OR Assistive technology OR
Electronic aid* OR Cognitive rehabilitation or rehabilitation.

Table 1.1: Comprehensive list of search terms

‘brain injury’	Brain injury OR Traumatic brain injury OR Acquired brain injur* OR cerebrovascular accidents/ or cerebral haemorrhage/ or cerebral ischemia
‘memory compensations’	Memory aid* or strateg* OR Assistive technology OR Assistive devices OR Electronic aid* OR Compensatory behav* OR Cognitive rehabilitation or rehabilitation
‘demographics’	Demographics OR Injury related variables OR Injury severity OR Time since injury OR Age
‘health beliefs’	Health behaviour or health attitudes OR Internal external locus of control OR Metacognition OR Illness representations OR Health indicators OR Self regulatory Model OR Adherence
‘stigma’	Stigma OR Attitudes towards
‘impaired self-awareness’	Awareness OR Impaired self-awareness OR Awareness deficits OR Insight

1.6.4 Inclusion/exclusion criteria

An initial search using the key concepts ‘brain injury’ AND ‘memory compensations’ was conducted. A second search was then undertaken using the initial two key concepts along with the addition of the search term ‘demographics’. The search term ‘demographics’ was then removed and replaced with the search term ‘health beliefs’. This process was repeated for ‘stigma’ and ‘impaired self awareness’. Titles and abstracts from brain injury research were examined. This resulted in 11 relevant papers for the search term ‘health beliefs’ and eight relevant papers for ‘stigma,’. Subsequently, studies from other populations were sought to see if they were relevant. Only papers that were available in English were reviewed. There was no specific restriction upon the age of participants in the studies. The initial search for Chapter 2 and Chapter 3 was set from 1996 to present date. This was to see if research had

addressed Wilson and Watson's (1996) statement. Searches revealed that a number of studies had specifically looked at demographic variables and the use of memory aids following ABI, in particular one study (Evans et al., 2003) aimed to replicate Wilson and Watson's (1996) findings. Only one study specifically looked at health beliefs and the use of memory compensations following ABI (Patel, 2008), however two other studies briefly addressed this issue (Kit, Mateer & Graves, 2007; Aben, Busschbach, Ponds & Ribbers, 2009). Kit, Mateer and Graves (2007) found that beliefs about one's memory capabilities as a measure of memory self efficacy (MSE) was significantly negatively correlated with the use of memory strategies following TBI and that memory strategies mediated the relationship between TBI and depression. However, Aben, Busschbach, Ponds and Ribbers (2009) found that MSE was not correlated with the use of strategies following stroke. One possible reason for this discrepancy is that participants in Aben et al. (2009) were inpatients on a stroke ward, so it is likely that they did not have as many opportunities to actively use memory compensations in comparison to participants in Kit et al.'s. (2007) study who were living at home.

Following the initial literature search, search dates were then extended to all dates available for each database to find other work related to any of the key areas. Reference lists from all papers that were kept were manually searched for other relevant papers and these were then obtained. Again any references and studies from these papers were also obtained if deemed to be of relevance.

The literature search for the thesis is reproduced in Table 1.2.

Table 1.2: Literature search strategy for Chapters 2 and 3.

<u>Search strategy - in title, abstract and full text</u>													
	Key Word	Found	Combined search	Manual or electronic Search	Abstract read	Abstract Kept/ used	Criteria rating of reviewed literature						
		PsychINFO; MEDLINE; EMBASE; CINAHL; Web of Science; ETHos					Quantitative Papers			Qualitative papers			Other
							Good quality	Acceptable quality	Poor quality	Good quality	Acceptable quality	Poor quality	
1	'brain injury'	313685											
2	'memory compensations'	16077	1 AND 2	799			-	-	-	-	-	-	-
3	'demographics'	441325	3 AND 1 AND 2	94	10	5	4	-	-	-	-	-	1 review paper
4	'health beliefs'	21915	4 AND 1	292	20	8	8	2	-	-	-	-	1 factor analytic paper
			4 AND 1 AND 2	20	5	3							
			4 AND 2	389	20	12	11	-	-	-	-	-	1 meta-analysis paper

<u>Search strategy - in title, abstract and full text continued</u>													
	Key Word	Found	Combined search	Manual or electronic Search	Abstract read	Abstract Kept/ used	Criteria rating of reviewed literature						
							Quantitative Papers			Qualitative papers			Other
							Good quality	Acceptable quality	Poor quality	Good quality	Acceptable quality	Poor quality	
5	'stigma'	31475	5 AND 1	69	10	8	5	-	-	3	-	-	-
			5 AND 1 AND 2	1	0	0	-	-	-	-	-	-	-
			5 AND 2	265	38	16	1	1	-	6	-	-	8 review papers
6	'impaired self-awareness'	19644	8 AND 1 AND 2	290	26	9	6	-	-	2	-	-	1 review paper

1.6.5 Results

In order to assess the quality of the papers selected, a checklist was developed by the author of this thesis based on Sale and Brazil's (2004) criteria for critically appraising qualitative and quantitative studies (Appendix A). In total 17 criteria were selected to assess the quality of quantitative studies. Papers were rated as: good quality if they met 14 or more of the criteria; acceptable quality if they met 9 - 13 of the criteria or poor if they met 8 or less. For qualitative papers a total of 14 items were included in the checklist. Papers were rated as good quality if they met 12-14 of the criteria; acceptable if they met 8-11 or poor if they met 7 or less. Tables 3 and 4 provide examples of the reviewed literature.

Despite the vast amount of literature available relating to brain injury there was a limited amount of research about factors that are associated with the use of memory compensations. To date, five studies have looked at demographic and injury related variables and the use of memory aids/strategies following ABI (Wilson & Watson, 1996; Wright, Rogers, Hall, Wilson, Evans, Emslie, and Bartram (2001a); Wright, Rogers, Hall, Wilson, Evans, and Emslie, 2001b Bajo & Fleminger, 2002 & Evans et al., 2003). One paper (Bajo & Fleminger, 2002) is a literature review and was therefore not rated. The remaining four papers were rated as good quality papers based on the quality criteria, however two studies were identified as being of greater relevance to the current thesis (Wilson & Watson, 1996; Evans et al., 2003) and are therefore discussed in more detail in Chapter 2. In summary, the most important demographic variables that predict use of memory aids are: being less than 30 years old at the time of injury, current age (i.e. being younger) and the more aids used premorbidly.

In total eleven studies were retrieved that relate to brain injury and health beliefs/psychosocial variables (Moore & Stambrook, 1992, Lubusko, Moore, Stambrook & Gill, 1994; Moore & Stambrook, 1995; Frank, Johnson, Morrison, Pollard & MacWalter, 2000; Bains, Powell & Lorenc, 2007; Kit, Mateer & Graves, 2007; Whittaker, Kemp & House, 2007; Patel, 2008; Cabassa, Lagomasino, Dwight-Johnson, Hansen & Xie, 2008; Izaute et al 2008; Medley, Powell, Worthington, Chohan & Jones, 2010). Of the eleven studies, one paper was not suitable for reviewing on the basis of the checklist as it was a factor analytic study (Cabassa et al., 2007), the remaining ten studies were all quantitative papers and based on the quality criteria two were rated as acceptable (Moore & Stambrook, 1992, Moore & Stambrook, 1995) and eight as good quality papers. Two studies that specifically related to health beliefs and ‘memory compensations’ (including rehabilitation) following brain injury (Kit et al., 2007; Patel, 2008) and were deemed to be most relevant to the study aims were retrieved. In addition, a further twelve studies relating to health beliefs and beliefs about control within other health populations such as asthma, heart attacks and multiple sclerosis (e.g., Whitmarsh, Koutantji & Sidell, 2003; Vaughan, Morrison & Miller, 2003; Jessop & Rutter, 2004; Spain, Tubridy, Kilpatrick, Adams, & Holmes; 2007; Barclay et al., 2007) were viewed as significant to the current thesis as they highlighted health factors associated with adherence to medication and rehabilitation. Of particular interest was the study by Verhaeghen, Geraerts, and Marcoen (2000) who explored the relationship between perception of memory complaints, coping and well being in older adults. Of the twelve studies one was a meta-analysis (Haggard & Orbell, 2003) so was not subject to a quality rating. The remaining eleven studies were quantitative studies and were considered good quality studies based on the checklist criteria. Overall it is noted that

research findings into control beliefs within ABI are comparable to those in other health populations. In summary, research about health beliefs suggests that those who perceive themselves to have greater control over their condition are more likely to have better outcomes. This is discussed in greater detail in Chapter 2 and Chapter 3.

Eight papers were identified about brain injury and stigma, however the majority of the literature related to misconceptions about brain injury held by the general public. Two of the eight studies (Simpson, Mohr & Redman, 2001; Linden & Boylan, 2010) were qualitative studies, and six were quantitative studies (Gouvier, Prestholdt, & Warner, 1998; Swift & Wilson, 2001; Redpath & Linden, 2004; Hux, Deuel Schram, & Goeken 2005; Linden, Rauch & Crothers, 2005; Chapman & Hudson, 2010), all were rated as good quality papers. These papers are not discussed in detail because the main focus of this thesis is about the use of memory compensations following brain injury. No literature about stigma, brain injury and use of memory compensations was found. However, studies about the use of assistive devices and stigma in other populations such as people with disability and older adults were identified. In total sixteen papers were relevant to the current thesis, and of the sixteen papers eight were review papers (Phillips & Zhao, 1993; Brookes, 1998; Joachim & Acorn 2000; Bender Pape, Kim & Weiner, 2002; Polgar, 2002; Parette & Scherer, 2004; Polgar 2006; Roulstone, 2007) and so were not subject to quality rating. Review papers by Bender-Pape, Kim and Weiner (2002), Parette and Scherer (2004) and Roulstone (2007) were deemed to be most relevant to the present thesis. Six of the remaining eight papers were qualitative studies (Aminzadeh & Edwards, 1998; Lund & Nygard, 2003; McCreadie & Tinker, 2005; Palmer & Seale, 2007; Capriani, Porter & Greaney, 2007; Resnik, Allen, Isenstadt, Wasserman, & Iezzoni 2009) and based on the quality criteria were rated as

good. Lund and Nygard's (2003) study was deemed to be of most importance for this thesis. The remaining two studies were quantitative studies; one was rated as a good quality paper (Roelands, Van Oosta, Buyssea & Depoorter, 2002) and the other as acceptable (Phillips & Zhao, 1993). This literature suggests that compensatory devices need to fit individual value systems and convey one's desired self image otherwise assistive devices are unlikely to be used. This is discussed in greater detail in Chapter 2 and Chapter 3.

No research associated with the use of memory compensations per se and self-awareness following brain injury was found. However, nine studies relating to self-awareness and rehabilitation were highlighted as being relevant to the current thesis (Fleming, Strong & Ashton, 1996; Dirette, 2002; Ownsworth & McFarland, 2004; O'Callaghan, Powell & Oyebode, 2006; Trahan, Pépin & Hopps, 2006; Fleming & Ownsworth, 2006; Ownsworth, Turpin, Andrew & Fleming 2008; Medley, et al., 2010; Lundqvist, Linnros, Orlenius & Samuelsson, 2010). One paper was a review study and was therefore not rated (Fleming & Ownsworth, 2006). Six of the remaining eight studies were quantitative studies and two were qualitative studies, all were rated as good quality studies based on the criteria derived from Sale and Brazil (2004). The two qualitative papers (Dirette, 2002; O'Callaghan et al., 2006) were deemed to be of most importance and highlight that real life 'aha' moments allow for a comparison of pre-injury and post injury abilities leading to increased awareness. In summary, the general awareness literature suggests that people who have a better awareness of their difficulties following brain injury are more likely to participate in rehabilitation. The most relevant studies to this thesis can be found in Table 3 and Table 4.

Table 1.3: Brain injury studies most relevant to the study for Chapters 2 & 3.

Brain injury studies deemed to be most relevant and significant for Chapters 2 and 3.				
Key area	Authors	Year	Participants & Type of study	Findings
<u>Demographics</u>	Wilson & Watson	1996	<u>Quantitative study</u> 43 people in a long-term follow-up study. 20 participants had pure amnesia; 23 had pure amnesia plus additional cognitive difficulties.	Hierarchical log-linear model used to explore interactions between a number of variables found to be predictive of independence following ABI. This study shows that age, severity of memory impairment, and additional cognitive deficits are important variables in predicting independence and use of compensations several years post-rehabilitation
	Evans, Wilson, Needham, & Brentall.	2003	<u>Quantitative study</u> 94 people with brain injury (64 male; 30 female TBI and ABI) and their carers participated in a quantitative questionnaire based study about the use of memory aids.	The use of memory aids correlated with level of independence; external memory aids such as diary, notebooks were the mostly used aids; current age, time since injury, number of aids used pre-morbidly, and degree of attentional functioning were the best predictors of the use of memory aids following brain injury.
<u>Health Beliefs</u>	Kit, Mateer, & Graves.	2007	<u>Quantitative study</u> 84 participants (42 TBI & 42 controls) took part in a quantitative questionnaire based study on beliefs about memory.	The TBI group endorsed lower memory self-efficacy, used more memory strategies and were more depressed than control participants. However, it was found that memory self-efficacy and the use of memory strategies mediated the relationship between TBI and depression. Kit et al suggest that memory aids may highlight a change in pre and post identity.
	Patel	2008	<u>Quantitative study (Clinical Dr Thesis)</u> 50 participants (32males & 18female) took part in a questionnaire study looking at health beliefs (IPQ-r) and the use of memory compensations following ABI.	Hierarchical regression analysis revealed that illness perceptions significantly added to the predictive value of demographic variables (education, severity of memory impairment) and emotional distress in predicting the use of memory compensations following ABI. Perceptions of greater treatment control and a more cyclical timeline and were the most significant predictors of memory compensations. The regression model explained 53% of the variance in the use of memory compensations.
<u>Stigma</u>	Simpson, Mohr & Redman	2001	<u>Qualitative study</u> 39 participants with TBI (Italian, Lebanese and Vietnamese backgrounds) and their family members were interviewed about their perceptions and experiences of TBI and accessing rehabilitation services.	There is a universal experience of TBI that transcends cultures and that rehabilitation services were valued, in particular families appreciated friendliness and guidance provided by rehabilitation staff. People with TBI from all three cultures experienced stigma and social isolation. It was noted that for Asian cultures the notion of shame brought by having a relative with TBI was upon the whole family and not just the individual. In addition, family support was not always available to the individual with TBI as a result of family conflict, which was also linked to stigma.

Brain injury studies deemed to be most relevant and significant for Chapters 2 and 3continued				
Key area	Authors	Year	Participants & Type of study	Findings
<u>Stigma cont</u>	Linden & Boylan	2010	<u>Qualitative study</u> 16 members of the general public in Ireland participated in semi-structured interviews about the role people have in society after a brain injury, the challenges faced by people and the characteristics ascribed to someone who has had a brain injury.	Participants often described people with a brain injury using negative labelling such as 'not normal', 'handicap', 'sad', 'mentally disabled' and the notion that people would be laughed at and dismissed following a brain injury. There was also a general failure to realise that a brain injury was a hidden disability and people identified the most common problems of a brain injury as relating to physical, cognitive, emotional and social functioning.
<u>Impaired self-awareness?</u>	O'Callaghan, Powell & Oyebode,	2006	<u>Qualitative study</u> 10 participants (7male & 3 female) aged 21-60 years participated in semi-structured interviews about their experiences of gaining awareness of their difficulties following ABI.	Eight master themes emerged from the transcripts. O'Callaghan et al highlight that: knowledge of deficits was acquired through personal experiences in real life situations as well as the reactions of others. Rehabilitation provided explanations for difficulties as well as a normalising and supportive environment that facilitated people in acknowledging their deficits.
	Lundqvist, Linnros, Orlenius & Samuelsson	2010	<u>Mixed methods study</u> 21 participants (9 male & 12 women) following ABI participated in a 6 month group therapy programme to improve self-awareness. Mixed methods were used to ascertain whether the intervention was successful.	Self-awareness and more use of effective coping strategies were found to be specific gains, while social and emotional effects were perceived general benefits of the group therapy. Participating in the group therapy programme had a positive impact on participant's life and work situation as well as on their self-confidence. In addition, it helped increase people's understanding of the consequences of their neuropsychological deficits, improve awareness of their impairments and helped them to develop coping strategies.

Table 1.4: Non Brain injury studies deemed most relevant for Chapters 2 and 3.

Non Brain injury research deemed to be most relevant and significant for Chapters 2 and 3.				
Key area	Authors	Year	Participants & Type of study	Findings
<u>Health beliefs</u>	Verhaeghen, Geraerts, & Marcoen	2000	<u>Quantitative study</u> 179 older adults completed the Metamemory in Adulthood Questionnaire in order to explore older adults memory complaints.	Perceptions of memory complaints set an appraisal mechanism in motion, in which heightened memory related anxiety and an increase in perceived seriousness of one's memory problem influenced coping behaviour. Verhaeghen et al. noted that people with a more internal locus of control believed they had greater control over their memory abilities and so were more inclined to look for and/or apply more efficient coping mechanisms/strategies.
	Spain, Tubridy, Kilpatrick, Adams, & Holmes	2007	<u>Quantitative study</u> 580 participants with confirmed multiple sclerosis were asked to complete a number of questionnaires in order to determine the impact of physiological factors and psychological factors on health-related quality of life (HRQoL).	Found that 38-71% of the variance in HRQoL was predicted by a combination of physiological and psychological factors. It was highlighted that illness perceptions was an independent factor contributing to HRQoL. In the domains of role and social function, activities most highly valued by patients with MS, depression, anxiety, fatigue and illness perceptions are key determinants, all of which have the potential to be improved through specific interventions.
<u>Stigma</u>	Lund & Nygard	2003	<u>Qualitative study</u> 17 participants with a physical disability participated in a qualitative study about their experiences of using assistive devices in their occupation and how they act on their experiences.	Three types of users were identified: pragmatic users; ambivalent users and reluctant users and represented different adaptive approaches to achieve a desired self-image. It was noted that whether an assistive device was functionally adequate was not the most important component in a person's decisions about whether to use it. The use of assistive devices was also found to encourage stigmatization and a handicap identity as a result of the devices being highly visible to others. It is suggested that the reasons assistive devices are used or discarded, goes beyond the tradition medical perspective that focuses on aspects related to actual performance.
	Resnik Allen, Isenstadt, Wasserman & Iezzoni,	2009	<u>Qualitative study</u> 61 community dwelling older adults from three groups: White non-Hispanic, Black and Hispanic participated in a qualitative study about older adults' perspectives of mobility aids.	The use of mobility aids as a result of aging and physical decline contributed to stigmatizing attitudes users reported that they were subject to negative biases. It was found that these stigmatizing attitudes deterred the use of mobility aids in ethnic minorities and that devices that were not visually appealing were often discarded. Older adults suggested mobility aids that were 'fashionable' would be more appealing.

1.7 Literature Review Chapter 4

In this section the literature search strategy and results for Chapter 4 are presented.

1.7.1 Chapter 4 Literature review strategy

The main aim of Chapter 4 was to use the principles and findings from the qualitative and quantitative study to help an individual implement a suitable memory aid (Google Calendar and mobile phone) to compensate for memory difficulties following ABI.

It has been noted that despite the effectiveness of external memory compensations, (e.g. a diary or notebook) assisting people to recall information following ABI (Sohlberg & Mateer, 1989; McKerracher, Powell & Obeode, 2005), remembering to use a memory compensation can itself be a memory task (Wilson Emslie, Quirk & Evans, 1999). One way of overcoming this difficulty is through the use of assistive technology as they often include a cueing device as well as the facility to store and retrieve information (Kapur, Glisky & Wilson, 2004). It is therefore important to review the literature around the use of assistive technology following ABI and evaluate whether these devices have had a positive impact in aiding memory.

1.7.2 Methodology

A systematic literature search was undertaken in order to identify relevant articles. Articles relating to people with brain injury and other populations were reviewed in order to gain as much information as possible about the devices available and whether they are effective in compensating for memory difficulties.

1.7.3 Search terms & Inclusion/Exclusion Criteria

A literature search was conducted in 2011 using the following databases: PsycINFO, EMBASE, MEDLINE, CINAHL, Web of Science and EThOS. Published papers were selected for further inspection if their titles or abstracts included any of the key areas; ‘brain injury’, and ‘assistive technology.’ Search terms relating to the use of assistive technology for aiding memory difficulty were used (Table 1.5). Wider use of search terms was captured by truncating some words using ‘*’ or ‘\$’ as well as combining searches using ‘OR’ or ‘AND’. Only those papers with outcome data relating to the use of assistive technology for memory were retrieved, all other papers that were not related to aiding memory, such as assistive technology to aid driving or those devices used within the home, were not reviewed. Only papers that were available in English were retrieved. Again there was no specific restriction upon the age of participants in the studies. The search was set to include all available dates within each database. References from all papers were manually searched for other relevant papers including those that looked at the use of assistive technology for aiding memory within other areas (e.g. older adults).

Table 1.5: Key search terms used for Chapter 4

‘brain injury’	Brain injury OR Traumatic brain injury OR Acquired brain injur* OR cerebrovascular accidents/ or cerebral haemorrhage/ or cerebral ischemia
‘assistive technology’	Assistive technology OR Assistive devices OR Electronic aid*

Table 1.6: Search strategy for Chapter 4.

<u>Search strategy - in title, abstract and full text</u>													
	Key Word	Found	Combined search	Manual or electronic Search		Abstract Kept/ used	Criteria rating of reviewed literature						
		PsychINFO; MEDLINE; EMBASE; CINAHL; Web of Science; ETHos					Quantitative Papers			Qualitative papers			Other papers
							Good quality	Acceptable quality	Poor quality	Good quality	Acceptable quality	Poor quality	
1	'brain injury'	313685											
2	'assistive technology'	16077	1 AND 2	267									
					NeuroPage & Pager systems	10 (9 NeuroPage 1 in-house pager)	4RCT						5SCED: 4 Good quality 1 Acceptable quality 1 audit review paper
					PDA's	7	3	1				1	2 SCED: 2 Acceptable quality
					Voice Organisers	4	4						
					Mobile Phones	7	3						4SCED: 1 Good quality 3 Acceptable quality
					Google Calendar	2	2						

1.7.4 Results

In order to assess the quality of papers selected for Chapter 4, the checklist based on Sale and Brazil's (2004) criteria for critically appraising qualitative and quantitative studies as outlined in section 1.6.5 was used (Appendix A). However, to appraise the quality of single case experimental design (SCED) papers in Chapter 4, the rating criteria as suggested by Tate et al. (2008) was used (Appendix A). Papers were rated as: good quality if they met 9 or more of the criteria; acceptable quality if they met 7-8 of the criteria or poor if they met 6 or less.

The literature search for Chapter 4 is presented in Table 6 and the most relevant literature to this thesis is presented in Table 7. An overall total of 35 studies that were relevant to the key terms 'brain injury' and 'assistive technology' were kept. Of these 35 studies, 30 studies directly evaluated the effectiveness of assistive technology in aiding memory following ABI (four were randomised controlled trials, 12 were quantitative studies, 11 were single case experimental design (SCED) studies, 1 qualitative study and one study was a follow up audit review paper). The remaining five studies were literature review papers (Kapur, Glisky, & Wilson, 2004; Scherer & Glueckauf, 2005; De Joode, van Heugten, Verhey & van Boxtel, 2010; Morris & Reinson, 2010; Scherer, Elias & Weider, 2010) that address the effectiveness of all assistive technology available for people with memory difficulties following ABI. A brief overview of the literature is discussed below, however a more detailed review can be found in the introductory section to Chapter 4.

Since the 1990s advances in technology have resulted in a number of studies investigating the use of assistive technology for people with memory difficulties. Eight studies (Wilson, Evans, Emslie & Malinek, 1997; Evans, Emslie & Wilson, 1998; Wilson, Emslie, Quirk & Evans, 1999; Wilson, Emslie, Quirk & Evans, 2001; Wilson,

Emslie, Quirk, Evans & Watson, 2005; Emslie, Wilson, Quirk, Evans & Watson, 2007; Fish, Manly, Emslie, Evans & Wilson, 2008; Wilson, Emslie, Evans, Quirk, Watson & Fish, 2009) have looked at the efficacy of a portable pager called NeuroPage that provides message alerts for prospective memory tasks. A recent addition to the NeuroPage literature looks at differences between initial users of NeuroPage and users ten years on (Martin-Saez, Deakins, Winson, Watson & Wilson, 2011). Martin-Saez et al. (2011) report that a similar number of patients were referred in both cohorts; that the most frequent message sent each week was related to medication and that in the second cohort (i.e. ten years on) NeuroPage is now used to send messages about mood management. Martin-Saez et al. (2011) highlight that NeuroPage meets individual service user needs at different stages of their rehabilitation.

Two of the eight studies that have evaluated the effectiveness of NeuroPage were single case studies (Evans et al., 1998; Wilson et al., 1999) and two papers were group single case studies (Wilson et al., 1997; Emslie et al., 2007). All four papers demonstrated that NeuroPage is able to increase independence following ABI and were rated as good quality studies based on the SCED checklist criteria. The remaining studies four were randomised controlled trial (RCT) studies (Wilson et al., 2001, 2005, 2009; Fish et al., 2008) and are the only randomised controlled trials to look at the effectiveness of assistive technology (De Joode et al., 2010). Based on the quality criteria all four papers were rated as good quality. In summary, NeuroPage has been found to be successful in aiding prospective memory in all studies and is deemed to be one of the most successful compensatory aids (De Joode et al., 2010; Martin-Saez et al., 2011). Following the success of NeuroPage, a single case study by Kirsch, Shenton and Rowan (2004), which was rated as an acceptable quality paper, reported that an ‘in-

house' paging system increased the number and quality of memory log entries following ABI.

Seven studies have looked at the use of Personal Digital Assistants (PDAs) (Kim Burke, Dowds, Robinson Boone & Park 2000; Wright, Rogers, Hall, Wilson, Evans, Emslie, et al., 2001; Wright, Rogers, Hall, Wilson, Evans, & Emslie, 2001; Thone-Otto & Walther, 2003; Gentry, Wallace, Kvarfordt and Lynch; 2008; DePompei, Gillette, Goetz, Xenopoulos-Oddsson, Bryen and Dowds, 2008; Gillette & DePompei, 2008). One paper was a qualitative (survey) study that provided case examples and was rated as poor based on the quality criteria outlined by Sale and Brazil (2004). A further two studies were multiple single case studies (DePompei et al., 2008; Thone-Otto & Walther, 2003) and were rated as acceptable quality based on Tate et al.'s (2008) quality criteria for single case studies. The remaining four papers were quantitative studies. Three of the quantitative studies were rated as good quality papers (Wright et al., 2001 a, b; Gillette & DePompei, 2008) and one as acceptable (Gentry et al., 2008). In general, there have been positive findings about using PDAs to aid memory following ABI. However, there has been mixed reviews about the suitability and usability of consumer-level (off the shelf) PDAs, with some researchers suggesting that PDAs that are specifically adapted for people with ABI are more accessible.

Two group quantitative studies (van den Broek, Downes, Johnson, Dayus & Hilton, 2000; Yasuda, Misu, Beckman, Watanabe, Ozawa & Nakamura, 2002) and one within-subjects trial study (Hart Hawkey & Whyte (2002) has also looked at the efficacy of a voice organizer as a memory aid following ABI. In addition, another quantitative study (Oriani et al., 2003) looked at the effectiveness of a voice organizer for people with dementia. All four quantitative studies were rated as good quality. All

four studies reported improvement in participants remembering prospective information when using the voice organizer.

Six papers have evaluated the use of mobile phones and smartphones in aiding memory following ABI. Four studies were single case studies; one was rated as good quality (Svoboda Richards, Polsinelli & Guger, 2010) and three were rated as acceptable quality (Wade & Troy, 2001; DePompie et al., 2008; Stapleton Adams & Atterton, 2010) based on the quality criteria outlined by Tate et al. (2008). Two papers were quantitative studies (Fish, Evans, Nimmo, Martin, Kersel, Bateman et al., 2007; Culley & Evans, 2010) and looked at the use of the mobile phone following brain injury and an additional quantitative study (Pijnenborg, van den Bosch, Evans & Brouwer, 2007) assessed the effectiveness of mobile phone text alerts for people with schizophrenia and associated memory difficulties. All three quantitative studies (Fish et al., 2007; Pijnenborg et al., 2007; Culley & Evans, 2010) were rated as good quality studies according to the criteria derived from Sale and Brazil (2004). All seven studies have reported general improvements in carrying out prospective memory tasks when using a mobile phone or smartphone. The study by Wade and Troy (2001) is important as it highlights that the mobile phone is a widely accepted device within everyday society thus any embarrassment about having to use a memory aid can be reduced by using a mobile phone.

A very recent published paper (McDonald, Haslam, Yates, Gurr, Leeder, & Sayers, 2011) looks at the effectiveness of a commercially available novel memory aid: Google Calendar, to help compensate for memory difficulties following ABI. McDonald et al. (2011) undertook a randomised control crossover within-subjects design study, and found that Google Calendar was more effective than a standard diary in aiding prospective memory tasks. In addition, an unpublished quantitative study also

highlights the effectiveness of Google Calendar (Diamond, Gerhand & Powell, 2011). In particular, the authors found that SMS text message reminders from Google Calendar were more effective at aiding individuals with mild to moderate memory difficulties than a tradition paper diary or a Dictaphone These studies are the most relevant and significant for this thesis and are rated a good quality studies.

Overall, the use of assistive technology has been positive and more recently Cicerone et al. (2011) state that there is now sufficient evidence that assistive technology is beneficial for those with moderate to severe memory difficulties following TBI or stroke.

Table 1.7: Assistive device research deemed most relevant for Chapter 4

Examples of research on the use of electronic memory aids				
Key area	Authors	Year	Participants & Type of study	Findings
<u>NeuroPage</u>	Wilson, Emslie, Quirk & Evans	1999	<u>Single case study</u> George a 23 year old male who sustained a TBI following a road traffic accident participated in a single case ABA design study. Seven target behaviours were identified and George was sent predetermined messages using NeuroPage, an electronic paging system, to aid him in recalling prospective memory information/tasks.	A significant improvement of target behaviours relative to baseline was reported when using NeuroPage. Preparing meals at 5.15pm increased from 50% at baseline to 100% during the intervention phase. This reduced further when NeuroPage was removed. Putting tablets on table increased from 0% success rate at baseline to 100% at intervention. Following the removal of NeuroPage George maintained this behaviour suggesting that NeuroPage had helped him establish a routine.
	Wilson, Emslie, Quirk & Evans.	2001	<u>Randomised controlled trial.</u> 143 people aged between 8-83 years the majority of whom had sustained a stroke or TBI. Participants either received the NeuroPage 2 weeks after baseline or 7 weeks after baseline.	Found that over 80% of participants who completed the 16week trial were significantly more successful in carrying out everyday tasks such as self care, taking medication, attending appointments when they used NeuroPage. They also noted that for some participants' recall of these tasks were maintained 7 weeks after returning the pager. Wilson et al suggest that using NeuroPage enabled people to develop and establish routines.
<u>PDA's</u>	Gentry, Wallace, Kvarfordt & Lynch	2008	<u>Quasi-experimental study</u> 23 community dwelling participants (16 male and 7 female) following severe TBI took part in a quasi-experimental study examining the efficacy of two basic unmodified off the shelf PDAs (Handspring Visor & Palm Zire).	Following a training period with the PDAs, people's self-rated assessment for how well they were performing everyday life tasks significantly improved. Changes occurred at least 1year after the participants had sustained a severe TBI, when spontaneous recovery effects are typically considered to have resolved, thus consumer level PDAs are effective memory aids for people following TBI when they are introduced using participant centred and home-based training interventions.
<u>Voice organisers</u>	van den Broek, Downes, Johnson, Dayus & Hilton	2000	<u>ABA experimental design study</u> Five people following ABI participated in a ABA experimental design study to evaluate the utility of a 'Voice Organiser' as a memory aid. Performance was assessed on two measures; a Message-Passing task requiring prospective recall after a delay of 9 hours, and a Domestic Task that involved the recall of household chores following a delay of 1-6 days.	All five participants benefited from the introduction of the aid on the Message-Passing task and four participants improved their prospective recall on the Domestic Task measure. Removal of the Voice Organizer resulted in a deterioration in performance, with the exception of two participants who had incorporated the tasking into their routine. The Voice Organiser can be programmed autonomously or by a carer and so can aid independence.

Examples of research on the use of electronic memory aids continued				
Key area	Authors	Year	Participants & Type of study	Findings
<u>Mobile Phones</u>	Wade & Troy	2001	<u>Case studies</u> Five individuals (3males & 2 females) aged 18-51 years old participated in effectiveness of a mobile phone as a memory aid following brain injury. Target areas (e.g. taking medication, remembering a weekly lunch meeting) were identified by each patient and data was recorded for a baseline period (up to 6weeks) and then for 12 weeks with the phone. this study which looked at the	They found that the mobile phone as a memory aid was effective in increasing self-initiated behaviours for all users. They note that the mobile phone was not only of benefit for everyday memory problems, but also assisted individuals who had problems with planning and organization. It was noted that the mobile phone, like Neuropage, was only needed for some participants on a short-term basis to help teach routine for target areas. Wade and Troy highlight that one of the advantages of using a mobile phone is that in today's society it is part of our everyday life. Therefore any such embarrassment at using a memory aid can be avoided or minimised.
	Culley & Evans,	2010	<u>Within subjects study</u> 11 people an attending out-patient rehabilitation service participated in the single-blind within subjects trial to investigate whether sending SMS text alerts to people following TBI increased recall of rehabilitation goals.	Results showed that rehabilitation goals within the 'SMS text alert' condition were significantly recalled better than those in the 'no text alert' condition. In both the cued recall and free recall condition more information was recalled when participants had received a SMS text alert then without. In addition, in both recall conditions there was a significant improvement in recall over time, with more information being recalled for rehabilitation goals within the 'SMS text alert' condition at 7 days than at baseline.
<u>Google Calendar</u>	McDonald, Haslam, Yates, Gurr, Leeder, & Sayers.	2011	<u>Randomised controlled trial</u> 12 participants (6 male & 6 female) aged between 19-65 years with ABI were recruited for a randomised control crossover within-subjects design study. Participants either received a standard diary followed by the google calendar or vice versa.	McDonald et al. found that 8 participants completed more prospective memory intentions when using the Google Calendar than when using standard diary. Both memory aids helped memory however Google Calendar was most successful. McDonald et al. highlight that those individuals with milder memory impairments performed considerable better with the Google Calendar and that those individuals with more severe and executive dysfunction benefited least from both memory aids. Nine of the participants indicated that they preferred using Google Calendar.

CHAPTER 2

A QUALITATIVE ANALYSIS

2.1 Introduction

As discussed in Chapter 1 of this thesis, memory impairment is a sequelae of ABI and much of the work in memory rehabilitation focuses on interventions that teach people to compensate for their impairment by employing external memory compensations, such as written or electronic diaries, tape recorders and electronic organizers (Wilson, 2010). However, it has been noted that whilst some individuals make efficient use of memory compensations others do not. This variation in use of memory compensations may be a result of people “feeling it is cheating” or thinking that by using memory compensations it “will reduce their chances of natural recovery occurring” (Wilson & Watson, 1996, p. 466). A number of studies using quantitative approaches have explored a range of factors that influence strategy use (Wilson & Watson, 1996; Evans, Wilson, Needham & Brentnall, 2003; Patel, 2008); however, there has been no qualitative study to date that has explored the perspectives of people with memory impairments in relation to the use of memory compensations.

Given there is little research within this specific area in people with ABI, it is helpful to initially draw upon this small area of research in ABI as well as work involving other populations, for example: older adults, those with physical disabilities (e.g. multiple sclerosis; spinal cord injury), those with congenital impairments (e.g. cerebral palsy) and those with acquired disability such as limb loss. So far, demographic and injury related variables such as current age and attentional skills, have been explored (e.g. Wilson & Watson, 1996; Evans et al., 2003). However, given that these

are static variables it is also important to examine modifiable variables that can be addressed in rehabilitation, such as health beliefs (Patel, 2008) memory self-efficacy (Kit Mateer & Graves, 2007; Aben, Busschbach, Ponds & Ribbers, 2009) and attitudes towards assistive devices (Parette & Scherer, 2004; Lund & Nygard, 2003). These factors can be considered to be potentially modifiable and so the studies have implications for rehabilitation professionals working with those who have memory impairments. A study by Patel (2008) that was based upon the common sense model of illness representation (Leventhal, Nerenz & Steele, 1984), explored health beliefs, specifically beliefs about memory difficulties, illness identity, consequences, personal and treatment control, timeline and emotional representations and how these influenced the use of memory aids in those with ABI. It was found that health beliefs accounted for 56% of the variance in the use of memory strategies (Patel, 2008). Although this study explains over half of the variance in memory compensation use, the emotional response that might explain the link between the generic questionnaire sub-scales and use of memory compensations remains unexplored.

Most of this research is quantitative in nature, and, although it has found factors that are associated with the use of memory compensations, there is still a need to address the issue from the individual's perspective that might provide insights that correlational studies are unable to provide. Key questions about why people do or do not use memory compensations, what makes them choose specific compensations as well as their experiences of using them have not been asked. Some research that has explored the patient's perspective has been undertaken in other populations, such as those with physical disabilities or developmental disabilities, (Parette & Scherer, 2004; Lund & Nygard, 2003), and so these findings can only be considered speculative with

respect to people with ABI. Questions therefore still remain unanswered about the factors that encourage or discourage the use of memory compensations amongst people with ABI.

Factors that have been associated with the use of memory compensations in people with ABI and in other populations with disability will therefore be discussed below.

2.1.1 Demographic and injury related variables

Five studies have systematically explored demographic and injury related variables including severity of cognitive deficits, pre-morbid use of compensatory aids, age, gender and education in people with ABI in order to identify the characteristics of people who make good use of memory compensations. Wilson and Watson (1996), Bajo and Fleminger (2002) and Evans et al. (2003) found that people with ABI with less severe memory impairments (i.e. those who had a profile score of 12 or more on the Rivermead Behavioural Memory Test) as well as those people without additional cognitive deficits were more likely to use six or more compensatory memory aids and were also likely to be more independent. However, consistent with Wilson, Evans, Emslie and Malinek (1997) observations for NeuroPage, Wright, Rogers, Hall, Wilson, Evans, Emslie, and Bartram (2001a) and Wright, Rogers, Hall, Wilson, Evans, and Emslie (2001b) found no significant correlations between any single measure (memory and other cognitive tests) and the total number of diary entries made or the total number of new diary entries made on either the Casio or HP pocket computer. A possible explanation may be due to the design of the Casio and HP computer interface. As options were unambiguous it allowed people to make sensible guesses about which buttons enabled them to accomplish goals such as changing diary entries, this ensured

that participants did not have to remember a number of steps to accomplish their goals (Wright et al., 2001b). It may be that similar to NeuroPage the pocket computers' simplicity made them easily usable and accessible for both those with severe and mild memory difficulties following ABI.

Participants in Wright et al.'s (2001 a, b) studies could be grouped into systematic users of memory aids prior to taking part in the research and those who were not. Wright et al. (2001a,b) found that people who used memory compensations prior to participating in the studies made significantly more new diary entries on the pocket computers than those who did not. This is consistent with other research which suggests that premorbid use of memory aids is a predictor of the use of memory compensations post injury, as people have a conceptual understanding of how to incorporate memory compensations into daily living (Wilson & Watson, 1996; Evans et al., 2003).

Studies that looked at age and use of memory compensations found that being under 30 years of age at the time of injury and current age (i.e. the younger the person either at the present time or time of injury) predicted the uptake of memory compensations (Wilson & Watson, 1996; Evans et al., 2003). Three studies found that higher educational attainment was also positively correlated with the use of memory compensations (Patel, 2008; Wright et al., 2001a, b). Correlations between educational attainment and strategy use have also been found in older adult populations (McDougall & Holsten, 2003; McDougall, 2004). It has been suggested that as educational attainment increases the demands made upon on working memory also increases. Thus, the low cognitive effort needed to use memory aids, such as a diary, consequently makes them an attractive tool to aid recall (Soler & Ruiz, 1996).

Although such demographic and injury related variables are predictive of strategy use, they account for a small amount of the variance in the use of memory aids, for example, Evans et al. (2003) found that: the number of aids used premorbidly, attentional skills, years since injury and current age (i.e. the younger the person either at the present time or time of injury) accounted for 27% of the variance in strategy use. Demographic and injury related variables are clinically important, as they enable therapists to predict who is more likely to be using memory compensations. However, it is also necessary to explore other variables which are potentially modifiable such as health beliefs and attitudes towards assistive devices, as these may further enhance our understanding of what factors influence the use of memory compensations in those with ABI.

2.1.2 Health beliefs

Patel (2008) undertook a study that was based upon the common sense model of illness representation (Leventhal et al., 1984) and reported that a number of health beliefs predicted the uptake of memory compensations in those with ABI. One of the strongest predictors of strategy use was the belief that treatment can control one's memory problem. Patel (2008) suggests it is not surprising that those who hold the belief that their condition is controllable use aids more frequently as this belief is likely to result in an active, problem focussed approach to coping. In fact, research in other populations such as epilepsy, breast cancer and Addison's disease (Haggart & Orbell, 2003) has demonstrated similar findings, suggesting that those who view their illness to be controllable change the way they look at their illness in order to find ways to adapt to it and reduce psychological distress (Haggart & Orbell, 2003). Further to this, Verhaeghen, Geraerts and Marcoen (2000) explored the relationship between perception

of memory complaints, coping and well being in older adults. They found that perceptions of memory complaints (as measured by perceptions of reduced memory capacity, memory change and perceptions of a lack of control over one's memory) sets an appraisal mechanism in motion, in which heightened memory related anxiety and an increase in perceived seriousness of one's memory problem influenced coping behaviour. This in turn was found to influence well-being. Locus of control was found to be an important variable which had a strong link with coping; they noted that people with a more internal locus of control believed they had greater control over their memory abilities and so were more inclined to look for and/or apply more efficient coping mechanisms/strategies. This resulted in enhanced well-being. Conversely, Kit, Mateer and Graves (2007) report no significant correlation between the sub-scale locus of control and the strategies sub-scale of the revised Metamemory in Adulthood Questionnaire (MIA-r) in people who had survived a TBI. The MIA-r is used to measure concepts of Metamemory and consists of five subscales: internal & external strategies, task, anxiety, achievement, locus of control and memory self-efficacy (MSE: measured by combining the subscales capacity and change) (Kit et al., 2007). It may be that for older adults, a decline in memory ability is accepted as part of the aging process and so they actively cope with the problem by employing external and internal strategies. However, people who have a sudden catastrophic event such as an ABI, and are younger, may not initially accept their difficulties and feel that they should have the ability to control their memory difficulties rather than employing coping strategies in the form of memory aids. Participants in Kit et al.'s (2007) study were on average 30 years younger than participants in Verhaeghen et al. (2000). There are also discrepant findings between Kit et al. (2007) and Patel (2008) who found that control beliefs were

significantly correlated to the use of memory aids following ABI. This may be due to the different measures used to assess locus of control. Patel (2008) measured personal control beliefs as well as treatment control beliefs using the revised Illness perceptions Questionnaire (IPQ-r; Moss-Morris et al., 2002) and found that treatment control beliefs were the second strongest predictor of the use of memory aids. In comparison, Kit et al. (2007) only measured beliefs about the ability to control one's own memory (personal control beliefs). It is hoped that the present study might resolve the discrepant findings between Verhaegan et al. (2000), Kit et al. (2007) and Patel (2008).

Interestingly, Patel (2008) found that the strongest predictor of memory strategy use was that those who believe their memory to be cyclical or variable were more likely to use memory strategies. This is interesting because symptoms of ABI are rarely considered cyclical and the timeline cyclical dimension of IPQ-r was developed to account for disorders that are deemed to have a cyclical component, for example skin complaints (Patel 2008). Patel suggests that those people with an unpredictable memory may feel the need to use memory compensations more often to avoid the problem especially if they believe compensations are effective. As this was a quantitative study it is difficult to understand this relationship, and so this may be elucidated by performing an in depth qualitative study.

Perceptions about memory abilities can change after ABI resulting in low memory self efficacy (MSE) and depression (Kit et al., 2007). MSE refers to beliefs about one's ability to use memory effectively and has also been found to influence the uptake of memory compensations (Kit et al., 2007). Kit et al. (2007) reported that individuals with TBI displayed significantly more depressive symptoms than those without. They suggest that after a TBI everyday tasks become more challenging and that

this can lead to a loss of confidence and a shift in identity from being an efficient to an inefficient rememberer. Using any form of memory compensation may bring home the fact that their memory abilities have changed and so explain the higher prevalence of depressive symptoms. In support of this notion, Kit et al. (2007) report that the strategies sub-scale of the MIA-r mediated the relationship between TBI and depression, that is, those with a TBI had higher depression scores than the control group because they used more memory strategies. Thus, people may not wish use aids as they wish to resist this new and unwanted cognitive identity. Scherer (1990) notes similarly, that for those with spinal cord injuries assistive technology was a poor substitute for their own skills and so served as a reminder of the independent skills they had lost. A qualitative study might provide greater clarification of this concept from the individual's perspective.

In keeping with Kit et al. (2007), negative emotions such as fear, anxiety, depression or anger have been found to influence the use of memory strategies. Patel (2008) found a significant positive relationship between emotional representations and memory strategy use, this finding was consistent with research by Gould, McDonald-Miszezak and King (1997) who report that high levels of memory related anxiety predicted the use of memory strategies for taking medication in older adults. Patel (2008) suggests that for those with ABI, a moderate amount of emotion (i.e. feeling worried, afraid, distressed, angry) encourages people to become active in coping with their memory problem, thus implementing problem-focused coping (i.e. memory compensations). Kit et al. (2007) also noted that a moderate amount of anxiety was significantly associated with increased use of memory strategies.

2.1.3 *Stigma and Attitudes towards assistive devices*

Stigma can be defined as a form of negative social stereotyping or categorization where the person being stigmatized is considered to possess different characteristics from people who are accepted by society (Goffman, 1963). There has been a small number of studies into stigma and brain injury, many of which have looked at public misconceptions about ABI (Gouvier Prestholdt & Warner, 1988; Swift & Wilson, 2001; Redpath & Linden, 2004; Hux, Schram, & Goeken, 2006; Chapman & Hudson, 2010, Linden & Boylan, 2010). These studies highlight that misconceptions about brain injury are commonly endorsed by the general public and that these can lead to negative social perceptions (Linden Rauch & Crothers, 2005; Linden & Boylan, 2010). Research has suggested that individuals who have acquired their brain injury as a result of an assault are judged more negatively than those who have had a haemorrhage (Redpath & Linden, 2004). In addition, individuals from higher social economic backgrounds are more readily received back into their communities following ABI than people from lower social economic backgrounds (Linden et al., 2005). Simpson, Mohr and Redman (2000) undertook a study of perceptions regarding ABI amongst Italian, Lebanese and Vietnamese survivors of ABI and their families. They found a powerful cultural dynamic in the feeling of shame at having an ABI, in particular it was noted that within Vietnamese culture having ABI was not only shameful for the person but also for the family. Simpson et al. (2000) also reported that following ABI many participants avoided social contact and isolated themselves as a result of stigma and a lack of understanding surrounding ABI.

Surprisingly, there has been no research into stigma and the use of memory compensations in people with ABI. However stigma and the use of assistive devices has

been studied in other populations. There has been mixed findings in older adult research regarding the use of assistive devices, some studies have found that older adults have favourable attitudes towards the use of compensatory aids and assistive devices such as walking frames, electric wheelchairs and bath seats as they increase independence (Roelands, Van Oosta, Buyssea & Depoorter, 2002). However, other studies suggest that despite the value of assistive devices fostering independence, many users acknowledge the social stigma attached to aging, disability, and device use (Aminzadeh & Edwards, 1998; Resnik, Allen, Isenstadt, Wasserman & Iezzoni, 2009) and that these impact on older adults' decisions to accept or reject mobility aids (Aminzadeh & Edwards, 1998). Resnik, Allen, Isenstadt, Wasserman and Iezzoni (2009) highlight that device functionality was not the sole contributor as to whether older adults were willing to use them and suggest that device attractiveness is an important factor. Several participants highlighted preferences for walking aids that had a sporty appearance in comparison to the standard medical-appearance. Resnik et al. (2009) suggest that devices that are viewed as fashion accessories are more likely to be accepted by older adults and may help combat the negative influence of social pressures.

Less positive attitudes about assistive devices have also been found in people with physical and developmental disabilities. Parette and Scherer (2004) note how negative attitudes in the form of stigma impact upon people with developmental disabilities and how this influences their use of assistive technology. For example, stigma has been associated with perceived increased visibility or attention when devices are used in public as well as perceptions that children using assistive technology will not attain important developmental skills. Thus, parents of children with disabilities choose not to use such assistive devices (Brookes, 1998). Assistive technology decision-

making teams (e.g., doctors, therapists, support workers) are also confronted with issues related to stigma that have the potential to substantively affect their decision whether to recommend the use of certain devices. For example, decision making teams must be sensitive to family expectations of assistive technology, such as immediacy of results and the practicality of devices as well as user and family values that include social acceptability of assistive devices (Parette & Scherer, 2004). It has been suggested that physical characteristics of the device itself may be important, that is, factors such as visibility of using the device in public settings, device aesthetics/cosmetics, and gender and age appropriateness of the device (Parette & Scherer, 2004). Polgar (2002) notes that people can feel stigmatized by devices that signal a loss in function, for example, people with progressive disorders such as multiple sclerosis may not want to use a walking device because it reinforces the loss of their abilities to walk unaided. Similarly, someone with an acquired disability (e.g. an amputee) may avoid the use of a cane despite its effectiveness in aiding ambulation, because the meaning attributed to the device has negative connotations, bringing unwanted attention and threatening the sense of 'fitting in' (Bender Pape, Kim & Weiner, 2002). It is therefore important to understand how physical characteristics of assistive devices influence people's attitudes towards using them, especially when considering the factors that influence the use of memory compensations. Personal and sociocultural meanings of using assistive devices are also important factors and are discussed below.

Lund and Nygard (2003) undertook a qualitative study that explored people with disabilities (spinal cord injury, multiple sclerosis, TBI, rheumatoid arthritis, muscular dystrophy, osteoarthritis and fractures) experiences of using assistive devices (mobility aids and aids for self-maintenance) within their occupations. These authors found that

whether an assistive device was functionally adequate was not the most important component in a person's decision about whether to use it. It was revealed that people either incorporated or resisted the use of assistive devices as a means of achieving a desired self-image. Some users had a more pragmatic approach that reflected the importance they placed on the desirable aspects of their assistive devices that enabled them to achieve their desired self image, such as increased participation within their occupation. Other users (ambivalent users) acknowledged the usefulness of devices but still felt unhappy that they were needed; whilst a third group (reluctant users) preferred to give up their occupations and retain their initial desired self image rather than acknowledge their dependence on the devices and have to adapt to a new self image that incorporates the use of assistive devices.

Lund and Nygard (2003) report that the use of assistive devices also had double-edged meanings; participants revealed that assistive devices made it easier to engage in activities because it saved them time and energy, increased independence and allowed them to engage in occupations. However, they simultaneously stated that the use of assistive devices made it difficult to engage in certain activities because they were cumbersome and reminded people that their lives were different to what they had planned. The use of assistive devices was also found to encourage stigmatization and a handicap identity as a result of the devices being highly visible to others. It is therefore suggested that the reasons assistive devices are used or discarded, goes beyond the aspects related to actual performance and Lund and Nygard (2003) state that "the medical perspective, which focuses on the role of assistive devices as preventing and compensating for impairment, fails to explain the meaning of assistive devices for people with disabilities and how they act on these experiences" (p.72). The same may

apply to people with ABI, but so far there has been no qualitative study that has explored this. A better understanding of these experiences could be useful to healthcare professionals and therapists who work in rehabilitation services so that they can support people to access compensatory aids, thereby increasing independence and participation in society.

2.1.4 Study aims

A number of quantitative studies have focused on factors that help predict the uptake of memory compensations and assistive devices after ABI. The principal aim of this qualitative study using Interpretative Phenomenological Analysis (IPA) was to understand people's perspectives and experiences of using memory aids and why they choose to use or to discard them following ABI. This study also aimed to expand upon current research addressing this issue. A better understanding of this research area may explain some of the associations found in current research, as well as providing guidance to therapists on how to encourage people with ABI to use memory compensations. Furthermore, this study is in keeping with the Department of Health policy which states that Service User involvement is an important and central aspect of improving client well-being and the development of services (Darzi, 2008).

2.2 Method

2.2.1 Epistemology

A qualitative technique was proposed as the basis for this study because qualitative methods aim to provide rich descriptive accounts of the phenomena under investigation (Elliot, Fischer & Rennie, 1999) and are particularly suited to the exploration of issues that have had limited focus (Smith, 2008). Qualitative psychology is generally engaged with exploring, describing and interpreting the personal and social

experiences of participants and there are several different approaches each with overlapping but different theoretical and/or methodological emphases (Smith, 2008). This study adopts a phenomenological position, in that the focus of the research will be on people's perceptions of a particular phenomenon and what this means to them: a focus on an individual's first-hand experience. Phenomenology aims to capture the way in which the phenomenon is experienced within the context in which it takes place (Giorgi & Giorgi, 2008). In particular, this initial study is interested in individual's lived experiences of what it is like to use memory aids and strategies to compensate for memory difficulties following ABI. For this reason interview data was analysed using IPA (Smith & Osborn, 2008). IPA aims to explore in detail "how participants make sense of their personal and social world" (p.53) by understanding the meanings particular experiences, events or states hold for each individual (Smith & Osborn, 2008). Simultaneously, IPA acknowledges the dynamic aspects of the analytical process which involves an active role for the researcher. Access to the participant's personal world can be complicated by the researcher's own preconceptions and belief systems and so a two-stage interpretation process is involved in order to "understand what it is like, from the point of view of the participants, to take their side" (Smith & Osborn, 2008, p.53). IPA is an idiographic mode of inquiry (a study of a small sample size) so it is possible to make specific statements about individuals because the data has been derived from examination of individual case studies (Smith & Osborn, 2008). As IPA takes an inductive approach to understanding the meanings people assign to particular experiences prior assumptions are therefore avoided (Reid, Flowers & Larkin, 2005). It was hoped that this approach would allow for a better understanding and more

insightful information of what it is like for people to have to use memory aids and strategies to compensate for memory problems following ABI.

2.2.2 Considerations when interviewing people with brain injury

Patterson and Scott-Findlay (2002) state that following a brain injury people are able to make significant contributions to qualitative research involving interviews, however there are a number of challenges (e.g. recall of events, intolerance to stimuli and image management) that must be taken into consideration. They suggest a number of strategies that can mitigate these challenges including: discussions with the research team about possible problematic scenarios; a preliminary interview or meeting with the participant in order to build rapport; flexibility in scheduling meetings to allow for fatigue. They also suggest that interview questions should be piloted so that the questions can be evaluated in terms of sequencing and phrasing and that researchers must look beyond the readily obvious when analysing interviews. Finally, they suggest that debriefing sessions should be incorporated as it provides participants with the opportunity to provide feedback about the research experience. In line with these recommendations, I (the researcher and author of this thesis) spoke to participants key workers prior to the interview session about any potential difficulties that were likely to arise. For example, it was noted that one participant would tend to drift off the topic and talk at a tangent, so I was aware of the need to ensure the conversation did not deviate from the main research aim. I was also assisting at the rehabilitation service so was able to build a rapport with participants and become aware of their difficulties. The interview schedule was also flexible in that participants were also made aware that if they felt fatigued or were not able to concentrate the interview could be conducted in two sessions or that they could stop for a break if necessary. Interviews were semi-structured

and careful consideration was taken when phrasing the initial questions. These questions were created by myself and my supervisor (Dr Theresa Powell), both have experience of working with people following ABI. Any other questions that were asked during the interviews were dictated by the participant's responses and so these could not be piloted. Following analysis of the transcripts participants were also consulted about the resultant themes to ascertain whether the true essence of their experiences had been captured.

2.2.3 Participants

Eight people attending an out-patient interdisciplinary brain injury rehabilitation service were included in the study. Five to eight participants was considered sufficient for a study of this nature (Smith & Osborn, 2003) in order to gain valuable insight into people's experiences of using memory compensations as a result of having memory difficulties. It was also a realistic number given the time resources available. Purposive sampling was employed in order to gain a closely defined group for whom the research question was significant (Smith & Osborn, 2008) and by recruiting a homogenous sample of participants we are able to make claims about the participants and their shared experiences (Langdridge, 2007). Thus, only people who reported memory difficulties causing significant day to day memory problems were approached. Severity of memory impairments was confirmed through formal testing using the List Learning subtask of the Adult Memory and Information Processing Battery (AMIPB; Coughlan & Hollows, 1985) (Appendix D). The extent of everyday memory problems was confirmed by asking participants to complete the Everyday Memory Questionnaire (EMQ-28 item; Sunderland, Harris & Baddeley, 1984) (Appendix E). Key workers were also asked to nominate both people who were willing and unwilling to use memory aids. Use of

memory compensations is a major focus of the rehabilitation programme from which participants were recruited. Although participants may have had other cognitive problems, key workers would be aware of who would need to use aids that would specifically address memory problems. Eight people were approached by their key workers and all eight agreed to participate in the study. Of these, three could be described as having mixed views about using memory compensations, three had positive views about the use of memory compensations and two could be described as having negative views about the use of memory compensations.

Participants ranged from 19 to 58 years of with a mean age of 37 years (SD=13.61). In terms of age the sample of participants was heterogeneous, which was important as it may help provide an understanding of how age impacts on the use of memory compensations. Participants' time since injury ranged from 9 months to 27 months with a mean of 17.5 months (SD =5.97). Six participants scored well below the 5th percentile cut-off (z score of -1.65 or lower) on the AMIPB. Two participants scored above the 5th percentile cut off (both participants scored between the 25th and 50th percentile i.e. within the average range) but were accepted as they self reported memory problems on the EMQ. The mean EMQ score was 1.53 (SD= 0.68) similar to Royle and Lincoln's sample of people with memory problems caused by stroke (Royle & Lincoln, 2008). Five of the participants were male, two of whom were White British and one was White Canadian, one participant was British Asian and one was Black British. All three female participants were White British. Four participants had sustained a TBI, three had suffered a vascular injury and one had a viral infection. At the time of injury three participants were unemployed, two were in full time education, one participant worked as a child care practitioner, one was a manual labourer and one participant was a

supervisor for a private removal company. Six participants were living at home with their family and two lived alone but received help and support from family members. All participants had a good command of spoken English.

On ethical grounds, participants were not approached if they were not able to give informed consent or if it was felt that they were not emotionally ready to take part. As data collection was in the form of semi-structured interviews, those who were not proficient in English were not approached to participate as I did not have access to an interpreter. To avoid any threats to the reliability of the study the same researcher (i.e. the researcher and author of this thesis) conducted all the interviews.

Participants were recruited because of their expertise in the phenomenon being explored (Reid et al., 2005). In order to demonstrate this, a small synopsis of each participant is given below.

Participant 1

Participant 1 was a 41 year old male who suffered a right frontal intercerebral haemorrhage approximately 10 months prior to the interview. He was unemployed at the time of his injury and lived on his own but had the support of his sister. Participant 1 could be described as having poor insight into his memory problems and although he implemented some memory aids and strategies they were not always used efficiently and so key information was often forgotten.

Participant 2

Participant 2 was a 28 year old male who suffered from left temporal and frontal lobe contusions as well as a midline shift as a result of a quad bike accident 22 months prior to the interview. Participant 2 was employed full time within the private sector prior to his accident and he was living in the family home with his parents at the time of the

interview. Participant 2 could also be described as having limited insight into his memory problems and he appeared to be opposed to any memory compensations that were suggested by therapists.

Participant 3

Participant 3 was a 52 year old male who suffered a cerebral haemorrhage as a result of a road traffic accident approximately 18 months prior to the interview. Prior to his accident Participant 3 was employed as a supervisor for a removal company. At the time of his injuries he was working abroad. He lived with his son at the time of the interview. He had mixed views about using memory aids and felt that he had to do something about his memory problems himself.

Participant 4

Participant 4 was a 24 year old male who had suffered a viral infection 27 months prior to the interview. At the time of contracting the virus he was in his final year at university. He lived with his parents at the time of the interview and was planning on continuing with his education. He was very pro-aid use and had employed a number of memory aids efficiently to help him.

Participant 5

Participant 5 was a 33 year old female who had suffered a subarachnoid haemorrhage 22 months prior to the interview, whilst working as a child care practitioner. She lived with her parents at the time of the interview and could be described as pro memory aids; however, she felt she had only recently become aware of her memory problems.

Participant 6

Participant 6 was a 19 year old female who suffered a TBI as the result of a road traffic accident 19 months prior to the interview. At the time of her injury she was attending

college and living with her parents. She could be described as gaining insight into her memory problems and knew that she needed to become more reliant on her own memory strategies than relying on her family.

Participant 7

Participant 7 was a 43 year old female who suffered a right-sided stroke approximately 14 months prior to the interview. At the time of her injury she was unemployed and lived at home with her husband and son. She could be described as having mixed views about memory aids and strategies, although she was happy to use a number of memory aids as long as they fitted her life style.

Participant 8

Participant 8 was a 58 year old male who had suffered a TBI after falling down the stairs 9 months prior to the interview. At the time of injury he was living with his partner and had been made redundant from his position as a training and development coordinator one month prior to his fall. He also had mixed views about using memory aids and although he used a number of aids he felt that he was not using them efficiently.

2.2.4 Measures

Participants were asked to complete a subjective memory assessment; the Everyday Memory Questionnaire (EMQ; Sunderland et al., 1984) as a measure of self reported everyday memory problems (Appendix E). The EMQ consists of 28 statements about memory failures and participants indicated how often they experienced each symptom of forgetting in the last three months. Participants were also asked to complete the List Learning subtask of the Adult Memory and Information Processing Battery

(AMIPB; Coughlan and Hollows, 1985) as a formal measure of memory impairment (Appendix D).

Demographic data including details about age, sex, ethnicity, type of injury, time post injury, current rehabilitation status (outpatient/inpatient), and employment and education history were collected from the participant. If the participant was not able to provide information on the type or date of injury their key worker was asked to provide this information (Appendix J).

2.2.5 Procedure

Key workers at the rehabilitation centre were initially briefed about the research and the criteria for participation (confirmed ABI; a good command of spoken English; and self reported memory problems of the EMQ and/or day to day memory difficulties confirmed by centre staff). Key workers approached clients attending the centre who they thought matched the inclusion criteria and who they felt would be interested in participating. If the clients expressed an interest in the research they were then approached by myself and I informed them about the research, provided each person with a participant information sheet (Appendix C) and answered any questions. Everyone was given a minimum of 24 hours to decide whether they wanted to participate. An interview time convenient for the participant was arranged, they were asked to sign a consent form (Appendix C) and it was reiterated that they had the right to withdraw at any time.

2.2.5.1 Data collection procedure

Data was collected using semi-structured interviews that consisted of a series of open-ended questions. Semi-structured interviews are regarded as the most widely used data collection tool for an IPA study, as it allows the researcher and participant to

engage in a conversation whereby the initial questions can be modified allowing for any prompts or questions depending on the richness and diversity of the responses given (Smith & Osborn, 2008). Each interview lasted approximately 50 minutes in length (range = 45 minutes to 1 hour 20 minutes) and all participants were interviewed at the rehabilitation centre. As the rehabilitation centre was a familiar environment to participants it was felt that this would enable them to feel more comfortable during the interviews. The interview schedule was developed according to the guidelines given by Smith and Osborn (2008) and the generation of ideas and concepts that were thought to be relevant to the research were developed in collaboration with my academic supervisor, Dr Theresa Powell.

Before each interview commenced, I introduced the topic of the interview by rereading the main sections of the participant information sheet. This was to ensure that each participant understood what was going to happen and what the interview was about, i.e. having memory difficulties, what things people found difficult to remember and using memory aids/strategies. At this point I made it clear that for the purpose of the interview a memory aid could be a physical device (I listed a number of memory aids that people may use in order to help them remember things e.g. diary; calendar; mobile; post-it-notes), or something that someone did (I listed a number of things that people may do, e.g. putting things in the same place, repeating things they need to remember to themselves). Participants were then asked if they had any questions about the interview process. All interviews were audio-taped and transcribed verbatim and all identifiable names were changed for pseudo names. Once transcribed the original audio-tapes were destroyed. A full version of the final research and initial interview questions are shown below.

2.2.5.2 *Interview schedule*

1) Can you tell me about your memory problem?

(How memory differs now in terms of the way it functions compared to before the ABI)

2) Tell me (a bit more) about the type of things you forget/ that are difficult for you to remember.

(What types of things do you think you need to use memory aids for? What sort of things do you remember or forget? Important things or less important things- what are these?)

3) How long do you think your memory problem will last? How does this influence your use of memory strategies?

(How variable is it, how long the problems will continue, any patterns in their memory problem)

4) What strategies/aids do you use to compensate for your memory problem(s)?

(External: e.g., lists; diaries; notebook; pager; mobile, internal: e.g., rhymes, environmental: e.g., labels; consistency-putting things in same place all the time.)

5) What made you choose these specific aids? (list those given in q4)

(Experience of using aids before the injury, anything about the way memory aid works, characteristic of the aid, size, style, format, ease of use)

6) How have you made the memory aids/strategies suit you?

(Modified/customised or changed them from their original format to suit you?)

7) What is your memory like without using memory aids/strategies?

8) (If you can answer this question) Prior to your ABI what were your views about using memory aids/strategies?

9) What are your family's views of you using memory aids/strategies? How does this influence you?

10) Do you think society (other people) has an influence on whether people will use memory aids/strategies? How are people influenced?

(Positive or negative views of using memory aids)

11) What is your present view of using aids/strategies?

12) How does this view (q11) influence your use of strategies/aids now?

Prior to the initial interview a pilot interview was conducted with my academic supervisor (Dr Theresa Powell). This ensured that I was confident with the interview schedule and was also aware of any questions that may “lead” the participant. It enabled me to gain feedback on the questions from an interviewee’s perspective and change any questions that were vague or leading. For example, the aim of question one was to understand participants’ initial views of how their memory differed and what things they found difficult to remember. After the pilot interview it was felt that the original question “Can you tell me about your understanding of your memory problem” may have been misinterpreted or difficult to understand and so this question was changed to “Can you tell me about your memory problem.” Prompts asking about how the participant’s memory differed after their injury were given in order to ensure the question was understood.

2.2.6 Data analysis- IPA

Initial analysis was carried out on the first three interviews so that any unexpected and interesting themes introduced by participants could be incorporated into subsequent interviews. IPA was conducted, following the process outlined by Smith and Osborn (2008). The preliminary stage of the analysis was done by myself and involved reading the first transcript whilst making initial notes of anything that was interesting or significant. At this level of the analysis the participant’s use of language, their responses

to certain questions and how they portrayed their experiences were also considered and noted. This was then followed by a more detailed reading in which themes that reflected the meaning of the text were identified. The emergent themes were then listed and connections between them were looked for. This was done in order to create superordinate clusters that linked several concepts together. (Extracts from three of the annotated transcripts can be found in Appendix N). It was at this level of the analysis that the emerging superordinate clusters were checked with the transcript to make sure that they were consistent with the participant's actual words and that my interpretation of what the participant was saying was actually embedded within the transcript. This process was then repeated for the remaining transcripts in order to determine similar and different superordinate clusters. After all the transcripts had been analysed and emergent clusters created, a "cyclical" process was undertaken where any emerging cluster themes in the latter transcripts were tested against the earlier transcripts. Once a list of emerging superordinate clusters had been derived from all eight transcripts a final stage of analysis was conducted in which my academic supervisor (Dr Theresa Powell) and I identified higher order clusters. This process involved clustering the emergent themes into "master" themes and sub-themes that reflected the whole group.

Throughout the analytical process the focus was always on what mattered to the participant and what their experiences were (i.e. phenomenology). In order to ensure that the data analysis was not stopped too early, the transcripts were initially analysed without reference to the research questions. At the end of the analysis process the themes were considered with the research questions in mind.

2.2.7 *Credibility, bias and personal reflections*

A number of methods were used to ensure validity of the resulting themes. Firstly, an independent researcher without experience of brain injury and who was not part of the research team reviewed two transcripts which had been annotated by myself and Dr Theresa Powell, comparing our analysis to hers and noting any similar or differing themes that emerged. This process was to ensure that interpretations were not biased by the analysts (Dr Theresa Powell and myself), who both have experience of brain injury (Dr Theresa Powell has 20 years experience in a regional brain injury service and I have assisted survivors of ABI back to employment). The independent researcher was in agreement with the emergent themes created by the researchers. The key outcome of this process ensured that I kept an 'open' approach to the analysis and avoided any personal preconceptions about the factors that influenced the use of memory compensations. Secondly, the master and sub-themes were developed through a process of discussion and negotiation between Dr Theresa Powell and myself. Referral back to the original transcripts ensured that themes were driven by the participants' experiences. Finally, Yardley (2008) states that participant feedback also known as 'respondent validation' enables participants to engage in a valuable way within the research as well as ensuring that their view points are not misinterpreted. Therefore, as recommended by Yardley (2008), I sought respondent validation by feeding back the master and sub-themes to a group of four of the original participants. Each participant was given a description and accompanying quotes that reflected each master theme and sub-theme and the group was asked whether the themes and their interpretation accurately represented their experiences. Overall the group agreed with the interpretation but some of the sub-themes were rearranged. For example the master

theme “It’s not in my nature” was initially divided into two sub-themes, however the feedback group felt that this was not necessary.

Throughout the course of the interviews I took a number of steps to ensure that participants provided honest and open accounts of their experiences of using memory compensations. Therefore, before the interviews an attempt was made to make participants feel comfortable. All of the participants appeared to be relaxed during the interview and they talked openly about their experiences.

2.2.8 Ethical approval

Ethical approval for this study was obtained from South Birmingham Research Ethics Committee on the 29th May 2009 (Appendix B). One of the main ethical issues was the possibility that participants may have become distressed during the interviews or disclosed any information that raised concerns about their health and well-being. Participants were made aware that any information given that was deemed to be a cause for concern would be shared with Dr Louise Lorenc, the Lead Clinical Psychologist at the out-patient interdisciplinary brain injury rehabilitation service. When participants were initially approached they were provided with a participant information sheet (Appendix C) that explained the purpose of the interview, intention to audio-tape and transcribe and the length of the interview. It also informed participants of their right to withdraw from the study at any time as well as highlighting that participating in the study would not affect their rehabilitation. Immediately before the interview the author of this thesis checked that the participant had understood the information sheet and ensured that any questions were answered. Written consent was obtained from all participants prior to the interview. For anonymity and confidentiality purposes any

identifying information from the interviews was not transcribed and pseudo-names were given to all participants and people they mentioned during the interview.

2.3 Results

Following analysis of the transcripts six master themes emerged and are presented with their sub-themes in Table 2.1 (Appendix O provides a diagram and representative quotes). A table of the total number of participants representing each master and sub-theme can be found in Appendix P, and additional participant quotes representing each sub-theme can be found in Appendix Q.

Table 2.1:

Master and sub-themes reflecting participants' experiences of using memory aids/strategies

<i>Master themes</i>	<i>Sub-themes</i>
Emotional barriers preventing acceptance of memory compensations	Not wanting to appear to need help Feeling embarrassed/ thick 'Silly things' Feeling different
Reverse effects	You have to know what it's like Style of reminding People doing too much for you "It would make me feel as if I have got a problem"
Beliefs about memory	Needing something to 'bring it home to you' Belief in memory improving Belief that rehearsal/repetition helps 'Use it or lose it'
"It's not in my nature"	
Type of information	
Back up strategies	

2.3.1 Emotional barriers preventing acceptance of memory compensations

The first master theme and one of the richest themes, was the notion that several emotional barriers need to be overcome before people would use memory compensations. The following statement was echoed by a number of participants "They'll do it when they're good and ready and I think until that point I don't think

you'll get anywhere with them coz they won't do it to be honest." (*Participant 5, Lines 493-495*)

The potential barriers to acceptance fell into four sub-themes, three of which related to the potential for negative evaluations by others. In particular many participants talked about the need to hide the use of any memory aid for fear for negative evaluations by others. For example, Participant 5 spoke about using a memory aid on the "low key" rather than "in front of people... as it would be quite hard to use a memory strategy and not care about what everyone else thinks..." (*Participant 5, Lines 384-390*).

In the first sub-theme, participants described their concern that using memory compensations might be an indication of needing help or being a weakness and this might make people "think less of them." Occasionally, a more negative global view of others was also expressed, for example: "...some people can be quite nasty aren't they or some people have got horrible attitudes or haven't got time to have an understanding or anything" (*Participant 7, Lines 452-453*). In the second sub-theme participants described several sources of embarrassment related to using aids and of having memory problems, including the possibility that people might "think you're a bit thick....they don't want to be given that label, that label that they're thick, they want to think themselves that they're bright ..." (*Participant 5, Lines 456-458*). It was also noted by one individual that because he did not appear to have any physical injuries which showed he had had a head injury he would be laughed at for using a notepad to help him:

You say "I've been a brain injury I carry a notepad" they're going to laugh at you, they're going to say "brain let me have a look, let me have a look what's

wrong, what's wrong, your head looks normal to me, what kind of brain injury?"
(Participant 2, Lines 431-434).

It was also possible to see how the inferences made by the same man led him to feel he would be completely rejected if he used a memory aid:

.... it's the people that you meet out there you can't carry dictaphone, notepad and book you know not even a little one and you know it might be important but if you can't remember it everyone will think you're dumb, that your thick that you can't remember things 'what's the point in me talking to you no more, I don't want to talk to you' that's what people will say, they won't say it to your face.... (Participant 2, Lines 603-608).

For a few participants the source of embarrassment was related to age and so they held the belief that only older people should need to use memory compensations "coz am so young it's not right if I go oh I can't remember I've got to do things differently"
(Participant 6, Lines 369-370).

However, some participants also gave examples of helpful cognitions that were associated with overcoming embarrassment and therefore a willingness to use memory compensations, for example:

.... once you've got used to it you use it and expect it and think 'sod everybody else' and do it for me..... People who can't understand it then or give time to understand it then they're not really worth bothering with are they (Participant 7, Lines 527-530).

Also, one participant described how they limited the impact of negative evaluations by others by remembering that "it's their memory that's not there" and that people after a

brain injury “are not thick,” that “in fact they’re actually quite intelligent” (*Participant 5, Lines 358-363*).

Some of the above statements were prompted by a question within the interview process about what might influence other people’s decisions about whether to use memory compensations. This was a small element of the interview and it should also be noted that when asked about their perceptions of using memory compensations people often talked in the third person using the term ‘people’ when describing their views.

In the third sub-theme it is interesting that participants often described the things that were forgotten as ‘silly things.’ It was initially difficult to define this concept however, with the help of the feedback group it was possible to classify three different ways in which this term was being used. Firstly, it appeared that participants were applying the term ‘silly’ to themselves for having forgotten information which they felt should be something that was everyday knowledge, for example one participant described it as ‘silly’ that she could not remember what day of the week it was or what they had planned for that day. During the interviews and in the feedback group some of the participants held the belief that if “it’s something silly... like got to sweep the garden today what time...” (*Participant 2, Lines 420-421*) that you need to use a memory compensation to help you remember then “that’s ridiculous.” Secondly, the term was used to describe things that would have been an automatic process before their injury and therefore carried out without any effort, such as remembering to turn off potentially hazardous appliances after use (e.g. hair straighteners or the hob), or remembering to take a bank card out of an ATM/cash machine after you have used it. These things were deemed ‘silly’ because they now required more effort and concentration to be remembered and people found it ‘silly’ that they could no longer

remember to do these tasks (usually deemed trivial) without prompts from other people. Although the term ‘silly’ was being used to describe the type of information that was forgotten it may be that people also felt that they were ‘silly’ themselves for forgetting this information and so definitions one and two can be seen to be intrinsically linked. Finally, the term was being used to describe things that would make participants look ‘silly’ to other people. For example, if they were with friends and forgot an important appointment, or forgot what they had been doing or where they had to go later on and they had to use a memory aid. People felt that this would be embarrassing and that others would judge them and see them as ‘silly’ if they could not recall this information naturally. As one participant demonstrates: “They’d think am silly yeah pulling out a notebook just for simple explanation, what the hell’s wrong with you that what they going to say....” (*Participant 2, Lines 161- 162*).

‘Feeling different’ is the final sub-theme in this master theme and describes how: having a brain injury, subsequent memory difficulties and using a aid made participants feel “not quite themselves.”

I don’t know... its coz before the accident I didn’t look at it before..... it was never in my routine to look at my diary I never used to write things down before so I just used to remember, I don’t know you just change.” (*Participant 6, Lines 51-53*)

Another lady stated “I look the same, I talk the same but am not the same” (*Participant 5, Line 317*). It was also noted that people talked about how they had become reclusive and in their “own box” (*Participant 1, Line 231*) since their brain injury and so they felt they were no longer the same person. Although this sub-theme is not entirely related to using memory aids the notion of ‘Feeling different’ is an emotional barrier that people

need to adjust to after an ABI and so has implications for accepting memory compensations.

2.3.2 *Reverse effects*

The second master theme consisted of factors that might intuitively be regarded as helpful or positive but participants described how they either made them less likely to use memory compensations or the approaches were unhelpful. For example, a number of participants said that someone ‘who knows what it’s like’ should promote the use of aids rather than therapists e.g. “...I’d try to use myself perhaps as an example and show how it helps me, how it works for me...” (*Participant 4, Line 431*). It was also suggested by the feedback group that “They [therapists] don’t have a clue what it’s like.”

Similarly, in the second sub-theme seemingly helpful reminding by others could have a reverse effect on motivation, depending on how reminders were delivered and by whom. One man said about his mother’s style of reminding:

...with Mum the trouble is coz she’s like that she’ll go on, it has to be every 5 minutes, have you remembered that, have you remembered that, every 5 minutes and am like yeah.....and then I admit I do get a bit annoyed at times coz it does just get too much, least with my strategy I have just one reminder, so when I need it I make sure I get it done not every 5 minutes making sure I get it done coz what I do so I find is with that I get so tired of being reminded that I just don’t want to do it anymore (*Participant 4, Lines 312-317*).

Another person described his reaction to his mother telling him what to do in comparison to his sister’s more ‘subtle’ approach

They tell me one once and that's it and I'll tell them be quiet, be quiet, walk away and that's it ... With my sister she calms me down or gets me to say what I'm doing tomorrow or what day I have to go to do that... (*Participant 2, Lines 229-234*).

These sentiments also link with timing, in that reminders that were given too early, for example by other people, were not helpful "... she says 'what have you got to do tomorrow?' and then I'll go and look and well but I won't remember in the morning" (*Participant 6, Lines 239-240*).

The third sub-theme 'people doing too much for you' was initially difficult to position in relation to a master theme but the feedback group suggested it be placed in 'reverse effects'. The essence is that people think they are being helpful to the person with the memory problem but the consequence is that memory compensations become unnecessary when, as one young woman described it perceptively, "I use my mum as my diary" (*Participant 6, Line 26*).

In the final sub-theme in this section one particular participant described how the memory aid itself could be experienced as an aversive reminder of their difficulties and so they were less willing to use it, e.g. "...it just shows the problem it reminds you that you've got a problem, and I, I don't like to think that I've had a brain injury, it's horrible to like think it" (*Participant 6, Lines 569-570*). Another lady spoke about how using memory compensations initially made her feel upset because they gave her the feeling "this isn't me" (*Participant 7, Lines 469-470*).

2.3.3 Beliefs about memory

This master theme consists of a collection of beliefs held about memory and memory compensations that influenced the likelihood of participants using them. The

first sub-theme describes how real-life events tended to ‘bring home’ the realisation and need to use memory compensations. For example one person described how forgetting where she had put her house keys and having to have the door locks changed made her realise that she could not continue in the same way and needed to instigate a strategy. Another participant talked about how being put into a situation forces people to make changes and accept what has happened to them and that this would also bring home the need to use memory compensations rather than having someone else there to remember for you “...because if you’re put into a situation where you have to do something you’ll do it and right now I’ve got it easy so I’m probably being lazy” (*Participant 8, Lines 307-309*).

In the second sub-theme theme in this section participants explained that if they had a sense that their memory was improving they would reduce the use of aids. The notion of improvement might be a hope or wishful thinking rather than the reality. “I tend to think that I am getting better in my memory and that I don’t need to do that...” (*Participant 8, Lines 86-87*). If a person’s memory is improving this belief can be adaptive, but when a person’s memory is not improving it would be considered unhelpful.

The final two sub-themes consist of mistaken beliefs about memory and memory compensations. There was a very strong belief that rehearsal/repetition of information is generally an effective memory strategy. A number of participants stated that they used repetition/rehearsal in order to remember information; in fact one participant cited this as his primary strategy and stated he would only write information down if after several repetitions he still didn’t remember it (*Participant 2, Lines 78-79*). The notion of ‘*use it or lose it*’ i.e. the belief that one’s memory will become ‘lazy’ and cease to work

completely if it is not exercised, was also a strongly held belief, for example one participant stated “I thought to myself if I start doing that (using a memory aid) I’d never get my memory back...” (*Participant 3, Lines 27-28*). This sub-theme highlights the resulting coping style which is an attempt to rely on one’s own internal resources “if I can rely on my own memory that’s one step forward, not by looking at it in a diary...” (*Participant 3, Lines 29-30*). Unfortunately the notion of relying on one’s own internal resources was not rich enough to be a separate theme but nevertheless it has links with ‘*use it or lose it*’ beliefs. Sentiments about relying on one’s own internal resources were echoed quite strongly by the feedback group.

2.3.4 “*It’s not in my nature*”

This master theme was a very rich theme to emerged from the transcripts with many of the participants describing how they had never been the ‘kind of a person’ to use certain memory compensations. One of the core elements of this master theme was the importance of individual choice and that everyone is different, so clinicians and therapists should consider people on an individual basis when suggesting the use of memory aids and strategies to help compensate for memory difficulties.

But sometimes I think they don’t look at us as an individual, they do here and that don’t get me wrong, but not everyone has the same problems or suffers from the same things or feels the same way about certain strategies or memory aids.... (*Participant 6, Lines 640-642*).

Many of the participants also suggested that memory compensations that were ‘just not me’ were often avoided, for example one participant spoke about how carrying a pen and paper was too much for him as “it’s a woman’s thing” (*Participant 1, Line292*). Another participant spoke about how she was not comfortable using a diary:

Because its, I couldn't be arsed like to look at it and things... I don't know...
Just the thought ... I don't know of writing a diary and looking at it, I definitely
wouldn't find that for me. Maybe some people would but it's not for me
(Participant 7: Lines 401-403).

Within this master theme is the notion that lifestyle is an important aspect of
whether memory compensations are used. A second participant spoke about how they
wouldn't make people use a diary if they weren't comfortable using one and if it didn't
suit their lifestyle. It was also noted that memory compensations that were not part of
past routines were subsequently difficult to adapt to as one participant suggests

.... for me it never has been in my routine so it's hard to just put a diary in my
life and think 'Oh I'll write that down and look at it' coz I've never been that
kind of a person so it's hard to its hard to write things down and look at it and
think 'Ah' coz I never had all these appointments and places to go before so it's
all new to me" (Participant 6: Lines 283-287).

2.3.5 *Type of information*

This theme is interesting as participants described contrasting views of when
memory compensations are needed. Three participants held the belief that information
which they deemed important would be remembered and so the use of memory aids was
not necessary.

Things that make my life better, like bringing money to make my life better my
kids life better then obviously I remember them things off the top of my head
(Participant 2: Lines 206-208).

On the other hand two participants spoke about how they used memory aids because the things/information they needed to remember was important to them and so they employed memory compensations to ensure the information was not forgotten. For example, Participant Seven stated that she had started putting important information/documents in a box next to her bed as she would forget where she had put them if she did not do this (*Participant 7: Lines 129-130*).

2.3.6 *Back up strategies*

This master theme describes the additional strategies that participants used to ensure that their main memory compensations were used effectively. One person described how he used an alarm to make sure that he checks his to-do-list; another described how she told her family the key locations where she was putting things. The backup strategies were however, very simple and need to be considered with caution as the feedback group suggested that too many memory compensations can feel overwhelming and one good strategy might be preferable to a range of ‘smaller’ strategies that are difficult to manage.

A number of factors that influence the use of memory compensations after ABI have been identified in the above master and sub-themes. During the course of the interviews participants also spoke about specific features and characteristics of the devices and strategies that encouraged their use. A list of the key characteristics identified by the participants is presented below, however, they were not subjected to interpretation and so this information is not considered as a standalone theme.

2.3.7 *Characteristics of memory aids*

The full list of characteristic of memory aids which were deemed to be positive aspects/features:

1. Practicality of the memory aid/strategy.
2. Simplicity of device/strategy. Doesn't require a lot of time to use the device i.e. not over complicated.
3. Memory aids and strategies that required minimal effort as decided by the individual person (what one person deems effortless is not necessarily the same for another individual).
4. Memory aids that are easily portable. Those aids that are one single unit such as a mobile phone and so do not require remembering lots of additional items e.g. paper diary also requires writing equipment.
5. Memory aids that have multiple functions such as a computer, mobile phone.
6. Memory aids that store large amounts of information e.g. mobile phone, diary.
7. Memory aids/strategies that can be personalized/made unique for a particular individual e.g. mobile phone can choose own alarm tones etc.
8. Memory aids that enable changes/modifications to be made easily.
9. Memory aids that allow you to see things that you have planned in advance, e.g. calendar, diary.
10. Memory aids that provide enough clear and visible writing space. In certain types of diaries and mobiles writing spaces are too small and so can be difficult to read notes or to fit all the necessary information in.
11. Memory aids that appear less conspicuous. Mobile phone a reminder can be disguised as a text message.

12. Certain memory aids such as a diary, calendar, notes tell you ‘what to do’ they don’t tell you ‘when’ an activity has to be done and so are not always efficient aids.
13. Memory aids with audio alarms to remind you ‘when’ something needs to be done as well as ‘what.’
14. Devices that can reduce the visibility of any difficulties to other people e.g. the predictive text on mobile phones can help with spelling but also the use of text language i.e. words can be shortened and/or abbreviated can hide spelling difficulties.

Of all the characteristics described by participants, practicality and simplicity appeared to be the most important features that were likely to influence acceptance or rejection of an aid e.g. “With a booklet you’ll be there...for like 10 minutes, pulling it out getting your pencil out and then your sharpener (*laughs*) ... too much for me” (*Participant 2, Lines 153-154*). In general, participants felt that memory compensations that were too effortful were less likely to be used. One person described how writing things in a diary was too effortful for her “whereas I can just stick things on the fridgeI probably wouldn’t know what I was writing. I’d get fed up with that” (*Participant 7, Lines 410-411*).

Participants also recognized that writing notes only ‘tells you what you need to remember’ whereas an alarm “tells me when to do it”, which was a feature that made the mobile phone very popular as a memory aid. In fact the mobile was cited as a useful memory aid on several occasions because of its portability and because it was such a well-established routine pre-morbidly that it was unlikely to be left at home. Another positive advantage of the mobile phone was that it could be personalised. Furthermore,

the predictive text function could assist with spelling and the alarm signal might be interpreted by others as an incoming text message and was thus not likely to lead to the embarrassment described earlier. The nature of alarms was also discussed, in particular the importance of setting reminders at the correct point in time rather than too early which would mean the appointment could still be forgotten;

... and then I'll remember appointment, doctors that day, on whatever time that day, because an alarm would go off at 6 o'clock and you got 15 minutes to go to the Doctors, so you got a bit of time in your head (*Participant 2, Lines 131-133*).

2.4 Discussion

The present study explored factors that influence the uptake of memory compensations in people with ABI. Previous quantitative studies have focused on factors such as type and extent of cognitive problems, age and premorbid use of aids all of which are non-modifiable variables. Despite being important predictors of the use of memory compensations these factors do not enable therapists and clinicians to encourage people with ABI to use memory compensations. Prior quantitative research has examined health beliefs and emotional representations relating to the use of memory compensations, but they do not help our understanding of the reasons why people hold such beliefs. The findings of the present study suggest that motivation to use memory compensations depends on complex processes that include social, emotional and practical factors, all of which through appropriate intervention programmes are potentially modifiable.

The most significant master theme to emerge from the present study was that of, ‘Emotional barriers preventing acceptance of memory compensations.’ This was a very rich theme and highlights the process of emotional adjustment not only to the injury itself, but also to the use of memory compensations. Bender Pape et al. (2002) echo this finding, suggesting that acceptance of and adaptation to a disability plays a major role in the use of assistive technology. Negative cognitions that may lead to difficulties accepting the use of aids are a key feature of this theme, but it is clear that some participants overcame the embarrassment associated with using memory compensations by employing adaptive cognitions such as thinking “you are not thick, that you are intelligent.”

It has been reported that following TBI people employ more avoidant coping strategies than non-clinical groups (Hinckley & Corrigan, 1990). However, greater use of avoidant coping strategies, such as escape and denial, are associated with higher levels of anxiety and depression (Finset & Andersson, 2000) and are linked with relatively poor outcomes (Moore & Stambrook, 1995). It is therefore important to understand how the negative cognitions described in this theme might lead to an avoidance of memory compensations. In terms of the stress-appraisal-coping model (Lazarus & Folkman, 1984), people appraise their situation in terms of how it affects their well-being (Folkman, 1984). Stressful appraisals (i.e. primary appraisals) for instance harm/loss, threat and challenge are associated with negative emotions such as fear, anger or resentment (Folkman, 1984). Once an individual has initially appraised their situation they then evaluate their own coping resources for dealing with a threat, i.e. secondary appraisal. Lazarus and Folkman (1984) highlight two forms of coping that are related to secondary appraisals. Problem-focused coping is when an individual

sees the problem as changeable and so aims to alter their situation. Patel (2008) suggests that the use of memory compensations is a form of problem-focused coping. Emotion-focused coping is when the person aims to manage the negative emotional responses that are associated with a problem and can include strategies such as avoidance, minimization, distancing and selective attention. The type of coping response employed as a result of the initial threat (i.e. primary appraisal) is mediated by an individual's evaluation of their own coping recourses (i.e. secondary appraisal) (Lazarus & Folkman, 1984).

In the present research the avoidance of conspicuous memory compensations can be understood as a response to an appraisal of negative social evaluation. For example, it was noted that many participants felt memory compensations were associated with appearing stupid and needing help, both of which echo the stigma and assistive device literature (e.g. Lund & Nygard, 2003). Negative social evaluations were appraised as a threat to an individual's well-being, therefore in order to cope with this threat people engaged in avoidant (i.e. a form of emotion focused) coping strategies rather than using memory compensations which can be seen as a form of problem-focused coping. Riley, Brennan and Powell (2004) also found that perceived negative social evaluations, such as the evaluations other people may make about a person with TBI, gave rise to threat appraisals and of those who reported instances of social negative threat appraisals, 44% of the participants subsequently avoided activities generally. It has been noted that following a brain injury individuals use concealment as a means of coping with the loss of their self-identity (Karlovits & McColl, 1999). Simpson et al. (2000) report that cultural reactions to disability specifically the feeling of shame, and the social stigma attached to disabilities resulted in both the individual with a brain

injury and their carers concealing information about their injury from extended family members, friends and health care professionals. Simpson et al. (2000) also report that those with a brain injury avoided social contact and isolated themselves as a result of stigma and a lack of understanding surrounding ABI. Furthermore, Nochi (1998) stated that people with TBI used strategies (e.g. controlling information about oneself; emphasising that their difficulties do not affect the more crucial aspects of completing tasks; modifying the meaning of the term normality by extending its meaning or attending to other aspects to regain the status of normality; using other terms such as head injury rather than TBI) to manage negative or stigmatised images that they felt were associated to having a brain injury. This is relevant to the present findings as the avoidance of memory aids that are deemed obvious may be a way of concealing one's difficulties thus enabling people to reduce any potential social embarrassment or stigmatization that they feel may be attributed to them having to use memory aids to compensate for memory difficulties. It was noted that people described the type of information they forgot as 'silly things' because they believed that forgetting important information, such as appointments, would actually make them as an individual look 'silly' to other people. Participants also felt embarrassed by the types of information they forgot and some participants suggested that using memory compensations to remember certain types of information was ridiculous. This also highlights the impact perceived negative social evaluations have on individuals with ABI. It is therefore important to find out whether people who appraise negative social evaluations as a threat, avoid using memory compensations generally.

The second master theme, 'Reverse effects' highlights factors that would appear to be potentially positive but in fact were de-motivating. The idea that the people no

longer feel like themselves is reinforced by the need to use memory compensations. The notion of 'feeling like I have got a problem' provides partial support for the assertion by Kit et al. (2007) that a shift in cognitive identity from an efficient to an inefficient rememberer is linked to negative affect. Thus a key factor in the avoidance of memory aids is that they can be an aversive reminder of the injury. Cognitions explaining this link are demonstrated in the sub-theme "It would make me feel as if I have got a problem." Gracey, Evans and Malley (2009) suggest that the threat of feared and actual catastrophic meanings associated with a post-injury situation can lead an individual to adopt coping strategies that may initially reduce the threat but result in a failure to resolve discrepancies in the long term that can lead to ongoing poor psychosocial outcomes. In terms of the present study the avoidance of memory compensations may initially serve as a protective function in order to delay the acceptance of a change in one's identity/personality, however it may result in poorer psychosocial outcomes as memory failures continue to occur. Yeates, Gracey and Collicutt-McGrath (2008) highlight the need for sensitivity, especially when addressing the self-protective function that an individual's behaviour and language may provide and suggest the need for integrated interventions that tackle the social contextual, neuro-cognitive and self representational systems that are involved in the acceptance of and adaptation to a new identity/personality change post injury.

Other factors which would appear to be potentially positive but in fact discouraged the use of memory compensations was other people providing reminders and remembering information for you, or the wrong person promoting the use of memory compensations. The former prevents people from independently using memory compensations thus becoming reliant on others and has been reported anecdotally in

previous studies (Wilson & Watson, 1996; Gartland, 2004). However, little attention has been placed on how memory aids are promoted or by whom. It was noted that a number of people felt that those who had survived an ABI consequently understood what it was like to have to use memory aids and so they were the best people to encourage their use. This is an area which perhaps needs more thought and exploration within clinical settings.

The third master theme 'Beliefs about memory and use of memory compensations' provides us with several forums for clinician intervention. The sub-theme 'needing something to bring it home to you' encompassed within this master theme suggests that the consequences of real life experiences of memory slips/failure are crucial in order to improve motivation to use compensations. Such experiences have also been linked with the process of gaining insight generally (Dirette, 2002; O'Callaghan, Powell & Oyeboode, 2006) and so the need for careful and sensitive exposure to real life memory failures might improve motivation to use memory compensations. They conclude that it is actual real life 'aha' moments outside of rehabilitation settings where critical incidents occur that allow for a comparison of pre-injury and post-injury abilities, the acknowledgement of others' reactions to their mistakes as well as personal discovery that leads to increased awareness (Dirette, 2002; O'Callaghan et al., 2006). As a result it has been noted that awareness interventions within rehabilitation settings that provide learning through practical exercises and individually tailored therapy can increase self awareness of deficits (Ownsworth Turpin, Andrew & Fleming, 2008). In the second sub-theme it is not clear where the strong belief in the benefits of mental rehearsal arose, not only is this an inefficient strategy for people with significant memory problems (Wilson & Watson, 1996), but it is unlikely to

be efficient for remembering prospective information such as appointments. The belief in repetition being an effective memory strategy is a cause for concern as it can prevent the use of other more efficient memory compensations. Interventions aimed at challenging this belief through reality testing during individual therapy sessions may then encourage people to employ more efficient strategies.

The final two sub-themes encompassed within this master theme also provide potential clinical interventions. As noted by Whittaker, Kemp and House (2007) providing information aimed at challenging inappropriate or maladaptive beliefs following ABI will aid recovery. It was noted that people who held beliefs about their memory improving (when it may not be) or the belief that using memory compensations will result in the loss of their memory ('Use it or lose it') did not want to use memory compensations, but rely on their own memory instead. Implicit in these statements is the desire to use one's own internal resources. However, these beliefs should be discouraged as there is no evidence to suggest that using memory compensations slows down natural recovery (Wilson & Watson, 1996). These sub-themes can be considered in the context of control beliefs, in particular those who possess greater personal control beliefs are more likely to employ problem-focused coping methods (Hagger & Orbell, 2003). Patel (2008) suggests that the use of memory strategies can be seen as a form of problem-focused coping in people with memory problems following ABI. Patel (2008) found that both personal and treatment control beliefs were significant predictors of the use of memory strategies. Consistent with Patel's (2008) findings, older adult research has reported a relationship between internal locus of control and memory strategy use (Verhaeghen et al., 2000). It has been noted that those with a more internal locus of control were more inclined to use memory coping strategies (Verhaeghen et al., 2000).

It is interesting that, whilst an internal locus of control is normally associated with a positive outcome (Moore & Stambrook, 1995), the present study suggests that this may not be the case when a person also holds inappropriate/maladaptive beliefs about their memory as there may be a reluctance to use memory compensations based upon a wish to use one's own internal resources. This may explain why Kit et al. (2007) found no correlation between the sub-scale locus of control and the strategies sub-scale of the revised MIA. It is hoped that the next stage of the research, i.e. a quantitative study, will elucidate this as it will explore whether inappropriate beliefs mediate the relationship between personal control beliefs and the use of memory compensations.

The idea that people will not use memory compensations that do not fit their lifestyle is highlighted in the next master theme "It's not in my nature." This theme explains why premorbid use of memory compensations is an important and strong factor in not only predicting whether people will use six or more memory compensations after ABI (Wilson & Watson, 1996; Evans et al., 2003) but also the type of memory compensation that will be used. By asking an individual about their premorbid use of aids and views of memory compensations this can help therapists eliminate those memory compensations that do not 'fit' a particular individual's lifestyle. In addition, Bender Pape et al. (2002) report that adaptive devices must fit value systems and convey the desired self image. Certain devices may be functionally adequate but if they do not reflect the persons point in their life cycle, family life stage, cultural heritage and desired social consequence they are unlikely to be used (Bender Pape et al., 2002). It has been suggested that assistive technology can be viewed as a panacea, with professionals looking at the functionality of devices rather than social consequences (Roulstone, 2007). McCreadie and Tinker (2005) and Lund and Nygard

(2003) also stress the need to look towards social aspects when encouraging the use of assistive devices. It is therefore important that rehabilitation services take care not to place too much emphasis on the functionality of memory compensations at the expense of social consequences.

The final master theme 'Type of information' describes the differences between participants' beliefs about remembering certain types of information. Some participants stated that they used memory aids to help them recall information which they deemed important. However, other participants held the belief that information, such as appointments, would be remembered simply because they considered it to be important to them. This can be considered to be paradoxical in nature, as it is perhaps expected that people would generally implement memory compensations for information they deem important. It may be that for some people placing a personal value on something that has to be remembered is an efficient internal memory strategy. However, it is when this strategy is not effective and the information/action is actually forgotten that it then becomes a mistaken belief and so has links with the master theme 'Beliefs about memory.' It may also be associated with limited awareness of memory difficulties. Clinical interventions that sensitively expose people to memory failures related to information which is deemed important may change this belief and so improve motivation to use memory compensations.

Key characteristics of memory compensations that were important to individuals were also noted during this study. Practicality of aids was one of the most important influences e.g. devices must be easily portable; have multiple functions. Research in other populations (e.g. older adults and people with physical disabilities) also suggests that assistive devices that are efficient, reliable, simple and easy to use, as well as those

devices that have multiple functions are more likely to be used (McCreadie & Tinker, 2005; Palmer & Seale, 2007; Capriani, Porter & Greaney, 2007). Characteristics of memory aids are therefore a key issue and need to be taken into consideration when deciding on the best memory compensations to suggest to those who have memory difficulties following ABI.

In summary, the present research is the first qualitative study to explore the factors that influence the uptake of memory compensations in people with memory difficulties due to ABI. In particular the theme ‘Reverse effects’, highlights areas and practices within the process of rehabilitation that might be de-motivating. By exploring beliefs about memory and compensation use, specific beliefs have been highlighted that result in the avoidance of memory compensations. Beliefs about memory, in particular the belief that rehearsal/repetition is effective for remembering prospective information and the belief that your memory is improving (when it may not be) were key beliefs that resulted in the avoidance of memory compensations.

2.4.1 Limitations

One of the original aims of this study was to find out why those people who viewed their memory to be variable and unpredictable were more likely to use memory strategies (Patel, 2008). It was hoped that a qualitative study would elucidate this finding; unfortunately a possible explanation was not established during the interviews. However, during the feedback group, participants suggested that as they were not able to predict whether their memory would be reliable from one day to another (e.g. on some occasions it would be worse than on other because they were tired), they used memory compensations because they could rely on the fact that by using them things were more predictable. If people feel they cannot predict the reliability of their own

memory then using memory compensations may be a way of coping and a safe guard to protect one's self from distress caused by forgetting important information. Participants in the feedback group also stated that using memory aids becomes part of your routine and so regardless of whether you feel your memory has improved, using them is second nature.

Although the study has provided new insights into factors that influence the uptake of memory compensations, one limitation of the present research is that participants were already attending a rehabilitation centre and so would have participated in sessions discussing memory compensations. To mitigate this, people with both positive and negative views regarding memory compensations were purposely interviewed. A surprising finding of this research is that whilst people talked about positive aspects of certain aids, for example an auditory alarm reminds you at a specific time when something needs doing, they only occasionally and briefly talked about the *general* benefits of using memory compensations, such as an improvement in remembering and attending appointments or being less reliant on other people. This is in contrast to other research that has explored attitudes towards assistive devices in people with physical disabilities (Palmer & Seale, 2007). A possible reason why the present research did not evoke discussions on the benefits of assistive devices may be due to the fact that our participants were in the relatively early stages of recovery and saw memory compensations as 'highlighting' their problem rather than as an integral part of themselves. Thus a different view of memory compensations might be obtained from people with ABI whose injury was sustained many years prior to the interview.

2.5 *Implications*

The findings of this research have implications for clinical practice and highlight that functionality of memory compensations are not the sole factor that encourages their uptake. Traditionally, rehabilitation therapists use a biopsychosocial model and this study demonstrates the importance of adhering to this model. It should also be noted that there is a need for emotional acceptance by the individual before they are willing to use memory compensations and that interventions aimed at helping people adapt and accept their brain injury may help increase the uptake of memory compensations. Psychotherapeutic interventions such as cognitive behavioural therapy (CBT) may be used to help people overcome perceived negative social evaluations that lead to avoidance. When an unwillingness to use memory compensations is a result of a lack of awareness of difficulties, it may be necessary to reduce the degree of support from friends and family and carefully expose the person to the consequences of their memory difficulties.

Further to this, the findings suggest that the rehabilitation of memory problems should incorporate assessment and interventions, such as CBT, aimed at changing mistaken beliefs about memory problems and the use of memory compensations. Changing mistaken beliefs may be particularly important for those individuals who also hold a strong sense of personal control over their memory.

For those individuals who possess a desire to use their own internal resources approaches such as Goal Management Training (GMT) (Levine et al., 2000) may help improve some memory difficulties, in particular those situations that require planning, organisation and problem solving. GMT is based on Duncan's 1986 theory of disorganisation of behaviour (Levine et al., 2000). It has been noted that human

behaviour is controlled by goal lists constructed in response to internal or environmental demands (Levine et al., 2000). When the current state of affairs does not match the goal state appropriate actions are consulted and then activated to reduce discrepancy between the two states (van Hooren et al., 2007). Goal lists impose coherence on behaviour by controlling the activation or inhibition of actions that promote or impose task completion. Disorganized behaviour after ABI can be attributed to impaired construction and use of goal lists (Levine et al., 2000). GMT therefore aims to teach people to identify situations characterized by cognitive failure and to state appropriate goals when confronted with such situations (van Hooren et al., 2007). There are five stages when using GMT, the initial 'stop' phase in which people are trained to assess the current state of affairs; Stage 2 in which goals are defined and are then divided into sub-goals in Stage 3; Stage 4 involves learning goals/sub-goals and Stage 5 involves checking that the outcome action is in line with the goal state (Levine et al 2000). Using GMT may enable people to have better control over their memory by teaching them to identify and implement goal lists for tasks such as remembering what items they need to take with them to the doctors. Levine et al. (2000) found that GMT aided meal preparation following ABI and they note that performance on the pencil and paper tasks was slower after GMT suggesting increased care and attention was taken when goal lists were implemented. However it may be difficult for people who have limited insight into their difficulties to employ GMT techniques, in particular the initial 'stop' phase requires people to be aware of their current difficulties (van Hooren et al., 2007). Therefore careful exposure to memory slips may also help to demonstrate the need for use of memory compensations or techniques such as GMT.

It is also important that memory compensations are customised to suit an individual's lifestyle and care should be taken not to overload people with too many strategies as this simply adds to the effort of coping with the effects of the injury. Finally, rehabilitation programmes should perhaps place more emphasis on an expert patient model with those who have successfully implemented aids being instrumental in promoting their use.

2.5.1 Implications for future research

This qualitative study has revealed several new factors that influence the use of memory compensations in those following ABI. The next chapter of this thesis therefore aims to determine which of these factors are the most important in predicting the use of memory compensations following ABI. Further explorations of the link between control cognitions and unhelpful beliefs in order to clarify discrepant findings relating to locus of control in previous quantitative studies will also be undertaken. It is hoped that this information will enable rehabilitation professionals to have a greater understanding of how to encourage people with memory impairments to use memory compensations.

2.6 Summary

This phenomenological study both concurs with and expands upon previous quantitative research in this area. It also highlights areas for clinical intervention. In particular, the findings suggest that social, emotional and practical factors all need to be taken into consideration when encouraging the use of memory compensations. This study exemplifies how participants' personal experiences of using memory compensations can provide rehabilitation professionals with greater insight into how the use of memory compensations can be encouraged thus increasing independence and participation in society.

CHAPTER 3

A QUANTITATIVE ANALYSIS

3.1 Introduction

As discussed in Chapter 2, despite the general consensus that memory compensations are effective in maintaining independence after an ABI, their uptake is extremely variable and people sometimes feel using memory aids “is cheating and believe they should not rely on aids, others feel compensatory aids will reduce their chances of natural recovery occurring” (Wilson & Watson, 1996, p.466). The second chapter in this thesis described a qualitative study that addressed what it is like from the individual’s perspective to have memory difficulties and use memory compensations following ABI. In this third chapter, a quantitative approach will be taken in order to build upon the qualitative findings and to explore the relative contribution of injury related factors, demographic factors and beliefs about using memory aids in the prediction of the uptake of memory compensations following ABI.

To understand the variables that predict the use of memory compensations, studies have systematically explored demographic variables such as: age at the time of injury, current age, time since injury, pre-morbid use of compensatory aids, sex and education (Wilson & Watson, 1996; Evans Wilson, Needham, & Brentall, 2003). The importance of demographic variables has been discussed in Chapter 2 and so only a summary of the findings is provided in this chapter.

It has been noted that: current age (i.e. being younger), being less than 30 years old at the time of injury and the more aids used premorbidly, are the most important demographic variables that predict uptake of memory aids (Wilson & Watson, 1996;

Evans et al., 2003). However, there are contrasting findings regarding time since injury. Evans et al. (2003) found that those who were more recently injured (i.e. shorter time since injury) were more likely to be using aids. In contrast, Wilson (1991) reported that people in her study only began to use memory aids after some time elapsed. The use of memory aids following ABI has been found to increase with higher educational attainment (Patel, 2008; Wright, Rogers, Hall, Wilson, Evans, Emslie, & Bartram, 2001a; Wright, Rogers, Hall, Wilson, Evans, & Emslie, 2001b) and current intellectual ability was found to predict the use of six or more aids (Evans et al., 2003). Similar correlations have also been found in older adult populations (McDougall, 2004; McDougall & Holsten, 2003). Although these studies (Wilson & Watson, 1996; Evans et al., 2003; Wright et al., 2001a, b; Patel 2008) have not found sex differences to have a significant relationship with the use of memory aids following ABI, sex differences have been found in older adults with females using a greater number of internal and external aids (de Frias, Dixon & Bäckman, 2003). All of these demographic variables were therefore included in the present study. Premorbid use of memory aids was not included in this study as it was likely to duplicate one of the study variables (Lifestyle 'fit', see below).

Injury related variables, in particular cognitive difficulties, have also been the focus of research studies looking at factors that predict the use of memory compensations following ABI. It has been reported that those with memory problems but without marked executive deficits or other cognitive deficits and those with less severe memory difficulties are more likely to use memory compensations (Wilson & Watson, 1996, Evans et al., 2003, Patel, 2008). In the present study only severity of memory difficulties was explored because degree of memory impairment was the only

variable found to negatively correlate with the use of more memory aids in all three studies (Wilson & Watson, 1996; Evans et al., 2003; Patel, 2008) and it was important to minimise patient's fatigue given an already lengthy questionnaire session.

Although demographic and injury related variables are helpful in alerting the therapist to those clients who might require extra support and encouragement to use aids, such variables are static. It is therefore important to look for modifiable variables such as beliefs about the use of memory aids which will be discussed below.

3.1.1 Beliefs about memory

It has been noted in many health conditions, that those who believe that their illness is controllable are more likely to employ problem-focused coping methods which result in psychological well being and better social functioning (Hagger & Orbell, 2003). Control beliefs can be defined as beliefs about the presence of factors that may further or hinder performance of the behaviour (Ajzen, 2002) and can be separated into personal control (that reflects one's beliefs about one's own ability to control one's condition) and treatment control (that reflects one's belief in the treatment or recommended advice) (Moss-Morris et al., 2002). Greater control beliefs have been linked to better adjustment in people with multiple sclerosis (Vaughan, Morrison & Miller, 2003; Spain, Tubridy, Kilpatrick, Adams, & Holmes; 2007) and adherence to medication in various health conditions (Jessop & Rutter, 2004; Whitmarsh, Koutantji & Sidell, 2003; Barclay et al., 2007). Research into control beliefs in people with ABI has found that people who possess an internal locus of control have: better psychosocial outcomes (Moore & Stambrook, 1995), less mood disturbance and less depression (Moore & Stambrook, 1992), and are more likely to return to pre-injury employment status (Lubusko, Moore, Stambrook & Gill, 1994). It was also noted that higher

perceptions of control positively correlated with reductions in functional limitations following a workbook intervention designed to increase perceptions of control in patients discharged from hospital following a stroke (Frank, Johnson, Morrison, Pollard & MacWalter, 2000). Thus, research findings into control beliefs and ABI are similar to that found in other health research areas.

As noted in Chapter 2, Patel (2008), investigated whether health beliefs correlated with use of memory compensations in people with ABI. She found that personal and treatment control beliefs were positively correlated with the use of memory compensations. Consistent with her findings, Verhaeghen, Geraerts, and Marcoen (2000) found a positive relationship between personal/internal locus of control and use of memory strategies in older adults. Personal and treatment control beliefs are therefore included in the present study.

The qualitative study in Chapter 2 of this thesis suggests that having a desire to rely on one's own inner resources (as would be indicated by greater personal control beliefs) may not be helpful in the presence of inappropriate beliefs, such as use it or lose ones memory or that repetition is an effective strategy for remembering prospective information (e.g. appointments). This research will therefore also explore whether holding inappropriate beliefs about memory and memory aids mediates the relationship between control beliefs (measured by personal control beliefs) and use of memory compensations. A mediator is a factor that accounts for the relationship between two variables (Baron & Kenny, 1986).

3.1.2 Awareness following ABI

In the qualitative study undertaken in Chapter 2 of this thesis it was found that people with ABI often reported initiating the use of memory aids after experiencing the

real world consequences of memory slips that ‘brought home’ the need to use memory compensations. To date, no studies have explicitly explored the impact of increased awareness of memory problems on the use of memory compensations.

A lack of self awareness is characterised by a lack of acknowledgement of acquired deficits, including the impact on daily life and a failure to adjust goals accordingly (Fleming, Strong & Ashton, 1996). Lack of self awareness has subsequently been associated with poorer outcomes, unrealistic goal-setting, heightened emotional disturbance and poor engagement/adherence to treatment/rehabilitation (Ownsworth & McFarland, 2004; Trahan, Pépin & Hopps, 2006). Similarly, it has been reported that those with greater awareness were better adjusted and in the best position to benefit and engage in rehabilitation, it is also associated with increased compliance in rehabilitation programmes and a willingness to describe problems and to follow therapists’ recommendations (Ownsworth, Turpin, Andrew & Fleming, 2008; Medley, Powell, Worthington, Chohan & Jones, 2010). As a consequence, interventions to improve awareness, such as psychotherapeutic approaches, game formats, direct feedback and structured experiences (Fleming & Ownsworth, 2006) have been developed with many studies reporting increased awareness of deficits after intervention (Ownsworth et al., 2008; Lundqvist, Linnros, Orlenius & Samuelsson, 2010). The present study therefore aims to investigate whether a lack of awareness of memory deficits is specifically associated with poor uptake of memory compensations as this has previously not been explored.

Awareness of difficulties is often measured by comparing patients’ own ratings with relatives’ or clinicians’ ratings. The discrepancy score is then used as a measure of awareness. Such comparison of patient self-ratings against the ratings of relatives or

clinicians is recommended in clinical practice and is considered to be an objective measure of awareness (Flemming et al., 1996).

Although events that ‘brought home’ the need to use memory aids were a positive factor in the use of aids, negative thoughts regarding what other people might think if one were observed using memory compensations, would sometimes put people off using those aids they deemed obvious. Such ‘threat appraisals’ are therefore discussed in the next section.

3.1.3 Threat appraisals

As previously discussed in Chapter 2, the stress appraisal coping model (Lazarus & Folkman, 1984) can be used to explain one possible reason why people avoid using memory compensations following ABI. ‘Emotional barriers preventing acceptance of memory compensations’ was the most significant theme to emerge from the qualitative study. It suggested that people tended to avoid (i.e. a form of emotion focused coping) memory compensations (a form of problem-focused coping) that were deemed obvious such as; carrying a diary or notepad/paper for writing notes, in order to avoid the negative social evaluations (e.g. appearing stupid or needing help) that might be made as a result of using such aids. Lazarus and Folkman (1984) termed such perceptions as ‘threat appraisals’.

A number of studies suggest that employing avoidant coping strategies in the face of ‘threats’ following ABI results in poorer psychological outcomes (Moore, Stambrook & Peters, 1989; Moore & Stambrook, 1992; Lubusko et al., 1994; Malia, Powell & Torode, 1995; Finset & Andersson, 2000; King, Shade-Zeldow, Carlson, Feldman & Philip, 2002; Donnellan, Hevey, Hickey & O’Neill, 2006). However, the literature has provided very little information on what has specifically been avoided and

why this is the case. Kendal, Shum, Lack, Bull and Fee (2001) attempted to rectify this gap in the literature by addressing the contexts and threats faced by those with ABI. They found that the type and number of coping strategies differed significantly across situations.

The threat appraisals in the form of negative social evaluations highlighted in Chapter 2 of this thesis are similar to those described by Riley, Brennan and Powell (2004). In particular, those described in their category 'Dealing with people' which encompassed social situations that focused on perceived negative evaluations other people may make about a person with TBI. Riley et al. (2004) found that 74% of those asked reported at least 10 threat appraisals and, in terms of threat-related avoidances, 74% reported at least one and 32% reported a minimum of 10. This suggests that threat appraisals and related avoidance are a frequent occurrence in those with TBI.

In Chapter 2, threat appraisals in the form of negative social evaluations (e.g. appearing stupid, needing help and the feeling of embarrassment at having to use memory compensations) tended to lead to the avoidance of memory aids that were too conspicuous. Unfortunately, Riley et al. (2004) did not include threat appraisals specifically associated with using memory compensations after a brain injury. There is therefore a need to address the issue of whether threat appraisals in the form of social negative evaluations by others results in the avoidance of memory compensations. It is hoped that a quantitative study may elucidate this finding.

Although threat appraisals in the form of negative social evaluations by others were a negative factor in the use of aids, the belief that the use of memory aids that did not reflect one's self identity would also deter people from using them. The notion that

memory compensations must suit an individual's lifestyle is discussed in the next section.

3.1.4 Lifestyle fit

In the initial qualitative study it was noted that factors that are associated with one's lifestyle, such as not having enough things to remember or other people providing reminders and remembering information for you, can prevent people from using memory compensations independently (Wilson and Watson, 1996; Gartland, 2004). Additionally, the importance of memory aids suiting someone's lifestyle was highlighted. It was recognised that memory compensations that did not 'fit' a particular individual's lifestyle were avoided and people highlighted the need for memory compensations to be something that 'they were comfortable doing' thus being consistent with a personal identity. It has been recognised that adaptive devices must fit value systems and convey one's desired self image if they are likely to be used (Bender Pape, Kim, & Weiner, 2002). Furthermore, the qualitative study found that a change in one's self identity and the notion that they no longer felt themselves was reinforced by the need to use memory compensations (Chapter 2). Surviving an ABI can have a huge impact on an individual's beliefs about themselves, as subsequent 'threats' and change to one's identity can mean people struggle to understand and identify with their post-injury selves, in particular within the context of cognitive, physical and psychosocial changes (Dewar & Gracey, 2007; Levack, Kayes & Fadyl, 2010). Kit, Mateer and Graves (2007) reported that using memory compensations highlighted a shift in cognitive identity from an 'efficient' to an 'inefficient' rememberer in people with TBI and that this was linked to negative affect. Thus a key factor in the avoidance of memory aids may be that they can be an aversive reminder of the injury and a threat to

pre-injury identity. Discrepant self-representations can contribute to distress following ABI (Dewar & Gracey, 2007) which can result in people adopting coping strategies that may initially reduce the threat (Gracey, Evans & Malley, 2009). Thus, in order to protect one's identity and minimise distress, people may avoid using memory compensations that do not fit their lifestyle, thus limiting the change to one's perceived self identity. The present study therefore aims to investigate whether lifestyle 'fit' has an important impact on use of memory compensations.

3.1.5 Study aims

A number of factors have been discussed that influence the uptake of memory compensations following ABI, many of which have not previously been explored e.g. awareness of memory deficits per se, threat appraisals and inappropriate beliefs. The findings from the qualitative study in Chapter 2 have therefore provided a framework to further explore which factors predict the uptake of memory compensations after ABI in addition to those demographic variables highlighted in previous studies.

3.1.5.1 Research questions

This study aimed to explore the following research questions:

- 1) Which of the following belief variables are the best predictors of the uptake of memory compensations: personal control beliefs; treatment control beliefs; lifestyle fit; threat appraisals; inappropriate beliefs or awareness of difficulties?
- 2) Do any of the belief variables add to the predictive value of demographic and injury related variables?
- 3) Do inappropriate beliefs about memory and memory compensations mediate the relationship between personal control beliefs and memory compensation use?

3.2 *Method*

3.2.1 *Design*

This study employed a cross-sectional questionnaire design using regression analysis to investigate the main research aims.

3.2.2 *Participants*

All potential participants who met the following inclusion criteria were eligible to participate in the study: 1) confirmed ABI, 2) a good command of spoken English and 3) self reported memory problems on the EMQ and/or day to day memory difficulties confirmed by centre staff.

Based upon the calculation for multiple regression sample size: $N > 50 + 8m$, where m is the number of independent variables (Tabachnick & Fidell, 2006) an initial sample size of 98 participants was calculated. However, according to Cohen's (1988) conventions for describing effect sizes as small, medium and large, the present study (with $N=6$) would require approximately greater than 140 participants in order to identify a small experimental effect, 97 participants in order to show a medium effect and 45 participants to show a large experimental effect (power = 0.8.; alpha = 0.05 two-tailed; OLS regression (with six predictor variables)). This was calculated using G*Power 3 (Faul, Erdfelder, Lang & Buchner, 2007). In clinical practice small or medium experimental effects may be of limited practical utility. Accordingly, a sample size of approximately 60 participants should provide a balance between economy and precision. As a result of time constraints and a limited number of people who met the inclusion criteria a total of 58 participants (35 male and 23 female) with ABI and self reported memory difficulties participated in the study.

Participants ranged from 18 to 65 years old ($M= 44.2$; $SD = 12.3$) with a mean age of 40 years at the time of injury ($SD= 13.7$). Fifty participants were White British; two were White other (American & Brazilian); three participants were Black British; two were Black African and one male participant was Yemeni. All participants were a minimum of six months post injury with a mean of 44 months ($SD= 61.9$). Twenty six participants had sustained a TBI (7 caused by a fall; 13 by a road traffic accident and 6 by an assault). Twenty six participants had a vascular injury, four had a viral infection and two had an anoxic brain injury.

3.2.3 Measures

Participants completed a demographics questionnaire, a memory assessment and three self-report measures.

3.2.3.1 Memory assessment

The List Learning subtask of the Adult Memory and Information Processing Battery (AMIPB; Coughlan & Hollows, 1985) (Appendix D) was administered in order to provide an objective measure of memory impairment. A list of 15 words was read to participants five times. After each presentation, participants were asked to recall as many of the items from the list as possible. After the five trials a distracter list of 15 different words was read, and participants were asked to recall as many of the distracter items as possible. Following the distracter list, participants were asked to recall as many

items as possible from the original list without the items being reread. Test-retest reliability correlations were reported to be 0.77 for the total recall scores for trials 1-5 and 0.73 for trial 6 recall (Coughlan & Hollows, 1985). Scores on the list learning task were converted to z-scores using the age-matched population norms in the test manual. In order to ensure all participants met the study criteria, participants' responses to the questionnaires were accepted if they scored below the 10th percentile cut off (z score of -1.31 or lower) on the initial recall of items (A1- A5).

3.2.3.2 *Revised Everyday Memory Questionnaire (EMQ-r)*

The EMQ-r (Royle & Lincoln, 2008) was used to measure participants' awareness of memory difficulties. Traditionally, research assessing level of awareness compares the patient's self report with a significant others' report and the discrepancy between the two is taken as a measure of awareness (Fleming, et al., 1996). This is standard practice both clinically and experimentally. The EMQ-r consists of 13 statements about memory failures and participants indicated how often they experienced each symptom of forgetting in the last month. A 5-point Likert scale was used with a scale of 0 (once or less in the last month); 1 (more than once a month but less than once a week); 2 (about once a week); 3 (more than once a week but less than once a day); and 4 (once or more a day) (Appendix F). The EMQ-r was also modified and a significant other version produced (EMQ-r significant other; Appendix F). The maximum possible score for the EMQ-r was 52 as was the maximum possible score for the EMQ-r significant other. A discrepancy score between the participant EMQ-r and significant other EMQ-r provided a measure of the participant's level of awareness of their everyday memory difficulties. In order to obtain a discrepancy score the participant total EMQ-r score was subtracted from the EMQ-r significant other total score. A large

positive discrepancy score indicated low awareness of memory difficulties (i.e. high EMQ-r difference indicated a lack of awareness of difficulties), a small positive discrepancy score indicated that participants rated their difficulties in line with their significant other (i.e. greater awareness) and a negative discrepancy score indicated that participants' perceived their memory difficulties to be worse than their significant other.

3.2.3.3 Memory Strategy Questionnaire

In order to measure participants' use of memory strategies the Memory Strategies Questionnaire (MSQ) was administered (Appendix H). This questionnaire is based on The Techniques to Remember Subscale of the Prospective Memory Questionnaire (Hannon, Adams, Harrington, Fries-Dias & Gipson, 1995) and was modified by Patel (2008). Internal coefficients for the original subscales of the Prospective Memory Questionnaire were between 0.78 and 0.90 (Hannon et al., 1995). Internal reliability analysis for the modified MSQ revealed a Cronbach's alpha coefficient of 0.92 (Patel, 2008). The MSQ consists of 19 statements of techniques and aids used to assist memory, and participants were asked to rate the frequency of use of each technique or aid on a 5-point Likert scale; 0 (never); 1 (once a week); 2 (two times a week); 3 (three time a week); and 4 (four or more times a week). Higher total scores on the MSQ reflect greater use of memory aids and strategies.

3.2.3.4 Beliefs about Memory Aids

The Beliefs about Memory Aids Questionnaire (BMQ) was developed specifically for the present study (Appendix G). Items were derived from the qualitative study described in Chapter 2. For example, the quote

I didn't like it because I've always relied on my own memory and my own thought and my own peace of mind and then to rely on something like that, I

thought it would make me lazy, which I try not to use it as much as I can.

(Participant Three: Lines 23-25)

led to the item ‘ Using memory aids will make my memory lazy.’ Fifty possible statements were initially generated by selecting quotes that highlighted the essence of each theme and subtheme from Chapter 2. The original 50 statements were reduced to 33 items after discussion between myself and Dr Theresa Powell (academic supervisor) on the basis that some were duplicating the same theme. All such items were therefore either combined with other items or removed from the list. These items were grouped intuitively into five subscales: threat appraisals (consisted of 9 items); lifestyle fit (5 items); inappropriate beliefs (5 items); treatment control beliefs (7 items) and personal control beliefs (7 items). In order to compare the present study with Patel’s (2008) findings, five of the seven items from the treatment control subscale (two items were kept) and all seven items from the personal control subscale were removed and replaced with the personal control and treatment control subscale questions from the revised Illness Perceptions Questionnaire (IPQ-r; Moss-Morris et al., 2002). The IPQ-r subscale personal control consists of 6 questions and the treatment control subscale consists of 5 questions. However, one item from the IPQ-r treatment control subscale (My treatment will be effective in curing my illness) was removed. This left a total of four IPQ-r treatment control subscale questions. The two items from the original BMQ treatment control subscale (“I wouldn’t have to rely on other people as much if I used a memory aid” & “I wouldn’t forget to do things if I used memory aids”) were combined with the IPQ-r treatment control subscale questions to make a total of six BMQ treatment control questions.

The IPQ-r treatment control item: ‘My treatment will be effective in curing my illness’ was deemed more reflective of an inappropriate belief and was therefore added to the BMQ subscale inappropriate beliefs. Items taken from the IPQ-r were adapted and the word ‘memory problem’ replaced the generic term ‘illness.’ This is standard procedure when using the IPQ-r for different clinical populations (Moss-Morris et al., 2002). The IPQ-r is a validated measure and has been used in a range of health care studies to evaluate health beliefs. It has shown good internal reliability for the personal and treatment control subscales (0.91 and 0.85 respectively) in people following ABI, with treatment beliefs being a strong predictor of the use of memory aids (Patel, 2008).

The final version of the BMQ therefore consisted of a total of 32 items divided into five subscales. Nineteen items measured participants’ beliefs about using memory aids and strategies and thirteen items measured beliefs about memory problems. Two subscales: threat appraisals (9 items) and lifestyle fit (5 items) remained unaltered and were grouped intuitively based upon the themes derived from the qualitative study (Chapter 2). Five items from the BMQ inappropriate beliefs subscale were also based intuitively upon the qualitative study and one item (My treatment will be effective in curing my illness) was taken from the IPQ-r (total of 6 items). Two subscales were derived from the IPQ-r: personal control beliefs (6 items) and treatment control beliefs (6 items: 4 items from the IPQ-r & 2 based on qualitative study). Each item in the BMQ is supported by an auditable trail from the interview extracts to the questionnaire (Clarke & Watson, 1995). Examples of how the interview extracts became subsequent BMQ items for the sub-scales treatment control and personal control are given in Table 3.1 and examples for the subscales inappropriate beliefs, lifestyle fit and threat appraisals are given in Table 3.2.

Table 3.1. Example of extracts forming subscales: treatment control and personal control for the Beliefs about Memory Aids Questionnaire (BMQ).

Example extract	Subscale question		BMQ Number
Treatment Control			
<i>With my reminder I don't forget things I have to do.</i>	I wouldn't forget to do things if I used memory aids.		BMQ 10
<i>Using memory aids I don't have to keep asking family about the things I need to remember to do.</i>	I wouldn't have to rely on other people as much if I used a memory aid.		BMQ 18
<p><i>Like for instance my phone it helps me to remember things.</i></p> <p><i>It makes it easier for myself so I can remember what I got to do. I put things there so I could make it easier for myself and remember what I've got to do.</i></p> <p><i>Using memory aids is a nice help.</i></p> <p><i>The easiest strategy would be writing it down that's the best strategy writing things down to remind me.</i></p> <p><i>They're good, very good because if people told me not to use memory strategies then that it... what am I going to do in my life nothing.</i></p>	There is very little that can be done to improve my illness.	There is very little that can be done to improve my memory problem	BMQ 6
	The negative effects of my illness can be prevented (avoided) by my treatment.	The negative effects of my memory problem can be prevented (avoided) by using memory aids.	BMQ 14
	There is nothing which can help my condition.	There is nothing that can help my memory problem.	BMQ 11
	My treatment can control my illness.	Using memory aids would help me to manage (have control over) my memory problem.	BMQ 12
Personal Control			
<p><i>If I can rely on my own memory that's one step forward, not by looking at it in a diary.</i></p> <p><i>I want to try to remember things I want to get back to a normal way.</i></p> <p><i>I do it of my own positive way of life.</i></p> <p><i>What I do for all my... for decisions about my life, what's going to be better for me that why I do my own things.</i></p> <p><i>I want to try and remember things</i></p> <p><i>I try to remember things myself and not rely on other things to remind me.</i></p> <p><i>I didn't like it because I've always relied on my own memory and my own thought and my own peace of mind.</i></p>	My actions will have no affect on the outcome of my illness.	My actions will have no effect on the outcome of my memory problem.	BMQ 1
	The course of my illness depends on me.	The course of my memory problem depends on me.	BMQ 9
	There is a lot which I can do to control my symptoms.	There is a lot I can do myself to control my forgetting	BMQ 22
	What I do can determine whether my illness gets better or worse.	What I do can determine whether my memory problem gets better or worse.	BMQ 23
	Nothing I do will affect my illness.	Nothing I do will affect my memory problem.	BMQ 25
	I have the power to influence my illness.	I have the power to influence my memory problem.	BMQ 26

Note. Items in red are IPQ-r questions and were modified accordingly. ²⁾ The BMQ items in blue measure beliefs about memory, and those items in black measure participants' beliefs about using memory aids).

Table 3.2. Example of extracts forming subscales: inappropriate beliefs; lifestyle fit & threat appraisals for the Beliefs about Memory Aids Questionnaire (BMQ).

Example extract	Subscale question	BMQ Number
Inappropriate Beliefs		
<i>I don't think I need, I don't need it that's what I think. I don't use it as often.</i>	My memory is ok so I don't need to use memory aids.	BMQ 2
<i>To rely on something like that, I thought it would make me lazy, which I try not to use it as much as I can.</i>	Using memory aids will make my memory lazy.	BMQ 3
<i>I keep repeating it to myself in my head, but not out aloud, it's like recording just keep going over and over things again in my head.</i>	Repeating things to myself works as well as a memory aid.	BMQ 4
<i>I try not to use them as much as I did the day before or the time before because I want to try and remember things.</i>	It's better to try to rely on my own memory than use memory aids.	BMQ 15
<i>The only thing I can do really is not use as many aids as I've used and hopefully my memory will come back to normal.</i>	I will never get my memory back if I rely on memory aids now.	BMQ 21
<i>My treatment will be effective in curing my illness.</i>	Using memory aids will fix the cause of (cure) my memory problem.	BMQ 29
Lifestyle Fit		
<i>I don't have much to remember at the moment to need to use them.</i>	I don't have enough things to remember to need to use memory aids	BMQ 8
<i>I have someone round me someone who takes care of these things for me.</i>	I can usually rely on someone to remind me so I don't need to use memory aids.	BMQ 16
<i>I don't know of writing a diary and looking at it, I definitely wouldn't find that for me.</i>	Writing things down just isn't me.	BMQ 20
<i>Probably sometime, yeah, like say 'do yourself a diary' I don't want to do a diary coz that's not am not comfortable doing a diary and that's not what I want to do. But for some people it is, we all just do it different ways.</i>	Using a diary just doesn't fit my lifestyle.	BMQ 28
<i>It does take a lot of effort and some of these people here they're marvellous at it, they fill it out top to bottom comprehensively every day.</i>	Using a memory aid is a lot of effort.	BMQ 31
Threat Appraisals		
<i>They don't like the idea of other people seeing it and that they start thinking that other people will be of the opinion that they're not as good, because they have something to help them.</i>	Using a memory aid would make me feel like I need help.	BMQ 5
<i>I think she remembers it so why shouldn't I remember it, it's my appointment and why can't then I think ah if I've got to do this tomorrow why wouldn't I remember it</i>	Having a memory problem makes me feel like I need help.	BMQ 7
<i>Am so young it's not right if I go 'oh I can't remember' I've got to do things differently. I don't know, I'd feel embarrassed. None of them use a diary.</i>	Only older people should need to use memory aids.	BMQ 13
<i>If you pull out a notepad for simple things, what they not going to take you seriously when you need a notepad, they say what for?</i>	People won't take me seriously if they see me using a memory aid.	BMQ 17
<i>I think instead of people looking at you thinking 'why do you need that for'. So at least you can look at it in your own privacy and not worry about what other people think.</i>	I would feel stupid if I had to use a memory aid in public.	BMQ 19
<i>They might be embarrassed but you don't know do you. You.... suppose don't want it to be seen as a weakness do you?</i>	Having a memory problem makes me feel less of a person.	BMQ 24
<i>I feel stupid, I forget silly things.</i>	Having a bad memory makes me feel stupid.	BMQ 27
<i>Some people may be of the opinion themselves that needing help is bad, so they can see it as people who are going to see them using it they're going to think less of them.</i>	People would think less of me if they knew I needed to use memory aids.	BMQ 30
<i>Yeah, because it makes you feel like you have got a problem and it reminds you that you have had a brain injury and it makes you feel different.</i>	Using a memory aid would just be an unpleasant reminder of my memory problem.	BMQ 32

Six attendees at the outpatient rehabilitation centre [REDACTED] were asked to consider the clarity of the final BMQ items and whether the items would be easily understood by people with ABI. As a result no further items were removed from the questionnaire.

Participants were asked to state how much they agreed or disagreed with each of the 32 items on a 5-point Likert Scale ranging from ‘strongly agree’ to ‘strongly disagree.’ The following instructions were given to participants before completing the BMQ:

We would like to know how you feel about your memory and about using memory aids. By memory aid we mean anything you use to help you remember things which could be either:

- *a tool you use to help you remember things such as a mobile phone, a diary, a notice board, a to-do-list or a calendar etc.*
- *or something you think or do to help you remember such as putting things in key places, creating mental pictures or rhymes to help you remember people’s names etc.*

So please tell us how much you agree or disagree with the following statements by ticking the box that applies to you.

High scores on the personal and treatment control subscales of the BMQ were deemed positive as this indicated strong personal and treatment control beliefs. High scores on the subscale ‘threat appraisals’ indicated participants were more attune to negative social evaluations by others, as well as indicating that participants believed using memory aids made them feel stupid/ less of a person and further highlighted their difficulties. High scores on the inappropriate beliefs subscale indicated participants held mistaken beliefs about memory problems or using memory aids such as using memory aids will make their memory lazy. High scores on the subscale ‘lifestyle fit’ indicated that participants believed that their lifestyle did not warrant the use of memory

compensations (as they could rely on others or had little to remember). In addition this sub-scale also indicated that participants believed that the use of certain memory compensations was not in keeping with their lifestyle. As this is an unpublished measure the subscales of the BMQ were subjected to reliability analysis which can be found in Table 3.5.

3.2.3.5 Additional Information

Demographic data including information on the type of injury, time post injury, current rehabilitation status (inpatient/outpatient) was collected as well as participants' educational attainment (measured by the participants' highest qualification) and employment history (Appendix J).

3.2.4 Procedure

Key workers at the rehabilitation centres and Day Service Managers at [REDACTED] were initially briefed about the research and the criteria for participation. They approached clients who met the inclusion criteria and who they felt would be interested in participating. If the clients expressed an interest in the research, I (the researcher and author of this thesis) explained the study to them and informed them that as part of the research it would be necessary to contact a relative or significant other via post to ask them to complete a short questionnaire about their views of their (i.e. the participants) memory problems. Each person was also provided with a participant information sheet (Appendix C) and any questions were answered. Everyone was given a minimum of 24 hours to decide whether they wanted to participate. A questionnaire session convenient for the participant was arranged and they were asked to sign a consent form (Appendix C). It was reiterated that they had the right to withdraw at any time. Participants were then seen for a one hour questionnaire session where they completed the three

questionnaires and the memory assessment. If the participant required support, I read each item on the measures to them as well as the responses. I then marked down the participant's response. Demographic data was also collected during the questionnaire session as well as a postal address for their nominated relative or significant other.

Relatives/significant others were only contacted via post. They received a participant information sheet (Appendix C) detailing the study aims as well as asking them to complete the EMQ-r (relative/significant other version) (Appendix F) and sign the consent form (Appendix C). A stamped addressed envelope was provided in order to return the completed questionnaire and consent form.

3.2.5 *Ethical Approval*

Ethical approval was gained for conducting this study and for the recruitment of participants

3.3 *Results*

3.3.1 *Demographic Data*

A total of 58 participants were recruited for the study (35 males and 23 females). The mean age scaled z-scores for the List Learning Task over five trials was -2.23 (SD= 1.28) and mean age scaled z-scores for the List Learning Task delayed recall was -2.15 (SD= 1.50). Forty three participants scored below the 10th percentile cut-off (z-score of -1.31 or lower) on the initial List Learning task of the AMIPB (A1-A5). Questionnaire data from 15 participants who scored above the 10th percentile cut off (i.e. those participants who scored within the low average to average range on A1-A5 of the AMIPB) were included as they reported memory problems on the EMQ-r. Furthermore, these could be people whose premorbid memory functioning was at a higher level so it

would be reasonable to include them as showing a deficit. The mean EMQ-r item score was 1.76 (SD= 1.07) similar to Royle and Lincoln's (2008) sample of people with memory problems caused by stroke. The National Qualifications framework (available through DirectGov; Appendix K) was used to measure educational attainment; however data was collapsed into a smaller number of categories to allow for analysis as there were very small numbers if all categories were used. Descriptions and frequency data for educational attainment can be found below in Table 3.3

Table 3.3. Frequency table for Education data

<i>Education attainment</i>	<i>N (58)</i>
No qualifications	11
O' level passes/CSE/GCSE; NVQ level 1&2; Intermediate GNVQ	25
AS/A' levels; NVQ Level 3; Advanced GNVQ (AVCE); Apprenticeship	10
First degree (BA, BSc); NVQ levels 4 and 5; HNC, HND;	9
Higher degree (MA, MSc, PhD, PGCE)	3

Employment status was scored according to the Standard Occupational Classification 2010 (a Government document used when collecting census data) (Appendix L) and this data was also collapsed. Descriptions and frequency data can be found in Table 3.4.

Table 3.4. Frequency table for Occupation data

<i>Occupational Status</i>	<i>N (58)</i>
Managers, directors and senior officials; Professional occupations; Associate professional and technical occupations	15
Administrative and secretarial occupations; Skilled trades occupations; Caring, leisure and other service occupations	14
Sales and customer service occupations; Process, plant and machine operatives; Elementary occupations	24
Unemployed	5

3.3.2 *Reliability of measures and descriptive statistics*

Data was analysed using SPSS version 18.0. As the BMQ was an unpublished measure its subscales were tested for internal reliability. The Revised Everyday Memory Questionnaire (EMQ-r 13-item) and the Memory Strategies Questionnaire (MSQ) were also subjected to internal reliability analysis. This revealed Cronbach's alpha coefficients ranging from .62 to .82 for subscales of the BMQ and all other measures revealed alpha coefficients above .70 (Table 3.5). Although, it has been suggested that alpha coefficients above .70 show good internal reliability (George & Mallery, 2003), Schmitt (1996) notes that there is no level of acceptable or unacceptable level of alpha and that in some cases, measures with low levels of alpha may be useful. This is because with alpha levels as low as .49 the upper limit of validity is .70, subsequently when a measure has other desirable properties such as meaningful content coverage and unidimensionality, a low reliability score may not be impeding. Further to this, Kline (1999) suggests that when dealing with psychological constructs alpha values below 0.7 can realistically be expected due to the diversity of the constructs (cited in Field, 2009).

Awareness of difficulties was measured using the discrepancy score between the EMQ-r participant and EMQ-r significant other score. In total, 51 significant other EMQ-r scores were subject to analysis as 7 were not returned. Analysis revealed a mean discrepancy score of 7.41 (SD = 15.54) suggesting that people with ABI tended to score their memory as slightly better than their relative or carer. Descriptive statistics including mean, standard deviation and range of scores are also presented in Table 3.5. A Kolmogorov Smirnov test for normality revealed no parameters varied from a normal distribution (Appendix R).

Table 3.5. Descriptive and reliability data (n=58)

<i>Measure/Variable</i> <i>(number of items)</i>	<i>Cronbach's</i> <i>Alpha</i> <i>coefficient</i>	<i>Min</i>	<i>Max</i>	<i>M</i>	<i>SD</i>
BMQ personal control (from IPQ-r)	.69	12	30	21.82	3.36
BMQ treatment control (from IPQ-r)	.62	15	28	22.24	2.95
BMQ lifestyle fit	.81	4	18	10.65	3.70
BMQ inappropriate beliefs	.76	6	29	15.27	4.11
BMQ threat appraisals	.83	12	38	23.94	6.19
Revised Everyday Memory Questionnaire (participant)	.93	1	51	23.17	13.98
Revised Everyday Memory Questionnaire (significant other, n=51)	.94	0	52	29.64	14.94
Discrepancy score (self awareness)	-	-22	43	6.76	15.82
Memory strategy questionnaire (MSQ total)	.83	3	60	31.12	15.83

3.3.3 *Memory strategy use*

Mean MSQ total is shown in Table 3.5 and details of the degree to which each type of memory compensation was used is shown in Table 3.6. Item 17 ('I put things in the same place so I can find them') was the most frequently used memory compensation and Item 11 ('I use things in piles so I know which ones to do first and which can wait') was the least used strategy. Patel (2008) also found Item 17 to be the most frequently used compensation; however she found that Item 16 ('I make up rhymes and create mental pictures to remember people's names') was the least used strategy. Patel (2008) found no additional memory strategies were reported, however, in the present study in addition to the memory strategies listed in the questionnaire, three additional memory

strategies were reported based upon an open question: a palm organiser, Google calendar and a picture diagram of an oven hob so that the participant could remember how to use it.

Table 3.6. Mean and standard deviation of items from the memory strategy questionnaire (n=58)

<i>Memory Strategy Questionnaire Items</i>	<i>M</i>	<i>SD</i>
1. I use a diary to remind me of what I need to do	2.03	1.89
2. I use a list of things I need to do.	1.70	1.64
3. I use reminder notes.	1.36	1.56
4. I plan my daily routine in advance so I will not forget things.	1.84	1.87
5. I repeat things I need to do several times to myself in order to remember	2.22	1.76
6. I use external reminders, like a notice board, in my house to help me remember to do things.	1.70	1.82
7. I rehearse things in my mind so I will not forget to do them.	1.93	1.81
8. I lay things I need to take with me by the door so I will not forget them (or get someone to do this for me).	1.98	1.78
9. I use Post-It (sticky notes) reminders and place them in obvious places.	.89	1.48
10. I create mental pictures to help me remember to do something.	.86	1.40
11. I use things in piles so I know which ones to do first and which can wait.	.37	.95
12. I lay in bed at night and think of things I need to do the next day so I won't forget to do them.	1.44	1.68
13. I try to do things at a regular time so I won't forget to do them.	2.13	1.83
14. I use reminders on my mobile phone so I won't forget to do things.	1.27	1.74
15. I ask someone I can rely on to tell me things.	2.58	1.52
16. I make up rhymes and create mental pictures to remember people's names.	.51	1.17
17. I put certain things in the same place so I can find them, e.g. keys or spectacles (or get someone to do this for me).	3.37	1.33
18. I use a diary of what has happened to remember what I have done in the past.	.74	1.46
19. I use a list whenever I go shopping.	2.10	1.79
MSQ total score	31.12	15.83

3.3.4 Aims 1 & 2: Which of the belief variables are the best predictors of the uptake of memory compensations and do any of the belief variables add to the predictive value of demographic and injury related variables

Pearson's correlation coefficients were carried out to ascertain whether there was a relationship between beliefs about memory problems (BMQ sub-scales), awareness of memory difficulties (as measured by the discrepancy between significant others and participants' EMQ-r total score) and use of memory compensations (measured by the MSQ total). As shown in Table 3.7 significant correlations were found in three subscales: lifestyle fit; inappropriate beliefs and treatment control beliefs. No significant correlations were revealed between use of aids and: personal control beliefs; threat appraisals or awareness of memory difficulties.

Table 3.7. Correlation matrix of AMQ subscales, EMQ difference (awareness) and MSQ total.

<i>N</i> = 58	BMQ personal control	BMQ treatment control	BMQ lifestyle fit	BMQ inappropriate beliefs	BMQ threat appraisals	EMQ-r difference (n=51)
MSQ Total	.05	.39**	-.60**	-.55**	-.11	-.08

** correlation is significant at 0.01 level (2-tailed).

Tabachnick & Fidell, (2006) suggest that in cases where: there is no theoretical reason for entering variables in a logical order, where the main question is to establish the overall degree of association between the dependent variable (DV) and independent variables (IV) and also to establish the unique contribution of each of the IV to the DV, the regression of choice is standard multiple regression. This was therefore performed using MSQ total as the DV and only those variables that correlated with it as IVs i.e. lifestyle fit, inappropriate beliefs and treatment beliefs. Table 3.8 shows the standard regression model and the semi partial correlations for each IV. The model accounted for

42% of the variance in use of strategies ($F_{3,54} = 14.88$, $p = .000$, Adjusted R square = .422) (Appendix S). Lifestyle fit was the most important predictor of use of memory compensations, inappropriate beliefs was the second most important predictor and added 7% of the variance when lifestyle fit was controlled. Treatment beliefs added only a small amount to the model and was not significant.

Table 3.8. Standard multiple regression of predictors of memory strategy use with MSQ total as the dependent variable (n=58)

<i>Predictor Variable</i>	<i>B</i>	<i>SE</i>	<i>Beta (β)</i>	<i>t</i>	<i>Sig</i>	<i>Semi partial correlation</i>
Constant	53.112	17.564		3.024	.004	
Lifestyle fit	-1.653	.549	-.387	-3.009	.004	-.303
Treatment beliefs	.620	.611	.116	1.014	.315	.102
Inappropriate beliefs	-1.189	.462	-.309	-2.570	.013	-.259

Pearson's correlation analysis was then conducted to ascertain whether there was a relationship between any of the demographic variables and use of memory aids. This revealed that there were no significant correlations between any of the demographic variables and MSQ total: AMIPB z scores (A1-A5: $r(58) = .20$, $p > .05$; A6: $r(58) = .23$, $p > .05$) and age ($r(58) = .08$, $p > .05$); age at time of injury ($r(58) = .01$, $p > .05$) or time since injury ($r(58) = -.01$, $p > .05$). Education was recoded as a continuous variable by allocating a score of zero for no qualifications; one for O' level passes/CSE/GCSE; NVQ level 1&2; Intermediate GNVQ; a score of two for AS/A' levels; NVQ Level 3; Advanced GNVQ (AVCE); Apprenticeship; a score of three for First degree (BA, BSc); NVQ levels 4 and 5; HNC, HND; and a score of four for Higher degree (MA, MSc, PhD, PGCE) according to the participant's highest qualification (see table 1). This allowed a correlation analysis to be conducted between education and MSQ total.

However, no correlation was found with education ($r(58) = .16, p > .05$). Employment was also recoded as a continuous variable by allocating a score of zero for Unemployed; a score of one for Sales and customer service occupations; Process, plant and machine operatives; Elementary occupations; a score of two for Administrative and secretarial occupations; Skilled trades occupations; Caring, leisure and other service; and a score of three for Managers, directors and senior officials; Professional occupations; Associate professional and technical occupations. However no correlation was found with employment ($r(58) = .12, p > .05$). An independent t-test also revealed no significant difference between males and females on MSQ total ($t = -1.71, df = 56, p > .05$).

Given there was no correlation between demographic variables and use of memory strategies, aim two could not be explored.

3.3.5 Aim 3: Do inappropriate beliefs about memory and memory compensations mediate the relationship between personal control beliefs and memory compensation use?

As discussed in the introduction of this chapter, the possibility that inappropriate beliefs may mediate the relationship between personal control beliefs and the use of memory compensations was explored. In order to prove mediation, a significant correlation must exist between: the BMQ subscale measuring personal control beliefs (independent variable) and inappropriate beliefs (mediator variable); between personal control beliefs and use of memory compensations (MSQ total; outcome variable); and between the mediator variable (inappropriate beliefs) and the outcome variable (MSQ total) (Baron & Kenny, 1986). No significant correlations were found between the independent variable (personal control beliefs) and the mediator variable (inappropriate beliefs) ($r = -.01, p = .938$) or the independent variable and the outcome variable (MSQ

total) ($r = .05$, $p = .6.69$). The only significant correlation found was between the mediator variable and the outcome variable ($r = -.55$, $p = .000$). It was thus unlikely that inappropriate beliefs could mediate the relationship between personal control beliefs and the use of memory compensations. Therefore the proposed mediation analysis could not be conducted.

3.4 Discussion

This study explored factors influencing the uptake of memory compensations following ABI. The results revealed that beliefs about memory problems and using memory aids, in particular those beliefs associated with lifestyle fit and mistaken beliefs about memory compensations, influenced the uptake of memory aids. As expected, beliefs about treatment were also found to influence the uptake of memory compensations. Demographic and injury related variables were not associated with the uptake of memory strategies.

The most commonly used memory compensation in the present study was 'I put certain things in the same place so I can find them' (Item 17) and this replicates Patel's (2008) findings. However the two studies differ with regards to the least used memory compensation. In addition, more participants utilised a diary and the use of a notice board in Patel's (2008) study. The present study also differs to Evans et al. (2003), who found that the most commonly used memory compensation was a wall calendar/wall chart. In the present study the second most commonly used memory compensation was to use other people to remind them of things, followed by the use of repetition to remember information/things to do. Evans et al. (2003) also found these compensations were utilized by people with ABI, however they highlight that the four most commonly used aids were external memory compensations (wall calendar/wall chart, notebook;

list, diary). Another difference that has been highlighted between the present study, Evans et al. (2003) and Patel (2008) is the increase in the use of electronic memory aids, in particular the use of the mobile phone. In the present study twenty-three participants used their mobile phone in comparison to only three participants in Evans et al. (2003) and Patel (2008) found a mean of .50 for the use of mobile phones in comparison to a mean of 1.27 in the present study. This highlights the increased usability of electronic devices by people with ABI that are readily available within the wider consumer market, particularly the mobile phone.

3.4.1 Which of the belief variables are the best predictors of the uptake of memory compensations?

The current study revealed that the most important predictors of the uptake of memory compensations were: lifestyle fit, inappropriate beliefs about memory difficulties and, to a much lesser extent, perceptions of treatment control. Of these, lifestyle fit was the strongest predictor of the use of memory compensations following ABI. Perceptions of greater personal control, negative social evaluations by others (threat appraisals) and awareness of memory difficulties were not associated with the uptake of memory compensations.

The importance of lifestyle fit echoes the initial qualitative study subtheme ‘It’s not in my nature’ (Chapter 2, this thesis) in which five out of eight participants noted that memory compensations must ‘suit’ an individual’s lifestyle and be something that they feel comfortable using on a daily basis. It has already been noted that people will continue to use memory compensations after rehabilitation if an aid suits an individual’s physical, social, cognitive and emotional characteristics as well as their personal lifestyle and routine (Fleming, Shum, Strong & Lightbody, 2005). Assistive device and

disability literature highlights the need for compensatory devices to fit value systems and convey the individual's desired self image otherwise devices are unlikely to be used (Bender Pape et al., 2002). Scherer (2002) also recommends that there should be more emphasis on the person as a unique user and that the selection of a device should be based on how well it satisfies not only a person's needs, but also their preferences as well as whether a device is deemed as attractive and appealing to the user. It has been suggested that professionals often look at the functionality of devices rather than the social consequences (Roulstone, 2007) and that a lack of consideration of users' opinions in the selection process can result in unwillingness to use them or poor adherence (Phillips & Zhao, 1993). Although this literature focuses on assistive devices to help those with physical disabilities, the same principles apply when encouraging people with ABI to use compensatory aids for memory difficulties.

As noted in the introduction to this chapter, having an ABI can have a huge impact on an individual and changes or 'threats' to one's identity can mean people struggle to understand and identify with their present selves (Dewar & Gracey, 2007). It has been suggested that following ABI people try to preserve their pre-injury self with discrepancies between pre and post injury selves being associated with anxiety and depression (Cantor et al., 2005). Gracey et al. (2009) propose that people may adopt coping strategies that reduce discrepancies in one's self identity. As can be seen in the present study (Chapter 2) the incorporation of memory compensations into an individual's preferred self image can be difficult. Subsequently, assistive devices which do not 'fit' value systems and reflect the persons point in their life cycle, family life stage, cultural heritage and desired social consequence (Bender Pape, et al., 2002) are

likely to be avoided. Memory compensations must therefore reflect an individual's sense of self and lifestyle and be in keeping with their value systems.

Certain contextual issues are also important in the selection of aids, for example this study suggests that for people who either did not have enough things to remember or could rely on someone else as their memory aid, there was no need to use their own memory strategies. Limited functional independence following TBI is negatively associated with life satisfaction, in particular depression (Resch, et al., 2009). Therefore, those who are less independent and rely on others are potentially at risk of developing depressive symptoms and are likely to experience reduced life satisfaction. In addition, being reliant on others may increase caregiver burden, thus having a significant impact on the lives of relative/carers.

The second most important predictor of the uptake of aids was whether individuals held inappropriate beliefs about the use of memory compensations and this is the first empirical study to demonstrate this in people with ABI. Inappropriate beliefs about memory (e.g. the belief that repetition is an effective memory strategy for remembering everyday events) and using memory compensations (e.g. the belief that 'using memory aids will make my memory lazy') influences the uptake of memory aids and strategies. There is no evidence to suggest that using compensatory aids stops natural recovery after a brain injury (Wilson & Watson, 1996) and it has been noted that repetition alone is likely to be of limited use for people with significant memory problems (Wilson, 2000). Such beliefs about brain injury and subsequent memory difficulties appear to be typical misconceptions held by the general public. For example in a general USA population, Hux, Schram and Goeken (2006) found lay beliefs such as: "people can have memory impairments so severe that they cannot remember prior

life experiences or recognize familiar people from their past, yet have no other cognitive, social, emotional or physical difficulties” (p. 549). In addition, they found that 29% of the general public believed that if a person received a second brain injury, that this could help a person remember things that were forgotten as a result of a prior brain injury as well they report that people believed how quickly a person recovers after brain injury depended on how hard they worked at recovering. Chapman and Hudson (2010) replicated the study in Britain and found that the British public held similar misconceptions to those reported by Hux et al. (2006). However, they found that misconceptions about brain injury were endorsed more by respondents in Britain than in the USA (Chapman & Hudson, 2010). Linden and Boylan (2011) also highlight public misconceptions about brain injury with people often using negative labels and failing to recognise that a brain injury may also be a ‘hidden’ disability as well as being visible. Further to this, Swift and Wilson (2000) noted that misconceptions about brain injury were not only common amongst the general public but also amongst health care professionals who did not have expertise in this area. Their qualitative study revealed misconceptions concerning inaccurate beliefs about recovery and the possible extent and diversity of problems following a brain injury. In particular, it was noted that many people often associated cognitive and motivational difficulties after a brain injury with being lazy. They also found that misconceptions about the capabilities of people following ABI were associated with the visibility or invisibility of their disability and a brain injury was often misidentified as either a mental illness or a learning disability. As noted in the present study and by Chapman and Hudson (2010) the endorsement of these misconceptions can have implications on rehabilitation and recovery.

Although treatment control beliefs did not significantly add to the variance in uptake of strategies when entered alongside lifestyle fit and inappropriate beliefs, it should perhaps be considered as a potentially important predictor, the importance of which may have been diminished due to its shared variance with the other two variables. The unique contribution of the IV can often be small despite a substantial correlation with the DV (Tabachnick & Fidell, 2006). This finding is generally consistent with the current health literature on treatment control beliefs. It is suggested that more strongly held beliefs about whether treatment will be effective are associated with adherence to medication and attendance at rehabilitation in health conditions such as asthma and myocardial infarction (Jessop & Rutter, 2003; French et al., 2006). Bains, Powell and Lorenc (2007) report that treatment outcome beliefs predicted participation in rehabilitation in people with ABI and Patel (2008), found that greater treatment control beliefs were the second most important predictor of the use of memory strategies in those attending a brain injury rehabilitation centre.

Surprisingly, the present study did not find a significant association between the use of memory compensations and personal control beliefs, a finding which has been reported in previous research (Patel, 2008). Respondent confusion in understanding the wording of some of the control items, particularly those with negative wording has been reported by Cabassa, Lagomasino, Dwight-Johnson, Hansen and Xie, (2008). This subscale also showed a relatively low internal reliability coefficient in the present study. During data collection participants did indeed ask for clarification of some of the statements, in particular, the statement 'My actions will have no effect on the outcome of my memory problem.' Furthermore, there may have been some ambiguity about

what 'control' in this context referred to i.e. control in terms of managing memory slips or control in terms of acting upon the memory impairment.

The present research did not find any correlation between the use of memory compensations and threat appraisals, which is surprising given that Riley et al. (2004) found that threat appraisals and related avoidance was prevalent in those who have survived a TBI. However, as Riley et al. (2004) note, not all threats result in direct avoidance. In the present study after completing the questionnaires some participants who agreed with the threat appraisal questions stated that although they felt this way, they had no choice but to use memory aids. One person stated it was 'sink or swim' because their memory was not good enough. Riley, Dennis and Powell (2010) found that those who made more positive secondary appraisals showed less avoidance in the face of threat appraisals. It may be that the participants in the present study perceive the use of memory compensations as a threat but they appraise their ability to cope with the threat (i.e. secondary appraisal) to be positive, as the alternative to forgetting important information is an even greater threat than negative evaluations by others.

Self awareness of difficulties is important in gaining insight generally (O'Callaghan, Powell, & Oyebode, 2006) and has also been found to increase compliance and active participation in rehabilitation programmes (Ownsworth et al., 2008). It was therefore surprising that the use of memory compensations was not associated with a higher level of awareness. This finding may be a consequence of the characteristics of the study sample. Participants were on average just under four years post injury (mean 44.74 months). It has been suggested that awareness of difficulties can improve with time (Godfrey, Partridge, Knight & Bishara, 1993; Fleming & Strong, 1999; Prigatano, 2005; Hart, Seignourel & Sherer, 2009) which may account for

participants being relatively aware of their difficulties. In addition, it may be that individuals who are aware of their memory difficulties may choose not to use the memory compensations that they have been encouraged to uptake during rehabilitation because they do not fit with their lifestyle. As highlighted in the present findings lifestyle fit is a significant predictor of the use of memory compensations.

3.4.2 Do any of the belief variables add to the predictive value of demographic and injury related variables?

The present study found no relationship between uptake of memory compensations and any of the demographic and injury related variables and so this aim could not be explored. In particular, the lack of a correlation between uptake of strategies and memory impairment does not support previous findings (Wilson & Watson, 1996; Evans et al., 2003). A possible explanation may be that the original version of the Rivermead Behavioural Memory Test (Wilson et al., 1985) used in Evans et al. (2003) contains items relating to prospective memory which is more closely aligned to the use of strategies than a general long term memory test such as the AMIPB. The reason the AMIPB was chosen for the present study was because the RBMT has been reported to lack sensitivity at both high and low ends of memory function resulting in ceiling effects (Lezak, 1995).

The present study found no relationship between age, age at time of injury or time since injury and the use of memory compensations. Again, this does not support previous research (Evans et al., 2003). One possible explanation may be due to the time difference between the two studies. As noted earlier there has been an increase in the number of people using electronic aids, in particular mobile phones. The present study found 23 people to be using mobile phones where as Evans et al. (2003) only reported

that three people used mobile phones and a further seven people used electronic organisers. In a recent report by Ofcom (2011) it was revealed that 95-96% of people between the ages of 16-54 used a mobile phone and that 77% of people over the age of 55 regularly used a mobile phone. It may be that eight years on due to the social acceptability and wide commercial use of electronic devices such as the mobile phone, there is now no longer a difference in the age of people using memory compensations, in particular electronic aids. The present study does concur with previous research that found no relationship between premorbid IQ (as measured by educational attainment) and the use of memory compensations (Wilson & Watson, 1996; Evans et al., 2003). This may be because following ABI participants in all three studies will have received some form of memory rehabilitation where the use of memory compensations is actively encouraged.

3.4.3 Limitations

Although this study provides new insights into the factors that influence the use of memory compensations, the research was based on a relatively small sample. One limitation of this study that must be considered is that previous research has noted that people without marked executive difficulties and those with less severe memory impairments are more likely to use memory aids (Wilson & Watson, 1996; Evans et al., 2003). The majority of participants in the present study scored below the 10th percentile on the AMIPB list learning task suggesting that they had severe memory difficulties, consequently participants may have been less likely to use memory aids because of the nature of their memory difficulties. Future research could look at people's beliefs about memory compensations and memory difficulties before they receive cognitive rehabilitation, as it was reported by Patel (2008) that there was a significant difference

in uptake of strategies between those who had and had not been exposed to cognitive rehabilitation. A longitudinal study exploring people's beliefs might also highlight differences in attitudes pre and post rehabilitation.

A further limitation of the present study and one that must be taken into consideration is that the sub-scale 'lifestyle fit' may in fact incorporate two sub-scales: 1) a set of contextual factors such as whether the environment creates a need for aids and 2) factors relating to the degree to which aids are in keeping with individual's sense of identity. This could also be an area for further research.

In the present study it is possible that people only avoided those aids which may be conspicuous, however, not all aids measured on the MSQ can be deemed obvious (e.g. repeating things to oneself, a mobile phone). It is possible that threat appraisals may be correlated with those aids which people feel highlight their disability and that these aids are more often avoided. Future research could consider whether people are more likely to avoid aids which are deemed conspicuous. The present study did not look at the impact of premorbid use of memory aids on post-injury use however, previous research has found a positive link. The present study provides an explanatory link for previous findings and suggests the association may be because the most important determinant is whether the aid suits the person's pre and post-injury lifestyle.

3.5 *Implications*

The findings from this research echo those of the original qualitative study and further highlight that functionality of memory compensations is not the main factor in determining whether people use aids. This study suggests that therapists should adhere to the biopsychosocial model of rehabilitation, with a stronger emphasis on social aspects when encouraging the use of memory compensations. Memory compensations

should be developed with the consideration of the user's lifestyle and personal values, which will not only increase their use but ultimately the individual's independence. With this in mind, it may be that no matter how severe a person's memory difficulties are or how long post injury they are, if the correct aid is chosen there *may* be a potential to help them compensate for their difficulties; the key is finding an aid that suits the individual.

There is also a need for therapists to take care when they are leading groups or providing individuals with education about cognitive strategies, in particular about memory aids. This is to ensure that they do not inadvertently introduce notions that may not be true for all types of memory problems, for example, techniques such as repetition and expanding retrieval aids the learning of factual information or people's names (Karpicke & Roediger, 2007) but it does not aid prospective memory.

Another implication of this study is the importance of dealing with secondary appraisals (i.e. how people appraise their abilities to cope with a threat) in one to one sessions. Although it was not significant in the present study, it has been noted that those who showed less avoidance to threats made more positive appraisals (Riley et al., 2010) and this therefore has implications for rehabilitation. Participants in the present study may have made more positive appraisals, despite seeing the use of memory compensations as a threat. However, this may not be the case for every individual following ABI; therefore interventions using cognitive behavioural principals can be used to help people develop more positive coping styles. This may ultimately increase the use of memory compensations and therefore increase independence.

Further to this, the present study also emphasises the need to incorporate assessment and interventions aimed at changing inappropriate or mistaken beliefs about

memory problems and using memory compensations. In particular, those who believe that using memory compensations will make their memory lazy or that repetition is an appropriate strategy for remembering prospective information may benefit from an educational intervention or from adapted CBT.

Finally, given the association between greater treatment control beliefs and use of aids, it may be useful and worthwhile for therapists to work with individuals to improve their perception of control. It has been noted that interventions aimed at changing perceptions of memory and health behaviours may be more successful if beliefs about control are addressed in conjunction with acquiring new skills, such as the use of memory compensations (Lachman, Neupert & Agrigoraie, 2011). A study looking at modifying older adult's perceptions of their memory found that those who received cognitive restructuring, which promoted adaptive and positive beliefs about memory, in conjunction with self-generated memory strategy training, showed an increase in their sense of control and perceived ability to improve memory (Lachman, Weaver, Bandura, Elliot & Lewkowicz, 1992).

3.6 Summary

The present study highlights that the most important determinant of memory strategy use is whether the aid suits the person's pre and post injury lifestyle. This could explain previous findings that premorbid use of memory compensations predicts the use of memory aids and strategies post injury (Wilson & Watson, 1996; Evans et al., 2003). Misconceptions about memory and memory aids may also deter people from using aids and would be a relatively easy issue to address clinically. Surprisingly, there was no link between demographic and injury related variables and the use of aids as suggested by previous research (Wilson & Watson, 1996; Evans et al., 2003). Although this latter

finding may be somewhat related to the characteristics of the study population and the measures used, it suggests that there is greater optimism for those who may otherwise be regarded as unlikely to use aids. The key is simply to match the aid to the individual.

CHAPTER 4

SINGLE CASE EXPERIMENTAL DESIGN STUDY

4.1 Introduction

This chapter focuses on a single case study that builds upon the principals and findings from previous chapters. This chapter highlights the need for initial assessment that includes an individual's motivation to use memory compensations and their beliefs about using memory aids/strategies and their beliefs about their memory problems, in particular: inappropriate beliefs about memory and memory compensations; beliefs about memory compensations 'fitting' one's lifestyle and beliefs about treatment (memory aids/strategies). In addition, this chapter emphasises the process of selection of a memory aid/strategy as well as how it was introduced, the assessment of the effectiveness of the memory aid/strategy and the re-assessment of motivation and beliefs about memory and memory compensations once a suitable aid/strategy was implemented.

People with cognitive difficulties often report difficulty with prospective memory (PM), such as remembering to carry out things they had intended to do (Fish, Wilson, Manley, 2010) for example; to telephone the doctors at a specific time or to remember the date of an appointment. Prospective memory difficulties can often impact on an individual's ability to function independently and, since memory difficulties following ABI are often long lasting, they require formal interventions in the form of cognitive rehabilitation (Sohlberg et al., 2007).

Research suggests that cognitive rehabilitation following ABI should primarily focus on compensatory cognitive strategies, rather than techniques which aim to

restore/retrain memory function (Cicerone et al., 2000; Cicerone et al., 2005; Sohlberg et al., 2007; Cicerone et al., 2011) and this has been discussed in more detail in Chapter 1 of this thesis. Most of the work relating to memory rehabilitation involves teaching and encouraging people to compensate for their memory difficulties by employing aids (Watson, 2010). In particular, external memory aids have been reported to be the most widely used compensatory strategies (Evans, Wilson, Needham & Brentall, 2003). The use of external paper based aids following ABI, such as notebooks, calendars, lists, diaries and so forth, have been shown to be effective methods of compensating for an individual's difficulties thus improving independence (Sohlberg & Mateer, 1989; McKerracher, Powell & Obeode, 2005). However, teaching people to use these compensatory aids can be complicated, as remembering to use a memory aid is a memory task itself (Wilson Emslie, Quirk & Evans, 1999). One way of overcoming this difficulty is through the use of electronic memory aids (also referred to as assistive technology) as they often include a cueing device as well as storage of information (Kapur, Glisky & Wilson, 2004). Cueing devices alert the individual that there is something to do or to remember. In this chapter an electronic memory aid (a mobile phone and text message alerts provided by Google Calendar) was utilised to improve the daily functioning of a man (TK) who had marked memory difficulties subsequent to a TBI. The remainder of this introduction will therefore look at the efficacy of electronic aids for people with memory difficulties following ABI.

In the UK today, an increasing number of people are using portable electronic aids that provide a means of communication and continuous memory support throughout the day. These include personal hand held pocket computers (mini notebook), tablets (e.g. iPad), mobile phones, smart phones and iPods (Evans, 2011).

These devices enable us to manage our daily lives, plan our day or week, remember to attend appointments and to keep our information organized so we are able to keep track of things (de Joode, van Heugten, Verhey & van Boxtel, 2010). Such devices are in keeping with current technological trends and are widely accepted. It is therefore important that therapists consider these devices as memory aids, as they are likely to fit an individual's social and cultural environment.

4.1.1 NeuroPage

The use of electronic memory aids has been found to increase functional independence for adults with mild to moderate cognitive difficulties following ABI (Morris & Reinson, 2010). As noted above, the advantage of using assistive technology is that they can alert the individual at a specific time that a task needs to be carried out. In the 1990s NeuroPage was developed to aid prospective memory difficulties following ABI. Eight studies have reviewed NeuroPage, a portable pager that provides audio/vibrator alerts and is worn on a waist belt (Wilson, Evans, Emslie & Malinek, 1997; Evans, Emslie & Wilson, 1998; Wilson, Emslie, Quirk & Evans, 1999; Wilson, Emslie, Quirk & Evans, 2001; Wilson, Emslie, Quirk, Evans & Watson, 2005; Emslie, Wilson, Quirk, Evans & Watson, 2007; Fish, Manly, Emslie, Evans & Wilson, 2008; Wilson, Emslie, Evans, Quirk, Watson & Fish, 2009). NeuroPage is linked to an independent messaging service, that sends personal messages at predetermined times. This reminds the user of set tasks such as taking medication, appointments or events. All eight papers reported a significant improvement of target behaviours relative to baseline when using NeuroPage. Wilson et al. (1997) reported that the implementation of NeuroPage significantly improved the prospective memory of fifteen participants, with a significant increase in the amount of daily activities completed, compared to

baseline. Furthermore, NeuroPage was shown to successfully cue behaviour, reducing the amount of prompting needed from carers and helped increase independence (Evans, Emslie & Wilson, 1998; Wilson, Emslie, Quirk & Evans, 1999). It was also noted that for some people who did not require NeuroPage on a long-term basis it could be used effectively in the short-term to teach people routines, which itself is considered a memory strategy (Wilson, Evans, Emslie & Malinek, 1997). A recent review of NeuroPage compares differences between the first 40 patients recruited to use the paging system and users ten years on (Martin-Saez, Deakins, Winson, Watson & Wilson, 2011). Advances in technology have meant that since 2007 NeuroPage messages can now be sent to a mobile phone via standard mobile phone networks as well as to a pager (Bateman, 2011). Martin-Saez et al. (2011) also compared users who preferred to receive messages to a mobile with those who used the pager. They report that in both cohorts the most frequent message sent each week was related to medication, however they note that ten years on (i.e. second cohort) NeuroPage is also being used to send messages about mood management. Martin-Saez et al. (2011) also found that there was no significant age or gender differences between those using the mobile phone to receive messages and those using the pager. However, they did find differences between type of injury and time since injury, with those who used the pager less likely to have sustained a TBI (i.e. individuals who tended to be diagnosed as having a stroke or other) as well as being longer post injury. One possible explanation given by Martin-Saez et al. (2011) is that in comparison to those individuals who used their mobile phone to receive alerts those individuals who used the pager were more likely to have been in the rehabilitation system for longer, thus, they are more likely to

have greater memory impairments and therefore require a simpler device that will be used on a long-term basis.

Hersch and Treadgold, (1999) state that NeuroPage has been found to be successful in aiding prospective memory and is deemed to be one of the most successful compensatory aids. However, Martin-Saez et al. (2011) note that ten years on there are fewer health authorities referring to the service. Although there have been many benefits associated with increased target behaviour and NeuroPage, one potential disadvantage of this device is that it requires the individual to send a list of reminders to the main centre in Cambridge. Reminder alters are then entered onto the central computer and users are required to contact the centre if they need to amend their appointments/reminder cues. Users are therefore not able to take complete control of the reminder system. The externally programmed cues/reminders may be an advantage for some people as NeuroPage is easy to use and does not require a great deal of learning to be used effectively (Kapur, et al., 2004). However, for those who wish to maintain complete independence NeuroPage may not be the most appropriate option. In addition, with a set up fee and rental costs of £60 per month (Bateman, 2011) NeuroPage may not be a financially viable option. It is therefore important to review assistive devices that may be more affordable alternatives for people following ABI.

4.1.2 Personal digital assistants

Since the success of NeuroPage, there have been further developments with a number of studies looking at personal digital assistants (PDAs) as memory aids for people following ABI. Kim, Burke, Dowds, Robinson-Boone and Park (2000) undertook a study looking at the experiences of 12 patients using palmtop computers to assist with memory difficulties. They found that at follow-up (between 2 months and 4

years) nine participants had found the devices useful during the study and that of those nine, seven participants had bought and continued to use similar devices to aid memory. One drawback to these findings is that the original study cohort consisted of 36 participants; subsequently we do not know whether the other 24 participants have continued to use the device post intervention. Two comparative studies have looked at the effectiveness of two different PDAs (Palm & Dell) against a list of times and tasks and a planner (Gillette & DePompei, 2008; DePompei, et al., 2008). In both studies they report an increase in the number of tasks that were executed on time when using an unmodified Palm PDA compared to an unmodified Dell PDA and a paper planner. In addition they also found that students with TBI and intellectual disabilities performed 25% better using the PDAs compared to the planner and 15% better compared to the list. Gillette and DePompei, (2008) also note that students preferred the Palm PDA in comparison to the Dell. However, a limitation is that the authors do not provide detail regarding features and differences between the two PDAs, and the information given by students with regards to the aids is very minimal and none descript.

In another comparative study, Gentry, Wallace, Kvarfordt and Lynch (2008) examined the efficacy of two basic unmodified off the shelf PDAs (Handspring Visor & Palm Zire) in a group of community dwelling individuals who had suffered a severe TBI. They found that following a training period with the PDAs, people's self-rated assessment for how well they were performing everyday life tasks significantly improved. Thone-Otto and Walther (2003) also conducted a comparative study looking at the effectiveness of a Palm m100 PDA and a mobile phone. They found that people with memory difficulties had a more significant reduction in the number of forgotten intentions for daily and experimental tasks when using the electronic devices. However,

they highlight that those with milder memory difficulties were able to use the devices more successfully than those with severe memory difficulties. They suggest that commercially available off the shelf aids are efficient compensatory aids for those individuals with mild memory difficulties but for those with severe memory difficulties devices need to be adapted. It has been noted that the amount of time spent training individuals to use electronic aids is important (de Joode et al., 2010). A possible explanation for the discrepant findings between Gentry et al. (2008) and Thone-Otto and Walther (2003) may therefore be the intervention itself, specifically the time given to train people to use the PDAs. Participants in Thone-Otto and Walther (2003) received only 6 hours of training in comparison to 9 hours in Gentry et al. (2008). In addition, participants in Gentry et al. had the devices for 8 weeks whereas participants in Thone-Otto and Walther (2003) only had access to the PDAs for 2 weeks. This may explain why those with severe memory difficulties in Thone-Otto and Walther's study were not able to navigate the PDAs as efficiently. Thus, providing longer training sessions and enabling people to become more familiar with using off the shelf PDAs may help those with severe memory difficulties learn how to use these devices effectively.

Two studies that have looked at the effectiveness of purpose-designed PDAs found that the unambiguous and explicit options on the PDAs interface enabled participants to make sensible guesses about which buttons accomplish goals, thus enabling participants to enter and retrieve information (Wright et al., 2001a, b). As Wright et al. (2001a, b) do not compare their purpose-designed PDAs with off the shelf PDAs it is not possible to say which are easier to navigate following ABI.

It has been noted that whilst PDAs offer a range of functions for an individual, such as; audio alarm cues with or without visual aids, the ability to set repeat alarms for

specific events, the addition of temporary storage for shopping lists as well as the permanent storage of addresses and phone numbers (Kapur et al., 2004). There are also some disadvantages of using PDAs. In particular, it is noted that although cheaper models are available these are often associated with poorer build quality and limited functions, whilst higher specification models often contain keys that are superfluous and can be confusing or difficult to navigate for individuals who also have visual difficulties (Kapur et al., 2004). Another disadvantage is the need for fine motor skills; PDAs are therefore not suitable options for individuals with dexterity difficulties. Research has therefore looked at alternative devices such as voice organisers to aid memory.

4.1.3 Voice organisers

A number of studies have looked at the efficacy of voice organisers in aiding memory. The voice organiser is similar to a Dictaphone, however it can be programmed so that an individual can replay messages at specific times. Studies by van den Broek, Downes, Johnson, Dayus and Hilton (2000) and Yasuda et al. (2002) have reported an improvement in remembering prospective information such as passing on messages and remembering therapy goals in people with ABI. Hart, Hawkey and Whyte (2002) found that therapy goals that were recorded on a voice organiser and that were then listened to at three different times throughout the day were recalled more often than therapy goals that were not recorded on the voice organiser. In addition, Oriani et al. (2003) report that a voice organiser significantly improved prospective memory in people with Alzheimer's disease, whilst a written list and free recall were not useful.

Despite the effectiveness of NeuroPage, PDAs and voice organisers one problem is that in today's society they are not widely used. In particular, it has been noted that NeuroPage is specifically designed for prompting memory and so may draw unwanted

attention to the issue of memory difficulties, potentially causing embarrassment (Wade & Troy 2001). One way of addressing this issue is by using technology that is widely used by today's society.

The importance of memory aids 'fitting' an individual's lifestyle has been highlighted in previous chapters in this thesis. 'Lifestyle fit' was found to be the strongest predictor of the use of memory compensations in people with ABI (Chapter 3). Scherer, Elias and Weider (2010) highlight that whether an assistive device is deemed useful or not does not only depend on whether it is simple to use but also on the extent to which the device meets the user's personal needs. Furthermore, literature on assistive devices and disability emphasizes the need for compensatory devices to fit value systems and convey the individual's desired self image (Bender Pape, Kim & Weiner, 2002). It is therefore important to consider devices such as mobile phones, as in the UK they are an integral part of our society.

4.1.4 Mobile phones

The use of mobile phones has dramatically increased in the last ten years. There are 80 million active mobile phones in the UK, 91% of the population owned a mobile phone in 2010 and 46% of people used a mobile phone as their main method of communication (Ofcom, 2011). In addition, since 2000 there has been a dramatic increase in the use of short message service (SMS) text alerts with 129 billion being sent in 2010 (Ofcom, 2011). Using technology that is widely utilized by the general public ensures that the memory aid is inconspicuous. This may facilitate a person's willingness to use it as a memory aid.

Four papers have reviewed the use of mobile phones in aiding memory following ABI (Wade & Troy, 2001; Stapleton, Adams and Atterton, 2007; Fish, Evans,

Nimmo, Martin, Kersel, Bateman et al., 2007; Culley & Evans, 2010). Wade and Troy (2001) undertook five single case studies using mobile phones to provide voice reminder alerts for those with memory difficulties. They found that the mobile phone as a memory aid was effective in increasing self-initiated behaviours for all five users. However as this study was not a controlled trial or a multiple baseline design, changes in target behaviours may have been due to developing established routines rather than as a result of the message alert. It was noted that the mobile phone, like Neuropage, was only needed for some participants on a short-term basis to help teach routine for target areas (e.g. taking medication, remembering a weekly lunch meeting). Once a routine had been established target behaviours continued to be achieved without the message alerts. These participants continued to use the mobile phone on a day-to-day basis as a means of communication. Stapleton, Adams and Atterton (2007) also conducted a series of five single case studies and found that only two people who had mild to moderate memory difficulties benefitted from the use of text message alerts for completion of target behaviours. It was noted that the three remaining participants who did not benefit from the mobile phone text alerts had severe memory impairments and had greater executive functioning difficulties. Two of the three participants were reported to either forget to take the mobile phone with them or ignored alerts on the occasions they did carry the phone, and the third participant was also reported to ignore all alerts despite carrying the phone with them. Wilson and Watson (1996) note that for those with severe central executive difficulties the use of memory aids may not be possible.

Fish et al. (2007) demonstrated the efficacy of a content free cue of 'STOP' sent in a text message in order to improve prospective task completion. Although the mechanisms by which the content free cue works is to redirect attention to the task and

not as a memory aid per se, it was noted that on days in which no cue was provided, task completion was unsuccessful. Culley & Evans (2010) undertook a single-blind within-subjects trial in which participants were sent text message alerts about three randomly selected goals three times a day. Three other goals were also selected but participants did not receive text reminders about these goals. Culley and Evans (2010) report that in comparison to goals that were not prompted by text reminders those that were resulted in participants' free and cued recall being significantly greater.

Pijnenborg, van den Bosch, Evans and Brouwer (2007) also found that SMS text alerts were effective in improving participation of daily activities with some but not all individuals with schizophrenia and associated memory difficulties.

Two studies look at the effectiveness of using smartphones as a memory aid (DePompie et al., 2008; Svoboda, Richards, Polsinelli & Guger, 2010). DePompie et al. (2008) found that the use of a smartphone increased memory and organisational independence of adolescent participants. They highlight that motivation to use such devices is an influential factor. Svoboda, Richards, Polsinelli and Guger (2010), also demonstrate that motivation to use an aid is a key factor in its use. Svoboda et al. describe a theory-driven training programme that is based on training techniques from behavioural and learning psychology and is comprised of two phases; basic skill acquisition (Phase 1) and real-life generalisation (Phase 2). The single case study demonstrates that following the theory-driven training programme their participant was able to independently use a smartphone to aid severe memory difficulties. In comparison to DePompie et al. (2008), the study design used by Svoboda et al. (a within-subjects ABAB single case design) enabled comparisons between baseline (A) and intervention (B) phases. They found that the rate of completing memory related

tasks (e.g. making phone calls at the correct time or attending social events) differed significantly between conditions, with task recall being significantly greater in the smartphone intervention phase (B). This robust study highlights that change was not due to spontaneous recovery, thus providing good evidence for the use of mobile phones, in particular smartphones, in aiding severe memory difficulties.

These studies draw attention to the potential use of mobile phones, in particular text message alerts. As mentioned previously, one of the advantages of using a mobile phone is that in today's society it is part of our everyday life. Therefore any such embarrassment at using a memory aid can be avoided or minimised (Wade & Troy, 2001). As mobile phones are an integrated part of our everyday lives it is important to consider services that can be used in conjunction with mobile phones and whether they are effective in aiding memory following ABI.

4.1.5 Google Calendar

A recent published study by McDonald, Haslam, Yates, Gurr, Leeder, and Sayers (2011) looked at the utility of using Google Calendar (an electronic calendar that can be accessed through the internet and which can also be synchronised with a mobile phone to provide text or email alert reminders) to aid prospective memory difficulties following ABI. McDonald et al. (2011) undertook a randomised control crossover within-subjects design study in order to directly compare the effectiveness of Google Calendar with a standard paper diary. Participants and family members identified routine target activities that they were to complete during the 15 week study (Baseline: no interventions for 5 weeks; Intervention A: Google Calendar or standard diary for 5 weeks; Intervention B: either Google Calendar or standard diary for 5 weeks). All participants attended training on how to use the calendar and the diary. McDonald et al.

(2011) found that both aids improved recall of prospective memory activities, however Google Calendar was found to be significantly more effective than the paper based diary in supporting participants to complete the prospective memory tasks. Participants highlighted that the timed text message alerts were the most beneficial feature of the calendar system, as they provided a visual prompt as well as the auditory alert. The efficacy of Google Calendar and the use of SMS text message alerts to a mobile phone for people with memory difficulties following ABI are further supported by a recent unpublished report undertaken by Diamond, Gerhand and Powell (2011). Diamond et al. (2011) undertook a case series of four ABAB reversal designs with three participants at an in-patient rehabilitation service and one participant who was receiving out-patient rehabilitation. All participants learned how to access the SMS text message alerts from their mobiles. Each participant's phone was synchronized to an individual Google Calendar account and during the two intervention phases they were sent SMS text message reminders about a particular event (prospective memory task) that needed to be carried out. In the control phases, participants used either a Dictaphone or paper diary. The authors report that the use of SMS text message reminders from Google Calendar were more effective at aiding individuals with mild to moderate memory difficulties than a tradition paper diary or a Dictaphone. Both studies highlight the efficacy of using Google Calendar to aid prospective memory following ABI.

4.1.6 Study aims

The present study aims to contribute to the growing body of research that demonstrates that using mobile phones, specifically text message alerts, are effective in aiding memory for the recall of prospective information such as appointments and events/occasions. In addition, it aims to provide further support for the effectiveness of

Google Calendar as a memory aid. This study investigated the use of SMS text alerts sent to a mobile phone via Google Calendar. Google Calendar is a free-time management web application provided by the search engine Google, and allows users to create their own online calendar that is accessible from any location that has an internet connection. With the recent development of smart technology, this means users are able to access their calendar from their mobile phones or from any computer, thus reducing the need to carry paper based aids, such as a diary, that may be considered conspicuous. Furthermore, Google Calendar enables users to set email alerts or alternatively SMS text alerts. Users can receive up to five SMS text alerts for each event added to the Calendar. Unlike calendar systems on mobile phones, Google Calendar allows the user the freedom of writing detailed descriptions and setting multiple reminders alerts. It is also a free service and can therefore be considered a cost effective option. Using Google Calendar as a memory aid is only a recent development and there has only been one published study evaluating its efficacy in people with ABI (McDonald et al., 2011). Subsequently there is a need to assess whether this free technology can be used effectively in helping people compensate for memory difficulties, and whether it is possible to teach people how to use the Google Calendar interface so that they are able to manage their own events and alert reminders.

This single case study was designed to explore the utility of using a mobile phone and SMS text messages provided by Google Calendar as a memory aid with a 43-year-old male who had memory difficulties following ABI.

4.2 *Method*

4.2.1 *Participant*

Initially any participant who met the following inclusion criteria was eligible to participate in the study: 1) confirmed ABI, 2) a good command of English, 3) self reported memory problems on the EMQ and/or day to day memory difficulties confirmed by centre staff and 4) they had not already implemented memory compensation(s) to aid memory difficulties.

4.2.1.1 *'TK'*

TK is a [REDACTED] male who has lived in the UK since the age of two. He was referred to the out-patient brain injury rehabilitation service in 2010 following a TBI 6months earlier as a result of an assault. TK had a Glasgow coma score of 4/15 on admission to hospital indicating that he had suffered a severe TBI. TK [REDACTED] [REDACTED] lived with his family. At the time of the study TK was living part time in the family home (visiting in the evenings) and part time in a shared house with two other people. TK had not returned to work following the incident, however, it was one of his long-term goals. As well as the cognitive difficulties described in section 4.2.1.2, TK had difficulties recognising changes in his behaviour during social situations or when talking to his family. In particular, TK was unaware of the change in his tone of voice or stance when talking to people and often became angry at his family's reactions when they suggested that his behaviour had become aggressive or confrontational. TK and his partner were attending couples therapy at the time of the study as a result of this. TK was also attending group sessions on social communication at the rehabilitation service and had also been attending relaxation therapy to help him cope when agitated and anxious. TK also had

mild expressive dysphasia and had mild difficulties writing as a result of his brain injury, he was receiving speech and language therapy, which had resulted in significant improvement in his communication skills.

TK had been attending the rehabilitation service for eleven months, but for the first eight months of his programme his attendance was sporadic and he was initially very resistant to engage in rehabilitation or the idea of using memory compensations. Two weeks prior to his key worker approaching him about the research TK had started to attend group sessions on cognitive strategies and acknowledged his memory difficulties and the need for a memory aid.

4.2.1.2 TK's cognitive problems

An initial interview took place with TK and his partner to establish the kinds of information TK had difficulty remembering. TK complained of severe everyday memory impairments including difficulties recalling people, events, where he had put things, conversations and appointments. He had missed important doctor's or hospital appointments and constantly relied on his family to remember information for him, including his days attending the rehabilitation service.

4.2.1.3 Neuropsychological assessment

TK's performance on the Spot the Word sub-test of the Speed and Capacity of Language Processing Test (Baddeley, Emslie and Nimmo-Smith, 1992) suggested that his premorbid IQ fell below the 5th percentile. Scores on other neuropsychological tests are presented in Table 4.1. His performance on the Brain injury Rehabilitation Trust (BIRT) Memory and Information Processing Battery (Coughlan, Oddy & Crawford, 2007) and the Rey Complex Figure Test (Meyers & Meyers, 1995) suggested that he had severe verbal and visual memory difficulties and slowed information processing.

TK also experienced difficulties with mental flexibility as reflected in his difficulty completing the Trail Making Test (norms used as in Tombaugh, 2004). TK had difficulties with response initiation and response inhibition on the Hayling Sentence Completion Test (Burgess & Shallice, 1997) indicating he also had executive functioning difficulties. TK demonstrated moderate to high levels of anxiety and depression as measured by the Hospital Anxiety and Depression Scale (HADS) (Zigmond, & Snaith, 1983) and the Beck Hopelessness Scale (BHS) (Beck, Weissman, Lester, & Trexler, 1974), and during the interview TK expressed anxiety about forgetting information and specifically about using a memory aid that would highlight his difficulties.

Table 4.1. Neuropsychological assessment results

	Raw or test standardised score	Percentile score
WASI* Verbal IQ	73	4th
WASI Performance IQ	78	7th
WASI Full Scale IQ	73	4th
The Speed and Capacity of Language-Processing Test (raw score)	38	<5th
BMIPB list learning A1-5 (raw score)	31	<1st
BMIPB list learning B (raw score)	4	18th
BMIPB list learning A6 (raw score)	3	<1st
BMIPB information processing (adjusted score)	20	<2nd
Rey complex figure copy (raw score)	32.5	16th
Rey complex figure intermediate recall (raw score)	14	5th
Rey complex figure delayed recall (raw score)	10	<1st
Trials Test A (time)	59 seconds	10th
Trials Test B (time)	208 seconds	<1st
Hayling sentence completion Speed A (test scaled score)	1	<1st
Hayling sentence completion Speed B (test scaled score)	1	<1st
Hayling sentence completion Accuracy (test scaled score)	1	<1st
Hospital Anxiety and Depression Scale (raw score)	16	
Beck Hopelessness Inventory (raw score)	9	

4. 2.2 Study Design

As a result of TK's brain injury and his subsequent difficulties TK had reduced the amount of daily activities he carried out compared to prior to his TBI. This limited the amount of information that could be recorded. Also due to the severity of TK's forgetting and the impact this was having on his partner it was considered unethical to remove the memory aid once it had been implemented, it was therefore not possible to include a withdrawal condition. However, the design does include control conditions. Following Tate, McDonald, Perdices, Togher, Schultz and Savage (2008) quality criteria for conducting a good single case study, the present study used a multiple baseline design, with 'A' representing baseline and 'B' representing the intervention phase. Six individual behaviours were defined, three of which were target behaviours and three control behaviours (see section 4.2.2.1). Initial baseline data (phase A) was collected for six weeks, after which a week of trialling the Google Calendar system was conducted. This enabled TK to familiarise himself with the SMS text message alerts and to carry out the reminders. Following the trial week, intervention data was collected for a further six weeks (phase B). An outline of the study design is summarized in Table 4.2.

Table 4.2. Design Phases

Baseline (Phase A)	Week 1-6
Google Calendar Memory aid Training	Week 3-6 during baseline phase and Week 8-10 during intervention phase
Trial Week using Google Calendar	Week 7
Intervention (Phase B)	Week 8-13

4.2.2.1 *Outcome Measures*

Six behaviours (type of forgetting) were initially highlighted by TK and his partner and three were identified as more significant: 1) forgetting appointments (including doctors, dentist, hospital and opticians). These were appointments which TK received appointment letters for or those which were made over the phone when his partner was present. 2) Forgetting to attend the rehabilitation service, (a weekly timetable was used to monitor his attendance) and 3) forgetting to attend [REDACTED]. This was monitored by his partner who was aware of the days TK was to attend. Three other behaviours were also highlighted and used as control behaviours/events:

1) loosing keys, which was monitored by the number of times TK could not find his keys/remember where he had left them and resulted in the family searching for them. 2) Forgetting social events (e.g. going shopping, friends coming around), these were events that TK's partner arranged and had asked TK to do or told him when they were happening. 3) Forgetting to pass on messages to his partner, which were monitored by his partner and was verified by friends and family phoning TK's partner in the evening to ask her if TK had passed on their messages. All behaviours were identified by TK and his partner. The outcome measures were recorded by TK's partner, who was provided with a weekly table to mark down any instances of forgetting or instances of having to remind TK about a behaviour/event (Appendix I). Instances of forgetting were defined as any instance in which TK missed or did not carry out an intended behaviour (e.g. missing a doctor's appointment; forgetting to call a friend or to pass on a message.) Instances of being reminded about an event were defined as carrying out an intended behaviour but only after his partner had reminded TK that he had something to do, otherwise it would not have been carried out (e.g. TK was not getting ready to attend

the rehabilitation service as he was still wearing his pyjamas and therefore needed reminding that he was being picked up in ten minutes).

During the initial interview, TK completed two self report questionnaires: The Beliefs about Memory Aids Questionnaire (BMQ) (Appendix G) and the Revised Everyday Memory Questionnaire (EMQ-r) (Royal & Lincoln, 2008) (Appendix F). The BMQ was initially developed for the second study in this thesis (Chapter 3) and was derived from the qualitative study described in Chapter 2. The BMQ consists of 32 items with five subscales (threat appraisals, lifestyle, inappropriate beliefs, personal control beliefs and treatment control beliefs) that measured participants' beliefs about using memory compensations as well as some beliefs about memory problems. In order to measure the degree of forgetting TK had experienced over the last month he was asked to complete the EMQ-r. The EMQ-r is a subjective measure of memory difficulties and consists of 13 statements about memory failures. TK indicated how often he experienced each symptom of forgetting. A 5-point Likert scale was used with a scale of 0 (once or less in the last month); 1 (more than once a month but less than once a week); 2 (about once a week); 3 (more than once a week but less than once a day) and 4 (once or more a day). Both measures were also completed at the end of the intervention phase so that pre and post intervention comparisons could be made.

4.2.2.2 Procedure

Key workers at the rehabilitation centre were initially briefed about the research and the criteria for participation. It was felt that TK met the inclusion criteria so his key worker approached him about the study. Only when TK had expressed an interest in the research, I (the researcher and author of this thesis) explained the study to him and informed him that, as part of the research, it would be necessary for a relative/partner or

significant other to be involved in the study. TK was provided with a participant information sheet (Appendix C) and any questions were answered. TK was given a minimum of 24 hours to discuss the research with his relative/ partner or significant other and decide whether they wanted to participate. Only when TK and his partner had verbally agreed to participate was an initial meeting arranged. During this meeting TK was asked if he had any other questions about the research and he was asked to sign a consent form (Appendix C). TK's partner was also provided with a separate participant information sheet (Appendix C) which outlined her role in the research. Any questions were answered and TK's partner was also asked to sign a consent form (Appendix C).

During the initial interview TK was asked to complete The BMQ and EMQ-r. TK and his partner were also asked what type of information TK had difficulty remembering and also about the type of memory aid TK wished to implement.

4.2.2.3 Choosing a memory aid

Although showing insight and acknowledging his difficulties TK remained resistant to any memory compensation that he felt highlighted his difficulties (e.g. diary, calendar, post-it-notes). TK had strong beliefs about certain memory aids such as a diary. He stated that only older people should use these and that he would not use any memory aid which was conspicuous. TK was very adamant that the memory aid should not be noticed by other people and must therefore be discrete. TK held very strong beliefs that people would think 'less of him' if his difficulties were highlighted by using a memory aid. This is demonstrated by TK's responses to the BMQ (Appendix T).

Based on the interview and the findings from the BMQ and EMQ-r, TK, his partner and I agreed on the following specifications:

- 1) The memory aid must be something TK feels comfortable using.

- 2) It must be discrete and therefore other people must not know that the device is being used as a memory aid.
- 3) The memory aid must have an alarm functions so that TK is alerted to when something needs to be carried out.
- 4) The memory aid must be small and easily portable.
- 5) There will be no hand written elements within the device.
- 6) The memory aid must have no additional costs.
- 7) The memory aid will help him remember information such as appointments.

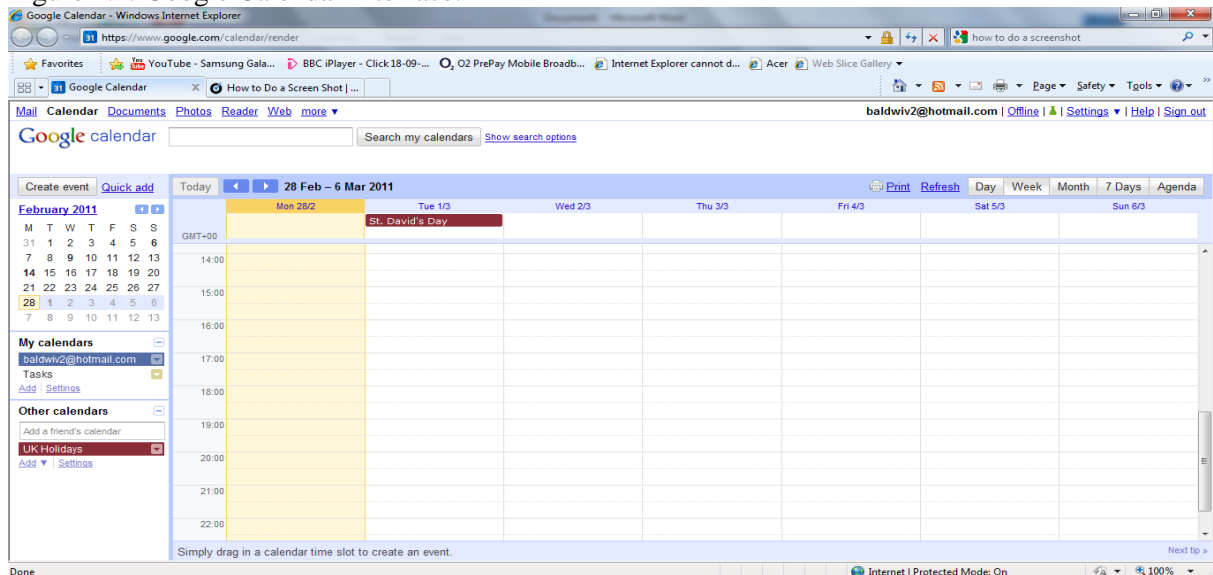
It has been noted that when considering the use of electronic aids for individual's with cognitive difficulties, the following must also be taken into account: the client's level of insight and motivation, that the device should be tailored to the client's cognitive needs to ensure ease of use, that training methods should incorporate errorless learning techniques and that learning how to use a device must include both the rehabilitation centre but also the home environment (Gartland, 2004).

Following the criteria set out by TK and Gartland (2004) the chosen memory aid was a mobile phone and SMS text alerts provided by Google Calendar. As noted in the introduction to this chapter, mobile phones are widely used and receiving SMS text alerts are an accepted part of everyday life. Furthermore, TK used a mobile prior to his TBI and has continued to use it post injury. As Google Calendar can be navigated using a step by step guide, errorless learning techniques can be utilised. In addition, the Calendar is freely available through the internet and therefore ensures that learning at the rehabilitation centre can easily be transferred to the home environment.

4.2.2.4 The Memory aid: Google Calendar

Google Calendar (www.google.com/calendar) is a free online service provided by the search engine Google (Figure 4.1). It is an online calendar in which the individual can specify the calendar's interface according to their own preference (e.g. whether the calendar displays daily, weekly, monthly events). Google Calendar allows the individual to enter an 'event' (e.g. appointment, meeting, occasion and so forth) at a specific time and date. It also enables the user to synchronize their mobile phone enabling them to receive SMS text alerts about the event, thus acting as a memory prompt. For each event added to the calendar a maximum of five SMS text alerts can be set. These can be set at times selected by the individual, for example a person can receive a SMS text alert the day before the event, 10 hours before the event, 4 hours before the event, 1 hour before the event and 20 minutes before the event.

Figure 4.1. Google Calendar Interface.



TK used his own mobile phone as he owned the phone for a number of years and used it prior to his injury. He therefore felt comfortable using this in public and did not need to learn how to retrieve text messages. A Google Calendar account was set up

for TK, and his own mobile phone was synchronized to this account. In order to do this TK's mobile phone number was entered on the account, and a text message containing a verification code was sent to TK. Once TK received this code it was entered onto the account, synchronizing the mobile phone and Google Calendar. This ensured that the SMS text message reminders for the events entered into the calendar were sent to the correct mobile phone.

4.2.3 Data collection

4.2.3.1 Baseline Phase

In order to assess the effectiveness of the intervention an initial six weeks of baseline data was collected. TK's partner recorded on a table (Appendix I) how often each day the specified behaviours occurred (e.g. forgetting an appointment) or how often TK was reminded about them. A stamped addressed envelope was provided to return the completed table at the end of each week. As TK's partner was the main family carer it was agreed that a text message reminder would be sent every evening to remind her to complete the table. This ensured that all possible events were recorded.

4.2.3.2 Training

For three weeks during the second half of the baseline phase, TK had individual one and a half hour sessions each week learning how to use Google Calendar. In order to facilitate learning, errorless learning techniques (Baddeley & Wilson, 1994) were used in each session when teaching TK how to input an event into the Calendar and also when teaching him to set SMS text alerts for each event. Cicerone et al. (2011) highlight that for people with memory difficulties following ABI errorless learning techniques are effective for teaching specific information and procedures. During the first session Google Calendar was demonstrated to TK and henceforth a step-by-step instruction

manual was used (Appendix M) and TK was encouraged to always refer to the instructions rather than guessing the next stage. During the last week of the baseline phase (week 6) TK inputted a number of agreed events into Google Calendar to complete during a trial week (week 7). This was to familiarise TK to the SMS text alerts outside of the training sessions. TK was asked to carry out a number of tasks including: ring the Doctor's surgery and make an appointment with the nurse; text the researcher stating the time and date of the nurses appointment; to ask a member of staff at the beginning of the session for the envelope containing a form to complete for his key worker; to complete the form at home and to return the envelope containing the completed form to his key worker in their next session. Unfortunately, due to reasons beyond the researcher's control some of the SMS text alerts were not received and therefore the latter activities (completing the form and returning it in the envelope to his key worker in their next session) were not carried out (see limitations for further details). To ensure the calendar system was functioning correctly, TK set reminder alerts to send a text message to me stating he had received the SMS text alerts. Once I was satisfied that the SMS text alerts were being received the intervention phase commenced the following week. During the intervention phase TK continued to have sessions on how to: navigate Google Calendar, enter events and set reminder alerts, as it would enable TK to use Google Calendar at home once the research was finished. After a total of seven weeks of training TK did not require any prompting and referred back to the instruction manual if he needed reminding. During the baseline and intervention phase TK did not have access to Google Calendar outside of the rehabilitation service, therefore teaching TK how to navigate the Calendar would not affect the study findings.

4.2.3.3 Intervention Phase

To ensure that all possible events were entered, TK's partner was asked at the beginning of each week about any upcoming appointments or events (if any events arose after this phone call, TK's partner was asked to text me with the details). TK was also sent a daily text message asking him of any appointments or events that needed to be put on the calendar. Any events during the intervention phase that were required immediately were entered onto the calendar by myself. However, to ensure TK was able to successfully manage his own reminders independently, TK also entered a number of his own events and reminder alerts during the training sessions when he attended the rehabilitation service. These were events that I had been informed about and were to occur the following week. Data was collected and recorded in the same way as during the baseline phase.

Once the intervention phase was completed (week 13) a meeting was arranged with TK at his home to make sure that he had access to Google Calendar on his home computer. During this session TK completed the BMQ and EMQ-r again so that they could be compared with the pre-intervention questionnaire scores. He also answered questions regarding how he felt about using Google Calendar and whether it had changed his feelings about using a memory aid. TK's partner was contacted by telephone to discuss her thoughts and feelings about TK using Google Calendar.

4.2.4 Ethical Approval

Ethical approval was obtained from South Birmingham Research Ethics Committee (Appendix B).

4.3 *Results*

Early researchers suggest that in single case research, visual representation in the form of graphs was an adequate approach to data analysis and interpretation (Kazdin, 1982). However, Tate et al. (2008) suggest that a good single case study should demonstrate the effectiveness of the treatment by statistically comparing the results over phases. Manolov, Solanas, Sierra and Evans (2011) state that based on data features identified by visual analysis of single case data a quantitative procedure can be selected. They identify three key stages to aid selection of the appropriate quantitative procedure: 1) is there a quadratic trend; 2) if not is there a linear trend and 3) if the data is neither quadratic nor linear is it autocorrelated or heteroscedasticity. They suggest that for data that is autocorrelated, nonoverlap of all pairs (NAP) analysis or slope and level change (SLC) analysis can be employed. Therefore in line with Manolov et al.'s (2011) suggestions visual analysis in the present study was supplemented by NAP analysis. NAP is a new method of measuring effect size (e.g. Area Under the Curve (AUC); Mann-Whitney's U) (Parker & Vannest, 2009). The degree to which data in the baseline (phase A) versus the intervention (phase B) do not overlap is an accepted indicator of the amount of performance change in a single case study (Parker & Vannest, 2009). In relation to the following areas: power and precision (confidence interval width); correlation with the established effect size index R^2 and its accuracy in predicting visual judgements, NAP analysis equalled or outperformed existing non-overlap-based indices, such as 'percentage of all nonoverlapping data' (PAND); percentage of phase B datapoints exceeding the median of the baseline phase' (PEM) and the 'percent of nonoverlapping data' (PND) (Parker & Vannest, 2009). NAP analysis also has advantages over parametric analysis (e.g. t-tests, ANOVA) because extreme outliers are

common in single case research and parametric effect sizes are disproportionately influenced by them (Parker & Vannest, 2009). Secondly, single case research, like in this study, often fails to meet parametric assumptions of serial independence, normality and constant variance of residual scores (Parker & Vannest, 2009).

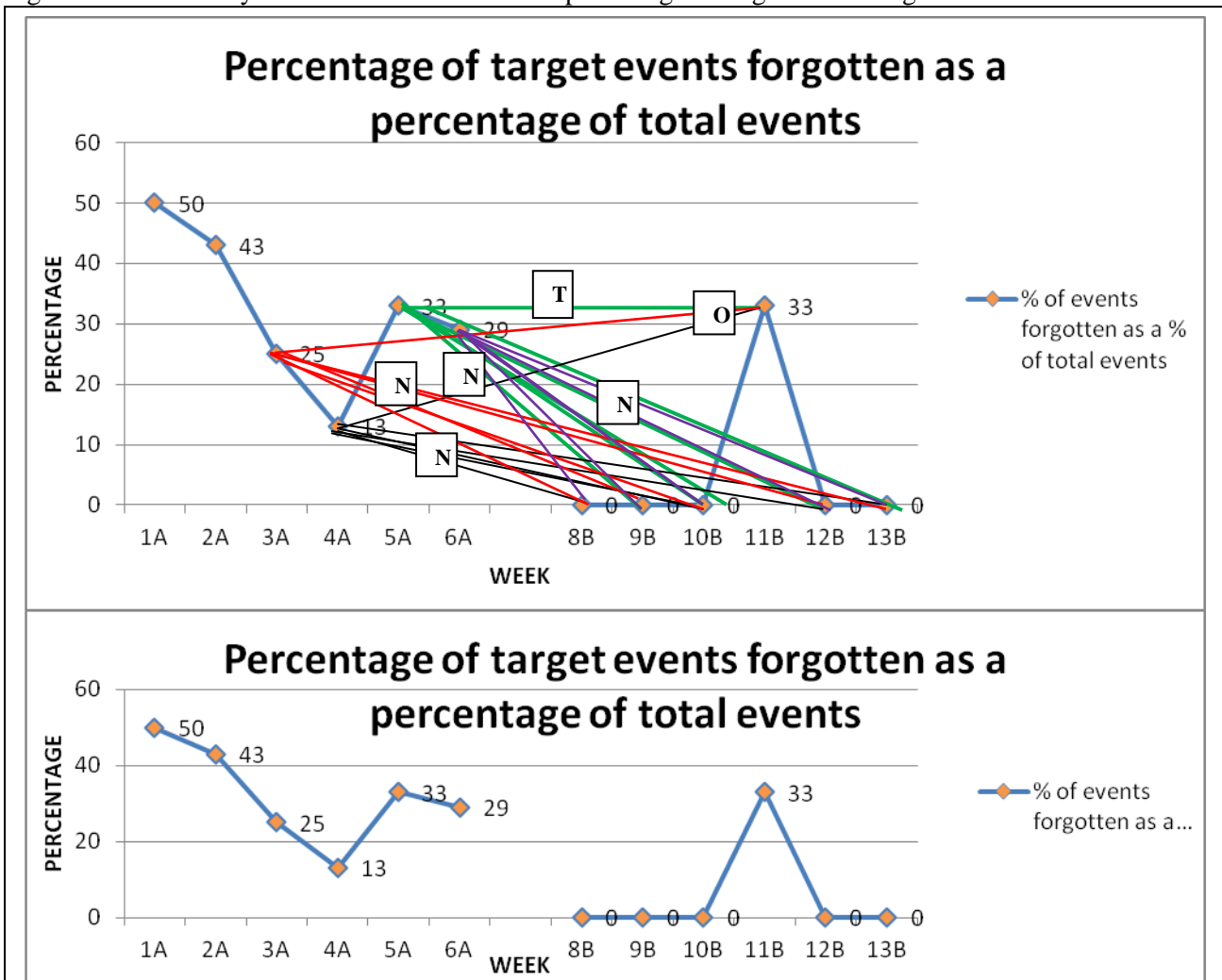
NAP analysis can be calculated by hand and assesses data overlap between each baseline (phase A) datapoint and each intervention (phase B) datapoint. NAP hand calculation has two options: 1) calculate all nonoverlapping data (i.e., a nonoverlapping pair will have a phase B datapoint larger than its paired baseline phase A datapoint). 2) Counting all overlapping pairs and then subtract from the total possible pairs to obtain a nonoverlap count. Total possible pairs (total N) is the number of datapoints in phase A times phase B ($N_A * N_B$) (Parker & Vannest, 2009).

In order to calculate NAP, all target behaviours (i.e., all appointments, days attend the rehabilitation service and days attend) were collated to create a total events score for each week. The number of times these events were forgotten was then calculated as a percentage of total events. NAP analysis was used to determine performance change between baseline (phase A) and intervention (phase B). Figure 4.2 shows the NAP analysis and hand calculation.

NAP analysis revealed there was a 90% change in performance between baseline (phase A) and intervention (phase B) for the number of target events forgotten (Figure 4.2). NAP analysis also revealed that there was a 100% change in performance for target events TK would have forgotten if he had not been reminded (Figure 4.3). Visual analysis of Figure 4.2 also shows that TK did not forget as many target events when using his mobile phone as a memory aid by receiving SMS text alerts from Google Calendar. At week 11 during the intervention (Phase B) there is a sudden

increase in forgetting events (33%) because his phone was taken without his knowledge from where it was usually kept. TK was therefore not able to receive any text message alert reminders and subsequently forgot to attend the rehabilitation service. This demonstrates the efficacy of the Google Calendar text alert system as when the mobile phone was returned, TK did not forget any other events during the remainder of the intervention phase.

Figure 4.2. NAP analysis and hand calculation for percentage of target events forgotten.



A= Baseline Phase
 B= Intervention Phase

NB Week 7= trial week
 (Week 3-6 during baseline phase and Week 8-10 during intervention phase Google Calendar training)

Total number of possible pairs = $N_A * N_B = 6 \times 6 = 36$

There is no overlap for 1A or 2A and all intervention phases. However there is overlap between: 3A, 4A 5A & 6A and intervention phases (Phase B).

Comparing 3A data point with all Intervention data points: (0,0,0,1,0,0)

Comparing 4A data point with all Intervention data points: (0,0,0,1,0,0)

Comparing 5A data point with all Intervention data points: (0,0,0,0.5,0,0)

Comparing 6A data point with all Intervention data points: (0,0,0,1,0,0)

Overlap sum = 1+1+.5+1= 3.5

Total possible pairs minus overlap sum = total non overlap (36-3.5= 32.5)

Total non overlap / Total possible pairs x 100 = NAP as a percentage (32.5/36 = 0.90 x 100 = 90%)

Figure 4.3. NAP analysis and hand calculation for percentage of events forgotten if not reminded.

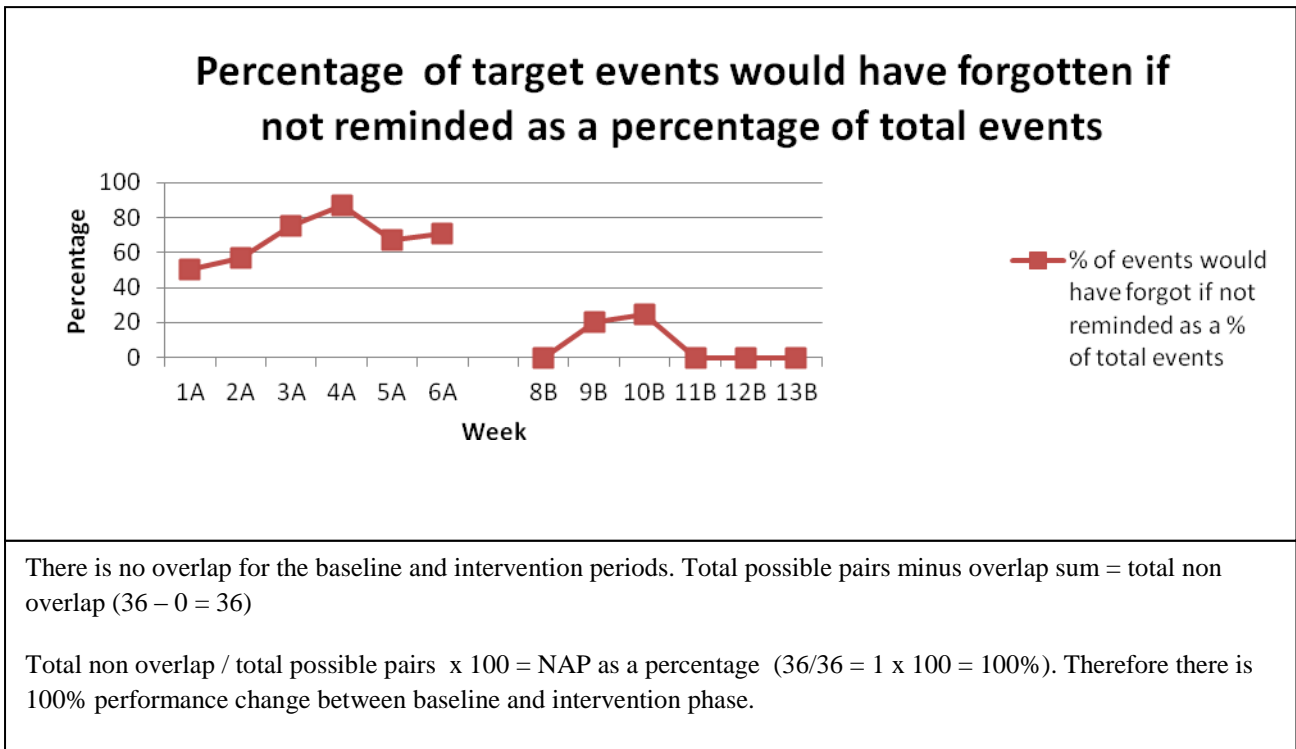


Figure 4.4. NAP hand calculation for percentage of times TK lost his keys (control condition).

Total number of possible pairs = number of data points in phase A (baseline) times number of data points in phase B (intervention)

$6 \times 6 = 36$

There is no overlap for 2A and the intervention phases. However there is overlap between 1A, 3A, 4A, 5A & 6A and intervention phases (Phases B).

Comparing 1A data point with all Intervention data points: (0.5,0.5,0,0.5,0,0) = 1.5

Comparing 3A data point with all Intervention data points: (1,1,0.5,1,0.5,0) = 4

Comparing 4A data point with all Intervention data points: (0.5,0.5,0,0.5,0,0) = 1.5

Comparing 5a data point with all Intervention data points: (0.5,0.5,0,0.5,0,0) = 1.5

Comparing 6A data point with all Intervention data points: (0.5,0.5,0,0.5,0,0) = 1.5

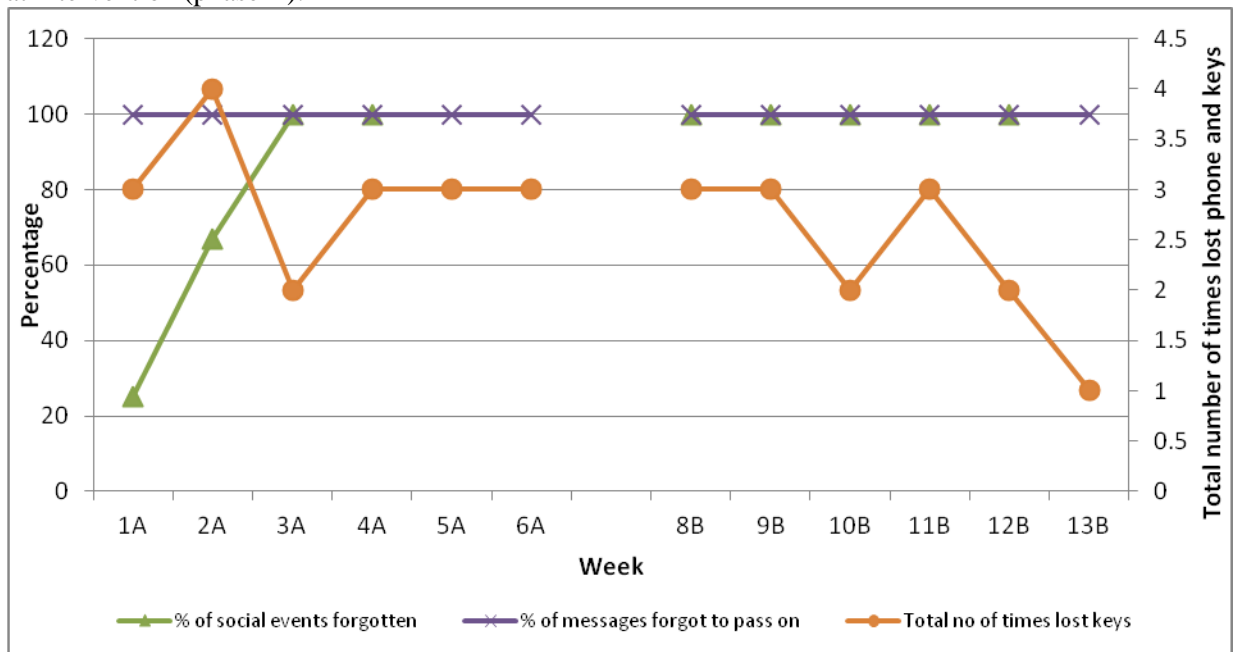
Overlap sum = 1.5+4+1.5+1.5+1.5= 10

Total possible pairs minus overlap sum = total non overlap (36-10= 26)

Total non overlap / total possible pairs x 100 = NAP as a percentage (26/36 = 0.72 x 100 = 72%)

NAP analysis could not be conducted on the control condition ‘forgetting to pass on messages to partner’ as this remained constant throughout both the baseline and intervention phase (Figure 4.5). ‘Social events forgotten’ could not be analysed as on some occasions no social events occurred (Figure 4.5). However, visual analysis shows that forgetting social events increased over the baseline period and then forgetting social events remained constant during the intervention phase. One possible explanation for the baseline increase may be that there was a change in his partner’s circumstances during the study and so she did not constantly remind TK about social events such as shopping. Total number of times TK lost his keys decreased between the baseline and intervention phases (Figure 4.5). NAP analysis revealed a 72% change in performance (Figure 4.4). During the initial baseline phase TK started to keep his phone in a specific place so that he knew where it was. As a result TK instigated the same strategy in order to remember where his keys were. This accounts for the decrease in the number of times TK lost his keys (Figure 4.5).

Figure 4.5. Displays the percentage of control events forgotten or lost at baseline (phase A) and at intervention (phase B).



TK completed the BMQ and EMQ-r prior to commencing the baseline phase and also at the end of the intervention phase. The results suggest that TK's personal control and treatment control beliefs had increased post intervention (Table 4.3). Inappropriate beliefs showed a decrease as did threat appraisals. Lifestyle beliefs increased slightly, particularly those questions suggesting that written memory aids did not suit his lifestyle. This highlights that following the intervention TK was more convinced that written aids were not in keeping with his lifestyle. It should be noted that the threat appraisal "using a memory aid would make me feel like I need help" (BMQ 5); "I would feel stupid if I had to use a memory aid in public" (BMQ 19) and the inappropriate belief "It's better to try to rely on my own memory than use memory aids" (BMQ 15) changed from agree at baseline to disagree post intervention (Appendix T).

The EMQ-r also showed a decrease post intervention, indicating that TK no longer experienced forgetting as many things as he had prior to the intervention (Appendix U). For example TK stated that he had only completely forgotten to do things he said he would do/planned to do once or less in the last month. In comparison, TK stated that he forgot to do these at least once or more a day pre-intervention. However, TK noted that he still forgot to pass on messages/important information to the same degree as prior to the intervention.

Table 4.3. Total BMQ sub-scale scores and EMQ-r pre and post intervention

	BMQ Personal Control Beliefs	BMQ Treatment Control Beliefs	BMQ Inappropriate Beliefs	BMQ Threat Appraisal	BMQ Lifestyle Fit	EMQ-r total score
Pre	16	22	18	37	15	52
Post	22	24	14	33	16	35

During the final meeting with TK he expressed that the memory aid had ‘helped him 100%’ and because it was discrete no one knew that the text messages he was receiving were memory prompts. TK also reported that sometimes he only needed to hear the message alert and it would ‘jog his memory’ and make him think about what he had to do, although he stated that he always looked at the message as well. TK noted that his anxiety about using a memory aid had reduced as it was something he ‘felt happy with.’ TK’s partner reported that implementing the Google Calendar and mobile phone as a memory aid had resulted in TK becoming less reliant on her, which reduced the pressure for her to remember his appointments as well as her own.

During the intervention and trial phase TK was sent SMS text alerts that asked him to respond to the researcher via text message (the author of this thesis). As this task was successfully completed on a regular basis, it was felt that one possible way of improving TK’s recollection of any messages he needed to pass on to his partner, was for a reminder alert to be sent to TK every evening. This alert message would provide the necessary prompt for him to pass on any messages he had been given. Once the study was complete TK added the event to the Calendar and included the appropriate reminder alerts.

TK attended a review meeting at the rehabilitation centre two months following the intervention phase. TK was sent one letter and attended the review meeting without the need for any prompts from the rehabilitation service or his partner. This would not have been achievable prior to the intervention. At the meeting TK stated that he continued to use the Google Calendar text alert system and his mobile phone, as it has helped him a great deal and he will continue to use them to help him remember important events and appointments.

4.4 Discussion

This single case multiple baseline study across behaviours/events describes the implementation of a mobile phone and Google Calendar text message alerts to help a 43-year-old male with severe memory difficulties and executive functioning difficulties i.e., remembering prospective information such as appointments. TK initially demonstrated marked difficulties in: remembering appointments, social events, when he had to attend the rehabilitation service and would forget where he had put things and fail to recall information he had been asked to pass on. Visual analysis of baseline data confirms that TK either failed to carry out a behaviour/event or only carried it out if prior to the behaviour/event passing his partner reminded him about it. There is a clear indication from the results that using Google Calendar as a memory aid was highly effective in reducing the number of times target behaviours/events were forgotten. The Google Calendar SMS text message alerts were found to improve performance in the recall of target behaviours/events by 90%. This improvement in recall was not due to spontaneous recovery as there was no change in two of the three control events. TK showed improvement on the third control event because he coincidentally learned to use a compensatory strategy.

This study demonstrates the effectiveness of SMS text message alerts and adds to the growing body of literature regarding the effectiveness of electronic memory aids in aiding prospective memory following ABI (Morris & Reinson, 2010). It supports the efficacy of alert reminders for people with memory difficulties (Wilson, 1997; Wilson, Emslie, Quirk, & Evans, 1999; Evans, Emslie, & Wilson, 1998; Wilson et al, 2001), and the recent literature regarding the use of mobile phones as an effective memory aid for those with cognitive difficulties (Wade & Troy, 2001; Stapleton, Adams and Atterton,

2007; Pijnenborg et al., 2007; Fish et al., 2007; Culley & Evans, 2010; Svoboda et al., 2010). The present study and those by McDonald et al. (2011) and Diamond et al. (2011) demonstrate the potential for improvement in memory slips through the use of SMS text message reminders sent by the Google Calendar system. Unlike participants in Diamond et al. (2011) who were not taught how to use the Google Calendar interface, the present study and that by McDonald et al. (2011) demonstrate that by using errorless learning techniques along with a step-by-step guide on how to navigate the Google Calendar system people can acquire the necessary skills to learn how to manage the Calendar system effectively. Thus the Calendar system was integrated effectively into real life settings and daily routines.

An advantage of receiving SMS text message reminders to a mobile phone over other electronic memory aids such as a pager, voice organiser or personal organiser is that in today's society mobile phones are widely used and an accepted and integral part of everyday life. There are over four billion mobile phone users worldwide (Electronics Take Back Coalition, 2010) therefore the majority of people who have had an ABI are likely to be familiar with this technology. This enables a mobile phone as a memory aid to be easily incorporated into everyday life rather than devices such as NeuroPage that are made exclusively for the intention of aiding memory performance. The discreteness that is offered by using a mobile phone as a memory aid may result in its prolonged use (Wade & Troy, 2001). Since it is a common device any potential embarrassment of using a mobile phone as a memory aid in public can be reduced. Additionally, a mobile phone may reduce beliefs that the aid further highlights an individual's difficulties. It has been noted in previous chapters in this thesis and within disability literature that assistive devices need to 'fit' a particular individual's lifestyle, convey their desired self

image and must fit their value systems if they are to be used (Bender Pape, et al., 2002). Furthermore, in the initial qualitative study (Chapter 2) it was highlighted that memory aids must be something that ‘they (people) were comfortable doing’ thus reflecting a sense of fitting one’s identity. In the initial interview TK expressed strong beliefs about written memory aids, in particular a diary being ‘for old people’ and that he would not use any aid that he believed made him stand out as having memory difficulties. By using pre-existing technology such as the mobile phone, because it is discrete and he was familiar with it pre and post injury, this has alleviated anxieties and reduced the number of negative beliefs TK associated with using a memory aid. Diamond et al. (2011) also noted that in their study one participant was more willing to use the mobile phone as a memory aid because it was not obvious. This highlights the need for therapists to adapt pre-existing technology to suit individuals’ needs as this is likely to encourage independence and for those individuals who possess beliefs about negative social evaluations it can alleviate the distress of using assistive devices in public.

It should be noted that the type of injury TK sustained may have influenced his beliefs about memory aids (BMQ). Riley, Brennan and Powell (2004) and Riley, Dennis and Powell (2010) report that those who had a subsequent TBI as a result of an assault were more likely to respond to threat appraisals with avoidance. TBI arising from assault can present difficulties associated with psychological adjustment because an assault can lead to a general loss of trust in others as well as threatening one’s self-esteem (Riley et al., 2004). It is therefore not surprising that TK scored highly on the threat appraisal sub-scale of the BMQ as well as wanting an aid that was inconspicuous. By using a device that is socially acceptable it reduced any further threat to his self-esteem.

In addition, being of Pakistani origin and living in the UK may have influenced TK's responses to the BMQ and must also be considered when ensuring an aid 'fits' an individual's lifestyle. Studies looking at the impact of cultural differences following ABI, report that Japanese families felt that changes in an individual's behaviour following ABI may bring disgrace to the family; Arabic and Italian participants with ABI noted feelings of shame at having an ABI and within Vietnamese culture having an ABI was not only shameful for the person but also for the family (Simpson, Mohr & Redman, 2000; Watanabe, Shiel, McLellan, Kurihara & Hayashi, 2001). It has been noted that in Asian cultures there is more emphasis on the family over the individual (Simpson et al, 2000), and that Asian cultures emphasise selfless subordination to the family and community, thus reducing beliefs in personal control (Sastry & Ross, 1998). In general, low personal control beliefs are associated with poorer rehabilitation outcomes and poorer psychological well-being (Moore & Stambrook, 1992; 1995), however, in Asian cultures it has been suggested that greater personal control beliefs are considered to violate the norm. Therefore unlike Western cultures, lower levels of personal control beliefs amongst Asians are not associated with poorer psychological well-being (Sastry & Ross, 1998). Placing greater emphasis on the family and community may explain why TK reported low personal control beliefs on the BMQ and also why he wanted to use a memory aid that was socially acceptable. It has been reported that cultural value systems are significantly associated with rehabilitation outcomes following ABI (Saltapidas & Ponsford, 2008). It is therefore important to acknowledge the impact that cultural background has on an individual's beliefs and sense of self and this must be taken into consideration when choosing a memory aid.

Despite the efficacy of electronic devices as memory aids, one main limitation is that a large majority of these devices have been adapted (Wilson, et al., 1997; Van den Broek et al., 2000; Kim, et al., 2000; Wade & Troy, 2001; Wright et al, 2001a,b; Gillette & DePompei, 2008) because consumer available aids have been considered too complicated for people following ABI (Thone-Otto & Walther, 2003). Therefore, these devices are normally only available for those taking part in studies and are not commercially available once the study has finished (Thone-Otto & Walther, 2003). On the other hand, devices such as Neuropage that are available commercially, require assistance from an external body thus the individual incurs an initial set up fee and a monthly rental charge (Bateman, 2011). In 2011, 77% of UK households reported having internet connection (Office for National Statistics, 2011), therefore as Google Calendar is accessible through the internet, it is likely that the majority of people with ABI will have access to this service. In addition, it has been noted that two thirds of people were using a computer following ABI and that half were using the internet with activities being comparable to those of the general public (Vaccaro, Hart, Whyte & Buchhofer, 2007). As noted previously, most individuals are likely to also have a mobile phone and so not only is Google Calendar a cost effective alternative, it is also an option for those users who wish to have complete control over the memory aid. The present study and that by McDonald et al. (2011) demonstrate that by using errorless learning techniques people can acquire the necessary skills to learn how to manage the Calendar system effectively in real life settings. This has subsequently increased TK's independence and reduced his reliance on family members. However, it should also be noted that for those individuals who may find it difficult to navigate the Calendar system it is possible to teach relatives/carers how to use it. This would enable people to

use the SMS text alert system in a similar way to NeuroPage but would alleviate the need to rely on an external body. This will therefore increase people's independence and so Google Calendar remains a viable cost effective alternative.

As mobile technology develops, there has been a rapid transition from standard mobiles to smartphones, with 26% of the UK population now using smartphones (Ofcom, 2011). Smartphones such as Android, iPhones and BlackBerry are high end mobile phones that combine the functions of a PDA. As well as having a built in music system (MP3) and camera, smartphones can access mobile internet (Wikipedia, 2011). In the UK alone 17.6 million people accessed the internet on their mobile phone in 2011 (Office for National Statistics, 2011). This function makes amending and entering events onto Google Calendar more easily accessible and can be done remotely. Svoboda et al. (2010) found that following a theory-driven memory intervention programme an 18 year old female (MK) with severe memory difficulties learned to use the calendar function on a smartphone and was also able to generalise the calendar to everyday activities as well as acquiring the skills to use additional software applications offered on the smartphone such as the phone address book, camera, voice recorder, to-do-list and MP3 player. MK showed increased confidence in dealing with memory demanding situations and found that the acquisition of a smartphone as a memory aid also benefited her family as she became more independent. This highlights the importance and effectiveness of using existing technology for people with memory difficulties following ABI.

4.4.1 Limitations

Although the study provides support for the use of a mobile phone and Google Calendar SMS text message alerts as an effective memory aid for remembering

prospective information, there are some limitations associated with this technology. One limitation of this particular aid, and specifically the use of any electronic aids that utilise phone networks, is that we are unable to control or rectify any difficulties that may occur to the signal systems operated by these networks. During the initial trial week, TK did not receive the SMS text alerts for a period of four days due to the local mobile phone mast being vandalised and so he forgot a number of tasks. Once the network problem had been rectified TK received all text message alerts for the remainder of the study. A second limitation is that technology and services are continually developed and updated as a result of growing consumer demand and competition, and such changes could cause a problem for people with memory difficulties. Changes to the Google Calendar system occurred during this study with additional functions being added. However, the core elements of the system and interface remained the same and there was no disruption to how events and alarms were entered. Nevertheless, it is something that users must be aware of.

Unfortunately due to the reduced number of activities TK participated in since his assault, data collection was limited. Therefore it was only possible to analyse the data using visual and NAP analysis as other data analysis techniques require more data points. However it is clear that the intervention resulted in a clinically significant change.

4.5 Implications for future research

This study highlights the effectiveness of emerging technology as an aid to increasing independence following ABI. Future studies could consider teaching individuals' who are motivated to use this technology how to access and use the Google Calendar system on their phone. As Google Calendar also offers email alert reminders it

is important to look at the effectiveness of email alerts compared to SMS text message alerts as an email alert allows for even more information to be recorded about the event. In addition, future research could compare internet calendar systems offered by alternative providers such as Microsoft Office- Outlook.

Future research could also explore how other functions that are offered by smartphones may benefit people following ABI. For example, smartphones offer voice recognition and typing programs that would enable people with dexterity difficulties following ABI to send SMS text messages or emails, thus enabling people to continue to socialise as before. For people with retrospective memory difficulties, smartphones may be used to capture film or photos throughout the day which can then be transferred to a computer. As smartphone technology is fast becoming an integral part of our everyday society, this may reduce anxieties associated with using aids that are purely devised for aiding memory. In addition, applications are constantly being developed for smartphones. A recent application called 'It's done' is available on iphones and allows users to create a to-do list and highlight whether they have completed tasks thus enabling people to recall with certainty if a task has been accomplished. In addition, the application also sends a text message alert to family members informing them that the task has been completed (PRweb, 2011). By collaborating with clinical scientists it may be possible to create applications that increase independence following ABI, for example applications that enable people with language difficulties to access pictorial calendars. This technology offers a multitude of functions as well as design aesthetics that has a broader appeal. Devices must aim to be inclusive of the wider community and not just for those with disabilities as this will increase acceptance and implementation.

4.6 Summary

The present study adds to the growing body of research into electronic devices as memory aids and demonstrates that for those individuals who may be regarded as unlikely to use aids, the key is to match the aid to the individual. This study highlights the potential for the efficacy and cost effectiveness of using pre-existing technology and the need for clinicians to look at using and adapting electronic devices that are available within the consumer market. This study draws attention to the effectiveness of using a mobile phone and Google Calendar SMS text alert system. As the choice of memory aid met all of TK's specifications he has not needed intense psychological therapy to address beliefs about social negative evaluations as well as anxiety about using a memory aid in public. A memory aid that was inconspicuous, suited TK's self image and was in keeping with modern technological advances resulted in an intervention that has had a positive impact on TK's well-being and increased his independence thus enabling him to take greater control of his life. The intervention has also had a positive impact for his partner as TK has become less reliant. A 90% reduction in instances of forgetting was apparent within the intervention. As noted throughout all three studies within this thesis, a key component in the successful uptake of memory compensations is the need to 'fit' the aid to an individual's lifestyle.

CHAPTER 5

SUMMARY

5.1 General Summary

5.1.1 Chapter Overview

As discussed in Chapter 1, research advocates the use of external memory compensations as an effective way to improve functioning in people with memory difficulties following ABI (Cicerone, Dahlberg, Kalmar, Langenbahn, Malec, et al., 2000; Cicerone, Dahlberg, Malec, Langenbahn, Felicetti, et al., 2005; Cicerone, Langenbahn, Braden, Malec, Kalmar et al., 2011; Sohlberg et al., 2007). In addition, studies have identified certain demographic and injury related variables that are associated with the use of memory compensations, such as being under 30 years old at the time of injury; current age (i.e. being younger), premorbid use of memory compensations, those with less severe memory impairments and those without additional cognitive deficits, (Wilson & Watson, 1996; Evans, Wilson Needham & Brentnall, 2003). However, despite the fact that these variables highlight people who might need additional encouragement from therapists to use aids, they cannot be modified through therapeutic interventions. Thus it was important to explore potentially changeable variables such as awareness of deficit, health beliefs and perceptions of aids, to see whether they explained why people do not always wish to use memory compensations and whether these more modifiable variables were able to predict the use of memory aids over and above demographic and injury related variables.

Chapter 2 describes the first empirical study in this thesis. The initial qualitative study used IPA to explore eight people's experiences of having memory problems and

using memory compensations following ABI and their motivation to use (or not use) them. In this initial study six master themes emerged. The most significant themes to emerge highlights that people tend to avoid memory compensations that they deem obvious in order to avoid the negative social evaluations (e.g. appearing stupid or needing help) that might be made by the public as a result of using them. In addition, the importance of memory aids suiting someone's lifestyle was also highlighted, as those aids that did not 'fit' a particular individual's lifestyle were also avoided. In addition, it also emerged that beliefs about memory was an important factor in the uptake of memory compensations. The initial qualitative study revealed that those individuals who held inappropriate beliefs such as 'use it or lose' ones memory or that repetition is an effective strategy for remembering prospective information (e.g. appointments) were less likely to use memory compensations following ABI. Previous research into health beliefs suggests that those who possess greater control beliefs are more likely to use memory compensations (Patel, 2008). However, it was noted that the desire to rely on one's own inner resources (as would be indicated by greater personal control beliefs) may not be helpful in the presence of inappropriate beliefs. The findings from this initial qualitative study suggest that memory compensations need to be something people are 'comfortable doing' thus being consistent with a sense of personal identity. This initial study demonstrates that motivation for strategy use depends on complex processes that include social, emotional and practical factors.

The second study in this thesis is a quantitative study that builds upon the findings from the initial qualitative study. Together with demographic and injury related variables, control beliefs and degree of awareness, Chapter 3 explores whether beliefs about memory compensations predict the uptake of memory aids and strategies

following ABI. In this cross sectional questionnaire study 58 participants completed a series of questionnaires including the BMQ which was developed from the themes identified in the qualitative study. Only the belief variables: treatment beliefs, inappropriate beliefs and lifestyle 'fit' significantly correlated with use of memory compensations and accounted for 42 per cent of the variance in a regression model. Lifestyle 'fit' was the most significant predictor; after accounting for Lifestyle 'fit', inappropriate beliefs added only seven per cent to the variance and treatment beliefs did not significantly add to the model. Unlike previous research, no link between demographic variables and the use of memory compensations was found. Previous studies have found a link with premorbid use of memory compensations and the findings from the quantitative study suggests this may be because the most important determinant is whether the aid suits the person's pre and post injury lifestyle. In addition, Chapter 3 is the first empirical study to highlight that it is important to address unhelpful beliefs that may deter people from using memory aids (e.g. 'using memory aids will make my memory lazy').

The final study of this thesis focuses on a single case study that draws upon the principals and findings from Chapter 2 and Chapter 3. It highlights the need for initial assessment, including the assessment of an individual's motivation to use memory compensations and their beliefs about using memory aids as well as their beliefs about their memory problems. The single case multiple baseline study across behaviours discussed in Chapter 4 highlights the effectiveness of SMS text alerts sent from Google Calendar to a mobile phone to help a 43-year-old male with severe memory and executive functioning difficulties. Nonoverlap of all pairs (NAP) analysis revealed a 90% change in performance for the number of target events forgotten. The single case

study adds to the growing body of research into electronic devices as memory aids, demonstrating that for individuals who may otherwise be regarded as unlikely to use aids, the key is to match the aid to the individual's lifestyle and sense of self.

5.1.2 Methodology Overview

Three different methodological techniques have been used in this thesis and this has provided a coherent and better picture about what factors influence the use of memory compensations following ABI. As there has previously been a limited amount of research into this area, by initially utilising a qualitative method not only did this provide an in-depth and rich understanding of people's lived experiences but it has also been noted that qualitative research is a prerequisite of good quantitative research, particularly in areas that have received little previous investigation (Pope & Mays, 1995). The use of qualitative and quantitative methods can be seen as complementary (Morgan, 1998) in that the initial qualitative study aimed to understand the initial phenomena, which then facilitated the development of the questionnaire for the quantitative study. The quantitative study was then able to provide a greater exploration of people's beliefs about memory compensations and about having memory difficulties. Using multiple methods has meant that they have provided mutual validation of the data (Morgan, 1998). The findings from both the qualitative and quantitative study were then used as a framework upon which the single case study was devised. This study enabled the findings from both the qualitative and quantitative studies to be implemented clinically. Thus, utilising a single case study design was useful in documenting outcomes and providing empirical evidence in support of the previous study findings that people who may be initially deemed unlikely to use memory compensations, are willing to use them if they fit their lifestyle and thus a sense of self. This was an

example of translational research showing that it is possible to translate empirical findings into the clinic.

5.2 *Implications for future research*

This thesis has highlighted a number of factors that are associated with the uptake of memory compensations. It emphasises that for individuals' who believe that using memory compensations will make their memory lazy or that repetition is an appropriate strategy for remembering prospective information there is a need to incorporate assessment and interventions, such as CBT, aimed at changing inappropriate or mistaken beliefs about memory problems and using memory compensations. In addition, given the association between greater treatment control beliefs and use of memory compensations, this thesis has suggested that it may be valuable for therapists to work with individuals to improve their perception of control. Furthermore, this thesis highlights that one of the most important factors that influences the uptake of memory compensations is whether or not the aid or strategy fits the individual's lifestyle. The sub-scale 'lifestyle fit' in Chapter 3 was found to be the most predictive variable for the use of memory compensations. It must be noted that this sub-scale may in fact incorporate two sub-scales. Firstly, a set of contextual factors such as whether the environment creates a need for aids, i.e. not having enough things to remember or being able to rely on someone else as their memory aid. As noted in Chapter 3 this is important because it can impact on functional independence as well as increase burden on the caregiver. Secondly, the sub-scale relates to the degree to which aids are in keeping with an individual's lifestyle and therefore a sense of identity that has implications for further research.

As noted previously within this thesis, having an ABI can have a huge impact on an individual and is one of the greatest challenges to an individual's quality of life (Seibert et al., 2002). In addition, changes or 'threats' to one's self identity can result as people realise they are no longer able to perform meaningful activities (Hoogerdijk, Runge & Haugboelle, 2011) and this can mean people struggle to understand and identify with their present selves (Dewar & Gracey, 2007). A number of studies highlight that following ABI there is tension surrounding one's self identity with people comparing their pre-injury self with their present (post-injury) self (Nochi, 1998a, b, 2000; Ylvisaker & Feenay, 2000; Cantor et al., 2005; Levack, Kayes & Fadly, 2010; Hoogerdijk et al., 2011; Gelech & Desjardins, 2011). It has been noted by Gelech and Desjardins (2011) that there is not a complete loss of self following ABI, but that post injury identity is developed and realigned as a process of combining elements of the old self with a new self. They suggest that this allows continuity (i.e. old self) and discontinuity (i.e. new self) thus enabling fundamental growth of the one's identity. It may be that memory compensations that are not in keeping with one's lifestyle and a sense of pre-injury identity do not enable elements of the individual's past to be encompassed within their post injury self. Gelech and Desjardins (2011) also noted that connecting to the past self was rewarding for an individual's development of their identity.

Research by Ylvisaker and Feenay (2000) found one young man believed that a sense of self had been imposed upon him by the medical community and others around him. Subsequently, he resisted ongoing rehabilitation and the implementation of compensations and modifications to support him following his injury. Again this may also have implications for therapists suggesting memory compensations. It may be that

for individuals who believe that those memory compensations suggested by therapists do not fit their sense of self or fit their lifestyle, feel that therapists are trying to impose a new identity upon them, which may ultimately be resisted. In addition, Nochi (1998) highlights that following ABI people attempt to selectively present 'normal' parts of themselves and Gracey, Evans and Malley (2009) propose that people may adopt coping strategies that reduce discrepancies in one's self identity following ABI. As can be seen in the present thesis the incorporation of memory compensations into an individual's preferred self image can be difficult. Hoogerdijk et al. (2011) note that self identity is closely tied to what we do, therefore, if someone does not identify their 'normal' self as using a diary for example, it is possible that they will be resistant to this as a memory compensation. It is therefore important to understand how an individual's sense and development of the self following ABI impacts upon the incorporation of memory aids into their daily life, as this may have a fundamental impact on whether people will use them or not.

A sense of self and self identity following ABI and the impact that the use of memory compensations has upon it is an important issue and has implications not only for those individuals who have survived a brain injury but also for those who work in rehabilitation services. By finding an aid that fits an individual's lifestyle and is in keeping with their sense of self this can have an important impact upon their independence and this is demonstrated in Chapter 4 of this thesis. The single case study described in Chapter 4 draws attention to the implementation of a memory aid by an individual (TK) who held negative beliefs about memory compensations. This study highlights that TK's beliefs about memory aids was addressed, not by treating his beliefs per se, but by simply providing an aid that suited his identity. By doing this it

addressed these issues indirectly as TK was able to incorporate the memory aid into his sense of self following his brain injury and therefore his daily routine.

Future research could concentrate on what it means to incorporate the use of memory compensations into one's daily routine and lifestyle following ABI. Understanding how people redevelop their sense of self following ABI is a relatively new area of research and as no research as specifically looked at the impact using memory aids per se has on one's self identity, a qualitative study using IPA could ascertain people's experiences of what it is like to have to develop a new self identity, enabling researchers to focus on understanding how people incorporate aids and strategies within their new sense of self and lifestyle. In addition, further research could look at cultural implications of using memory aids following ABI. It has already been highlighted in Chapter 4 that cultural value systems are significantly associated with rehabilitation outcomes following ABI (Saltapidas & Ponsford, 2008). A qualitative research study could also address how culture impacts on an individual's beliefs about the use of memory compensations and the development of a new sense of self following ABI. This would enable researchers to identify whether cultural beliefs and differences influence the uptake of memory compensations. For example it could identify whether the use of memory compensations was deemed shameful or draws unwanted attention to an individual and their family.

Upon reflection, I identified some changes that I would make to this thesis if I were to undertake it again, both of which would be within Chapter 2. The first change I would make would be to explore whether there was a relationship between the factors identified by Wilson and Watson (1996) and by Evans et al. (2003) (such as: absence of marked cognitive deficits; absence of marked executive deficit; above average pre-

morbid IQ; the use of five or more aids premorbidly; using at least two more aids post injury than premorbidly; undergone inpatient rehabilitation; undergone postacute specialist rehabilitation; mood; attentional skills and current general intellectual ability) and the use of three or more aids or six or more aids, so that direct comparisons to their findings could be made. This would entail administering neuropsychological assessments such as the Rivermead Behavioural Memory Test (Wilson et al., 1985); the Test of Everyday Attention Map Search (Robertson, Ward, Ridgeway, & Nimmo-Smith, 1994); Dysexecutive (DEX) Questionnaire from the Behavioural Assessment of Dysexecutive Syndrome (Wilson, Alderman, Burgess, Emslie, & Evans, 1996); the General Health Questionnaire 12 (GHQ; Goldberg, 1972) as well as collecting additional data such as premorbid use of aids. In addition, I would also ask a significant other to verify whether the aids and strategies participants identified in the MSQ, was an accurate representation of their use. I feel that these changes would make the quantitative study more robust and would improve the thesis. I would not make any other changes to the overall thesis. This thesis has used mixed methods to explore the factors that influence the use of memory compensations following ABI. As noted throughout all three studies, a key component in the successful uptake of memory compensations is the need to 'fit' the aid to an individual's lifestyle and a sense of self and future research may wish to look at the implications of this. This thesis provides optimism for those who may initially be considered unlikely to use memory compensations as it may be that the key is to 'fit' the aid to the individual.

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APPENDIX

APPENDIX A

Checklist criteria for critically appraising qualitative and quantitative studies.

Checklist based on Sale & Brazil 2004 quality criteria	
QUANTITATIVE METHODS	QUALITATIVE METHODS
<p>SECTION A</p> <ol style="list-style-type: none"> 1. Informed consent stated 2. Ethical review stated 3. Statement that confidentiality protected <p>SECTION B</p> <ol style="list-style-type: none"> 4. Statement of purpose of study/hypotheses 5. Study objective explicitly stated/described 6. Description of intervention if appropriate 7. Study design stated 8. Outcome measures defined 9. Sampling selection described & study population stated 10. Inclusion/exclusion criteria stated 11. Control/comparison group described if appropriate 12. Statement about attrition/non respondents if appropriate <p>SECTION C</p> <ol style="list-style-type: none"> 13. Data gathering procedures described 14. Data collection methods stated <p>SECTION D</p> <ol style="list-style-type: none"> 15. Statistical procedures defined 16. Power calculation to assess adequacy of sample size, or sample size calculated for adequate power 17. <i>p</i> values stated Clinical and statistical significance acknowledged. 	<p>SECTION A</p> <ol style="list-style-type: none"> 1. Informed consent stated 2. Ethical review stated 3. Statement that confidentiality protected <p>SECTION B</p> <ol style="list-style-type: none"> 4. Statement of purpose of study/hypotheses 5. Study objective explicitly stated/described 6. Rationale for qualitative methods 7. Description of study context if appropriate 8. Sample procedure described 9. Description of participants <p>SECTION C</p> <ol style="list-style-type: none"> 10. Data gathering procedures described 11. Audio taping & transcription stated 12. Data analysis/coding described 13. External audit of data/triangulation for validation 14. Statement about researchers assumptions

QUANTITATIVE METHODS	Good quality = a total of 14-17 criteria met
	Acceptable quality = a total of 9-13 criteria met
	Poor quality = a total of 8 or less criteria met
QUALITATIVE METHODS	Good quality = a total of 12-14 criteria met
	Acceptable quality = a total 8-11 criteria met
	Poor quality = a total of 7 or less criteria met

Tate et al.'s 2008 quality criteria for single case experimental design studies

1) Clinical history	Study provides critical information regarding demographic & injury characteristics of research subject(s)
2) Target behaviour	Identifies a precise, repeatable and operationally defined target behaviour that can be used to measure treatment success
3) Design	The study allows for examination of cause and effect relationships to demonstrate treatment efficacy
4) Baseline	To establish that sufficient sampling of behaviour had occurred during pre-treatment period to provide an adequate baseline measure
5) Sampling Behaviour during treatment	To establish sufficient sampling of behaviour during treatment phase has occurred to differentiate a treatment response from fluctuations in behaviour that may have occurred at baseline.
6) Raw data record	To provide an accurate representation of the variability of the target behaviour
7) Inter-rater reliability	To determine if the target behaviour measure is reliable and collected in a consistent manner
8) Independent of assessors	To reduce assessment bias- someone who is not involved in the study to provide an evaluation of the patients
9) Statistical analysis	To demonstrate the effectiveness of the treatment by statistically comparing results over the study phases
10) Replication	Demonstrating that the application and results of the therapy are not limited to a specific individual or situation
11) Generalisation	To demonstrate the functional utility of the treatment in extending beyond target behaviours or therapy environment into other areas of the individual's life.

SINGLE CASE EXPERIMENTAL DESIGN STUDIES	Good quality = a total of 9-11 criteria met
	Acceptable quality = a total 7-8 criteria met
	Poor quality = a total of 6 or less criteria met

APPENDIX C

Participant information sheet and consent form.

APPENDIX C~ Qualitative Study (Chapter 2)



UNIVERSITY OF
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School of Psychology
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Birmingham B15 2TT
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Telephone 0121 414 4932
Fax 0121 414 4897

Participant Information Sheet

**Title:- Factors affecting memory strategy use in people with
acquired brain injury**

Invitation

I would like to invite you to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and talk to others about the study if you wish. Please ask if anything is not clear or if you would like more information.

What is the purpose of the study

The purpose of the study is to find out what makes people with memory problems more likely to use memory strategies or aids. We hope that by doing this we can help therapists choose the right strategy for the right person in the future.

Why have I been invited?

I am inviting people to take part who have day to day memory problems as a result of a brain injury and who are attending a rehabilitation centre. You have been invited to take part in the study because your key worker thinks that you might be suitable for the study.

Do I have to take part?

No, taking part is entirely your choice and even if you do decide to take part, you can still change your mind at any time without giving a reason. I will ask you to sign a consent form to say that you want to take part; however this does not commit you to staying in the study if you do not wish to.

What will happen if I take part?

If you take part in the study you will be given more details about the research and if you are still happy to take part I will ask you to sign a consent form. We will then set a time to meet at the rehabilitation centre or at your home if that is easier.

What will I have to do?

I will ask you some questions about your views of memory strategies and this interview will be recorded. The interview will last approximately an hour. I will also carry out a brief test of your memory that takes around 10 minutes and involves learning a list of words. I will also ask you to fill in a questionnaire about any day to day memory problems you have which should take around 10 minutes.

Your recorded interview will then be typed up and the tape will be destroyed. You should only need to be interviewed once, unless you would prefer to split the time into two sessions. All together the interview and assessments will take around 80 minutes. You can have a break at any time during the session. At the end of the session you will have the opportunity to ask any questions you wish to. After this you will not be asked to meet me again.

What are the possible disadvantages and risks of taking part?

The interview and assessments could be tiring as they take 80 minutes but we will have a break if this is the case. If the interview makes you feel frustrated or uncomfortable you will have the choice of ending it, and with your permission I will ask your key worker or one of your other therapists to discuss anything that has arisen for you.

What are the possible benefits of taking part?

It is unlikely that the study will help you personally. However, it is hoped that the results of this study will help therapists gain better insight into why people with memory problems do or do not use memory strategies to compensate for their problems. This information will help therapists to decide what support to offer people in the future.

What happens when the research stops?

Once the research has finished and all interviews have been done you will be given a written summary sheet of the results of the study.

What if there are any problems?

As mentioned before, you can pull out of the study at any time. If you have a problem, concern or complaint you should contact either:

The researchers:

[name]	[name]
[address]	[address]
[email]	[email]

Or if you wish to make a complaint to someone who is not involved in the research study, you may contact the rehabilitation services PALS representative;

PALS:

[name]	[name]
[address]	[address]
[email]	[email]

What will happen if I don't want to carry on with the study?

You can choose to withdraw at any stage. With your permission, we may continue to use any information that has been obtained with your consent.

Will taking part be kept confidential?

All information collected will be kept confidential and in line with the Data Protection Act. Your name will be replaced by a code so that information kept on a computer will not identify you and if you mention any name in your interview, these will be removed. The computer will also be password protected so that only the research team (Vicky Baldwin and her supervisor, Theresa

Powell) will be able to access it. Your name and personal details will not be mentioned anywhere in any reports about the study in order to protect your identity.

Involvement of your General Practitioner (GP)/ Family Doctor.

It is not necessary to tell your GP that you are taking part but we will send a letter to your Rehabilitation Consultant explaining that taking part should not affect any aspect of your rehabilitation.

What will happen to the results of the research?

The study will form part of my PhD thesis which will be submitted to the University of Birmingham. It is hoped that the study will also be published in an academic journal and results will also be presented at conferences on brain injury.

Who is organising and funding the research?

The research is funded by the School of Psychology, University of Birmingham and [redacted] Rehabilitation Centre.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee in order to protect your safety, rights, wellbeing and dignity. In this case South Birmingham Research Ethics Committee have approved the study.

Further information and contact details

If you require any further information please contact:

[name]	[name]
[address]	[address]
[email]	[email]



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Edgbaston
Birmingham B15 2TT
United Kingdom
Telephone 0121 414 4932
Fax 0121 414 4897

Centre Number:

Study Number:

Patient Identification Number for Study:

CONSENT FORM

Title of Project: Factors affecting memory strategy use in people with acquired brain injury

Name of Researcher: Vicky Baldwin

**Please
initial
box**

1. I confirm I have read and that I have also had the information sheet dated 05/05/2009 (Version 2) for the above study fully explained to me. I am fully aware of what is required from me and understand all procedures. I have had the time and opportunity to consider the information, ask any questions and had these answered satisfactorily.
2. I am fully aware that my participation is voluntary and that I may withdraw from the study at any time and without giving any reason, and that my medical care or legal rights will not be affected.
3. I understand that relevant sections of my medical notes and the data collected during the study may be looked at by individuals from the University of Birmingham, regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records and study data.
4. I agree to take part in the above study
5. I agree that information and resultant data collected can be published and that personal details will be made anonymous within the paper if published.

Name: _____ Signature: _____ Date: _____

Researcher: _____ Signature: _____ Date: _____

Name of person taking: _____ Signature: _____ Date: _____
consent (if different from Researcher)

When complete, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes



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Centre Number:

Study Number:

Patient Identification Number for Study:

CONSENT FORM

Title of Project: Factors affecting memory strategy use in people with acquired brain injury

Name of Researcher: Vicky Baldwin

**Please
initial
box**

1. I confirm I have read and that I have also had the information sheet dated 05/05/2009 (Version 2) for the above study fully explained to me. I am fully aware of what is required from me and understand all procedures. I have had the time and opportunity to consider the information, ask any questions and had these answered satisfactorily.
2. I am fully aware that my participation is voluntary and that I may withdraw from the study at any time and without giving any reason, and that my medical care or legal rights will not be affected.
3. I understand that relevant sections of my medical notes and the data collected during the study may be looked at by individuals from the University of Birmingham, regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records and study data.
4. I agree to take part in the above study
5. I agree that information and resultant data collected can be published and that personal details will be made anonymous within the paper if published.

Name: _____ Signature: _____ Date: _____

Researcher: _____ Signature: _____ Date: _____

Name of person taking: _____ Signature: _____ Date: _____
consent (if different from Researcher)

When complete, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes

APPENDIX C~ Quantitative Study (Chapter 3)



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Participant Information Sheet

**Title:- Factors affecting memory strategy use in people with
acquired brain injury**

Invitation

We would like to invite you to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Please talk to others about the study if you wish. Please ask if anything is not clear or if you would like more information. Please take your time to decide whether or not you wish to take part.

What is the purpose of the study

The purpose of the study is to find out what makes people with memory problems more likely to use compensatory memory strategies or aids. We hope that by doing this we can help therapists choose the right strategy for the right person.

Why have I been invited?

This research study is specifically interested in adults who have everyday memory problems as a result of an acquired brain injury and who are currently attending a rehabilitation centre. You have been invited to take part in the study because your key worker has identified you as a suitable participant in this research study.

Do I have to take part?

No. It is entirely your choice whether or not you want to take part. Even if you do decide to take part, you can pull out at any time without giving a reason. I will ask you to sign a consent form to say that you want to take part; however this does not commit you to the study.

What will happen if I take part?

If you take part in the study you will be provided with further details regarding the purpose of the research and if you are still happy to take part I will then ask you to sign a consent form. A time to meet at the rehabilitation centre, or if it is more convenient at your home, will then be arranged. During this time you will be asked to participate in a series of questionnaires which will assess your views about your memory and memory strategy use. I will also carry out some brief assessments to assess your memory.

You should only need to be involved in one questionnaire session, unless you would prefer to split the time into two sessions. Altogether the questionnaire session and assessments will take approximately 95 minutes. You can have a break at any time during the session. At the end of the session you will have the opportunity to ask any questions you wish to. After this you will not be asked to meet me again.

If you take part we would also like to contact your partner/significant other to ask them to complete a short questionnaire about how often they think you make memory slips, as we wish to compare your views of your memory problems with their views. The questionnaire they will complete is similar to one of the questionnaires you will complete during the questionnaire session. However, we will only contact them if you give us permission to do so.

What will I have to do?

All you have to do complete a series of questionnaires about your views of your memory and of using memory strategies as well as completing two memory assessments.

What are the possible disadvantages and risks of taking part?

Although there are no predicted disadvantages or risks to taking part, you will be required to spend 95 minutes of your time completing questionnaires and assessments. It is possible that participating may be tiring or you may feel frustrated or uncomfortable talking about some of the issues. If this happens you will have the choice of terminating the session, and with your permission I will ask your key worker or one of your other therapists to discuss anything that has arisen for you.

What are the possible benefits of taking part?

We are not able to promise that the study will directly help or benefit you personally. However, it is hoped that the information obtained from this study will help therapists gain a better insight into the reasons why people with an acquired brain injury do or do not use memory strategies to compensate for memory problems. This information may help therapists better decide on what support they offer people in the future.

What happens when the research stops?

Once the research has finished and all questionnaire sessions have been undertaken you will be given a written summary sheet of the results of the study.

What if there are any problems?

As mentioned before, you can pull out of the study at any time. If you have a problem, concern or complaint you should contact either:

The researchers:

[name]	[name]
[address]	[address]
[email]	[email]

Or if you wish to make a complaint to someone who is not involved in the research study, you may contact the rehabilitation services PALS representative;

PALS:	
[name]	[name]
[address]	[address]
[email]	[email]

What will happen if I don't want to carry on with the study?

You can choose to withdraw at any stage. With your permission, we may continue to use any information that has been obtained with your consent.

Will taking part be kept confidential?

All information collected will be kept confidential and in line with the Data Protection Act. Any information that is entered onto a computer will be entered in such a way

that your name can not be linked with the information. Any personal information will be solely identified by a code so you are kept anonymous. The computer will also be password protected meaning that only I will be able to access it. Your name and personal details will not be mentioned anywhere in the study in order to protect your identity.


Involvement of your General Practitioner (GP)/ Family Doctor.

It is not necessary to notify your General Practitioner (GP)/ Family Doctor of your participation in the study. However the Rehabilitation Consultant will be notified by letter of your participation, ensuring them that the rehabilitation and standard of care you are receiving will not be affected in any way whilst participating in this research.

What will happen to the results of the research?

The study will form part of my PhD thesis which will be submitted to the University of Birmingham. It is hoped that the study will also be published in an academic journal and results will also be presented at conferences on brain injury.

Who is organising and funding the research?

The research is funded by the School of Psychology, University of Birmingham and  Rehabilitation Centre.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by South Birmingham Research Ethics Committee.

Further information and contact details

If you require any further information please contact:

[name]	[name]
[address]	[address]
[email]	[email]



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Telephone 0121 414 4932
Fax 0121 414 4897

Centre Number:

Study Number:

Patient Identification Number for Study:

CONSENT FORM

Title of Project: **Factors affecting memory strategy use in people with acquired brain injury**

Name of Researcher: Vicky Baldwin

- | | |
|---|-----------------------------------|
| | Please
initial
box |
| 1. I confirm I have read and that I have also had the information sheet dated 15 th /6/2010 (Version 3) for the above study fully explained to me. I am fully aware of what is required from me and understand all procedures. I have had the time and opportunity to consider the information, ask any questions and had these answered satisfactorily. | <input type="checkbox"/> |
| 2. I am fully aware that my participation is voluntary and that I may withdraw from the study at any time and without giving any reason, and that my medical care or legal rights will not be affected. | <input type="checkbox"/> |
| 3. I understand that relevant sections of my medical notes and the data collected during the study may be looked at by individuals from the University of Birmingham, regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records and study data. | <input type="checkbox"/> |
| 4. I understand and agree that the Rehabilitation Consultant will be made aware of my participation in the above study. | <input type="checkbox"/> |
| 5. I agree to take part in the above study. | <input type="checkbox"/> |

6. I agree that the researcher may contact my partner/relative and ask them to complete a short questionnaire about my memory problems.

7. I agree that information and resultant data collected can be published and that personal details will be made anonymous within the paper if published.

Name: _____ Signature: _____ Date: _____

Researcher: _____ Signature: _____ Date: _____

Name of person taking: _____ Signature: _____ Date: _____
consent (if different from Researcher)

When complete, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes



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Participant Information Sheet (Relative/ significant other)

**Title:- Factors affecting memory strategy use in people with
acquired brain injury**

Invitation

We would like to invite you to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Please talk to others about the study if you wish. Please contact the researcher (contact details at the end of this sheet) if anything is not clear or if you would like more information. Please take your time to decide whether or not you wish to take part.

What is the purpose of the study

The purpose of the study is to find out why people with memory problems do or do not use memory strategies or aids. We hope that by doing this we can help rehabilitation therapists to have a greater understanding of how to encourage people with memory impairments to use memory aids/strategies.

Why have I been invited?

This research study is specifically interested in adults who have everyday memory problems as a result of an acquired brain injury and who are currently attending a rehabilitation centre. You have been invited to take part in the study because your partner/relative is currently attending a rehabilitation centre and has also agreed to take part in this research; we would therefore like you to complete a small questionnaire (13 questions) about your partner/relatives everyday memory problems.

Do I have to take part?

No. It is entirely your choice whether or not you want to take part. Even if you do decide to take part, you can pull out at any time without giving a reason. I will ask you to sign a consent form to say that you want to take part; however this does not commit you to the study.

What will happen if I take part?

If you take part in the study I will ask you to sign a consent form and complete a short (13 item) questionnaire about your relative/significant other memory problems.

What will I have to do?

All you have to do is complete the questionnaire about your partner/relatives memory problems, indicating how often different types of memory slips have occurred in the last month. This should take no more than 5 minutes.

What are the possible disadvantages and risks of taking part?

There are no disadvantages or risks to taking part in the research. All data will be made anonymous.

What are the possible benefits of taking part?

It is hoped that the information obtained from this study will help therapists gain a better insight into the reasons why people with an acquired brain injury do or do not use memory strategies to compensate for memory problems. Hopefully they will then be able to provide better support to people with memory problems in future.

What happens when the research stops?

Once the research has finished and all questionnaire sessions have been undertaken you will be given a written summary sheet of the results of the study.

What if there are any problems?

As mentioned before, you can withdraw from the study at any time. If you have a problem, concern or complaint you should contact either:

The researchers:

[name]	[name]
[address]	[address]
[email]	[email]

Or if you wish to make a complaint to someone who is not involved in the research study, you may contact the rehabilitation services PALS representative;

PALS:

[name]	[name]
[address]	[address]
[email]	[email]

What will happen if I don't want to carry on with the study?

You can change your mind about taking part at any time, or ask the researchers to withdraw your response from the study at any stage up until the point we analyse the data (December 2010).

Will taking part be kept confidential?


All information collected will be kept confidential and in line with the Data Protection Act. Any information that is entered onto a computer will be entered in such a way that your name cannot be linked with the information. Your questionnaire will only be identified by a code so your response is anonymous. The computer will also be

password protected meaning that only I will be able to access it. Your name and personal details will not be mentioned anywhere in the study in order to protect your identity.

What will happen to the results of the research?

The study will form part of my PhD thesis which will be submitted to the University of Birmingham. It is hoped that the study will also be published in an academic journal and results will also be presented at conferences on brain injury.

Who is organising and funding the research?

The research is funded by the School of Psychology, University of Birmingham and  Rehabilitation Centre.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by South Birmingham Research Ethics Committee.

Further information and contact details

If you require any further information please contact:

[name]	[name]
[address]	[address]
[email]	[email]



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Fax 0121 414 4897

Centre Number:

Study Number:

Participant Identification Number for Study:

CONSENT FORM (Relative/ Significant other)

Title of Project: **Factors affecting memory strategy use in people with acquired brain injury.**

Name of Researcher: Vicky Baldwin

**Please
initial
box**

1. I confirm I have read and that I have also had the information sheet dated 15th/6/2010 (Version 1). I am fully aware of what is required from me and understand all procedures. I have had the time and opportunity to consider the information and any questions I have had have been answered satisfactorily.

2. I am fully aware that my participation is voluntary and that I may withdraw from the study at any time and without giving any reason.

3. I agree to take part in the above study

4. I agree that information and resultant data collected can be published and that personal details will be made anonymous within the paper if published.

Name: _____ Signature: _____ Date: _____

Researcher: _____ Signature: _____ Date: _____

Name of person taking: _____ Signature: _____ Date: _____
consent (if different from Researcher)

When complete, 1 (original) for participant; 1 for researcher site file;



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Centre Number:

Study Number:

Participant Identification Number for Study:

CONSENT FORM (Relative/ Significant other)

Title of Project: **Factors affecting memory strategy use in people with acquired brain injury.**

Name of Researcher: Vicky Baldwin

**Please
initial
box**

1. I confirm I have read and that I have also had the information sheet dated 15th/6/2010 (Version 1). I am fully aware of what is required from me and understand all procedures. I have had the time and opportunity to consider the information and any questions I have had have been answered satisfactorily.

2. I am fully aware that my participation is voluntary and that I may withdraw from the study at any time and without giving any reason.

3. I agree to take part in the above study

4. I agree that information and resultant data collected can be published and that personal details will be made anonymous within the paper if published.

Name: _____ Signature: _____ Date: _____

Researcher: _____ Signature: _____ Date: _____

Name of person taking: _____ Signature: _____ Date: _____
consent (if different from Researcher)

When complete, 1 (original) for participant; 1 for researcher site file;

APPENDIX C~ Single Case Study (Chapter 4)



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School of Psychology

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Birmingham B15 2TT
United Kingdom
Telephone 0121 414 4932
Fax 0121 414 4897

Participant Information Sheet

**Title:- Factors affecting memory strategy use in people with
acquired brain injury**

Invitation

We would like to invite you to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Please talk to others about the study if you wish. Please ask if anything is not clear or if you would like more information. Please take your time to decide whether or not you wish to take part.

What is the purpose of the study

The purpose of the study is to help someone who has difficulties remembering things learn how to use a carefully chosen memory aid and to monitor how much it reduces their memory slips.

Why have I been invited?

This research study is specifically interested in adults who have everyday memory problems as a result of an acquired brain injury and who are currently attending a rehabilitation centre. You have been invited to take part in the study because your key worker has identified you as a suitable participant in this research study.

Do I have to take part?

No. It is entirely your choice whether or not you want to take part. Even if you do decide to take part, you can pull out at any time without giving a reason. I will ask you to sign a consent form to say that you want to take part; however this does not commit you to the study.

What will happen if I take part?

If you wish to take part you should tell your key worker and we will then arrange a time to meet. I will explain the study in more detail and you will be able to ask questions. If you are still happy to take part I will then ask you to sign a consent form.

There are then three phases to the study: 1) preparation for using a memory aid 2) a period of monitoring your memory slips without using a memory aid and 3) a period of monitoring your memory slips with the memory aid (to see whether it makes a difference).

If you take part we would also like to contact your partner/significant other to ask them to complete a short questionnaire about how often they think you make memory slips, as we wish to compare your views of your memory problems with their views. The questionnaire they will complete is similar to one of the questionnaires you will complete during the initial questionnaire session. We would also like to ask them to help support you whilst you are using your chosen memory aid at home, however, we will only contact them if you give us permission to do so.

What will I have to do?

As part of the preparation for using a memory aid you will be asked to complete two short questionnaires that will take around 20 minutes. Then we will spend some time together deciding whether you would like to use a memory aid and if so, what kind of memory aid you would like to use. We may also ask one of the Clinical Psychologists at [REDACTED] for their help with this. If and when you feel ready to use a memory aid but before you start using your chosen aid, we will ask you to complete one of the questionnaires again.

Once you have identified the kind of memory aid you want to use and what it will help you remember, we will spend around two weeks monitoring how often you forget to do those things before you start to use the memory aid.

You will then learn how to use your chosen memory aid with the help of the researcher, and we will continue to record whether any memory slips still occur.

What are the possible disadvantages and risks of taking part?

It is possible that participating may be tiring or you may feel uncomfortable talking about some of the issues that arise during the preparation phase of the study. If this happens you will have the choice of terminating the sessions, and with your permission I will ask a Clinical Psychologist or your key worker to discuss anything that has arisen for you. A further possible disadvantage of taking part is that you may find the memory aid unsuitable or too complicated to use. If this occurs using the memory aid will be stopped immediately and if you wish an alternative or more appropriate memory aid will be found.

What are the possible benefits of taking part?

Unfortunately, we cannot guarantee that your new memory strategy will make a difference but we hope that through careful preparation and by using your chosen memory aid regularly, this will result in reducing the number of memory slips you make.

What happens when the research stops?

Once you have been using your chosen memory aid for a number of weeks and the recording of memory slips has stopped, you will be given a summary sheet that will show you whether using the memory aid has helped you to remember things. Once the research has finished, if you wish to, you can continue to use your chosen memory aid to help you.

What if there are any problems?

As mentioned before, you can pull out of the study at any time. If you have a problem, concern or complaint you should contact either:

The researchers:

[name]	[name]
[address]	[address]
[email]	[email]

Or if you wish to make a complaint to someone who is not involved in the research study, you may contact the rehabilitation services PALS patient representative;

PALS:

[name]

[address]

[email]

What will happen if I don't want to carry on with the study?

You can choose to withdraw at any stage. With your permission, we may continue to use any information that has been obtained with your consent.

Will taking part be kept confidential?

All information collected will be kept confidential and in line with the Data Protection Act. Any information that is entered onto a computer will be entered in such a way that your name can not be linked with the information. Any personal information will be solely identified by a code so you are kept anonymous. The computer will also be password protected meaning that only I will be able to access it. Your name and personal details will not be mentioned anywhere in the study in order to protect your identity.

Involvement of your General Practitioner (GP)/ Family Doctor.

It is not necessary to notify your General Practitioner (GP)/ Family Doctor of your participation in the study. However the Rehabilitation Consultant will be notified by letter of your participation, ensuring them that the rehabilitation and standard of care you are receiving will not be affected in any way whilst participating in this research.

What will happen to the results of the research?

The study will form part of my PhD thesis which will be submitted to the University of Birmingham. It is hoped that the study will also be published in an academic journal and results will also be presented at conferences on brain injury.

Who is organising and funding the research?

The research is funded by the School of Psychology at the University of Birmingham and [REDACTED] Rehabilitation Centre.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by South Birmingham Research Ethics Committee.

Further information and contact details

If you require any further information please contact:

[name]	[name]
[address]	[address]
[email]	[email]



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Telephone 0121 414 4932
Fax 0121 414 4897

Centre Number:

Study Number:

Patient Identification Number for Study:

CONSENT FORM

Title of Project: **Factors affecting memory strategy use in people with acquired brain injury**

Name of Researcher: Vicky Baldwin

1. I confirm I have read and that I have also had the information sheet dated 8th/10/2010 (Version 4) for the above study fully explained to me. I am fully aware of what is required from me and understand all procedures. I have had the time and opportunity to consider the information, ask any questions and had these answered satisfactorily.
2. I am fully aware that my participation is voluntary and that I may withdraw from the study at any time and without giving any reason, and that my medical care or legal rights will not be affected.
3. I understand that relevant sections of my medical notes and the data collected during the study may be looked at by individuals from the University of Birmingham, regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records and study data.
4. I understand and agree that the Rehabilitation Consultant will be made aware of my participation in the above study.

**Please
initial
box**

5. I agree to take part in the above study.

6. I agree that the researcher may contact my partner/relative and ask them to complete a short questionnaire about my memory problems and that they may be asked to support me whilst I am using my chosen memory aid.

7. I agree that information and resultant data collected can be published and that personal details will be made anonymous within the paper if published.

Name: _____ Signature: _____ Date: _____

Researcher: _____ Signature: _____ Date: _____

Name of person taking: _____ Signature: _____ Date: _____
consent (if different from Researcher)

When complete, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes



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Participant Information Sheet (Relative/ significant other)

**Title:- Factors affecting memory strategy use in people with
acquired brain injury**

Invitation

We would like to invite you to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Please talk to others about the study if you wish. Please contact the researcher (contact details at the end of this sheet) if anything is not clear or if you would like more information. Please take your time to decide whether or not you wish to take part.

What is the purpose of the study

The purpose of the study is to help someone who has memory problems learn how to use a chosen memory aid to help them remember the things they forget.

Why have I been invited?

This research study is specifically interested in adults who have everyday memory problems as a result of an acquired brain injury and who are currently attending a rehabilitation centre. You have been invited to take part in the study because your partner/relative has agreed to take part in this research. We would therefore like you to complete a small questionnaire (13 questions) about your partner/relatives everyday memory problems. If it is appropriate, you may also be asked to support them at home whilst they are learning to use their chosen memory aid.

Do I have to take part?

No. It is entirely your choice whether or not you want to take part. Even if you do decide to take part, you can pull out at any time without giving a reason. I will ask you to sign a consent form to say that you want to take part; however this does not commit you to the study.

What will happen if I take part?

I will ask you to sign a consent form and to complete a short (13 item) questionnaire about your relative/significant other's memory problems. Later on, when they are learning to use the memory aid, you may be asked to support them at home with this.

What will I have to do?

You will have to complete a questionnaire about your partner/relatives memory problems, indicating how often different types of memory slips have occurred in the last month. This should take no more than 5 minutes. Later on, I may ask you for example, to prompt and encourage your relative to use their memory aid at home when necessary.

What are the possible disadvantages and risks of taking part?

There are no predicted disadvantages or risks for you in taking part. However, if any issues should arise you will be able to discuss these with the researcher and a Clinical Psychologist at the rehabilitation centre.

What are the possible benefits of taking part?

We are not able to promise that the study will directly help or benefit you or your relative/partner personally. However, it is hoped that using a memory aid will result in reducing the number of memory slips that your relative/partner makes.

What happens when the research stops?

Once your partner/relative has been using their chosen memory aid for a number of weeks and the recording of memory slips has stopped, you will both be given a summary sheet that will show you whether using the memory aid has helped them to remember things.

What if there are any problems?

As mentioned before, you can withdraw from the study at any time. If you have a problem, concern or complaint you should contact either:

The researchers:

[name]	[name]
[address]	[address]
[email]	[email]

Or if you wish to make a complaint to someone who is not involved in the research study, you may contact the rehabilitation services PALS representative;

PALS:
[name]
[address]
[email]

What will happen if I don't want to carry on with the study?

You can change your mind about taking part at any time. With your permission, we may continue to use any data that has been collected up to that point.

Will taking part be kept confidential?


All information collected will be kept confidential and in line with the Data Protection Act. Any information that is entered onto a computer will be entered in such a way that your name cannot be linked with the information. Your questionnaire will only be identified by a code so your response is anonymous. The computer will also be password protected meaning that only I will be able to access it. Your name and

personal details will not be mentioned anywhere in the study in order to protect your identity.

What will happen to the results of the research?

The study will form part of my PhD thesis which will be submitted to the University of Birmingham. It is hoped that the study will also be published in an academic journal and results will also be presented at conferences on brain injury.

Who is organising and funding the research?

The research is funded by the School of Psychology, University of Birmingham and  Rehabilitation Centre.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by South Birmingham Research Ethics Committee.

Further information and contact details

If you require any further information please contact:

[name]	[name]
[address]	[address]
[email]	[email]

Everyday Memory Questionnaire

Instructions

The 28 statements listed below are about forgetting things, something everyone does to an extent. I would like you to tick the box which best indicates how often each statement has happened to you over the last 3 months.

For example on the first statement, if you think that you forget where you put things around the house more than once a day you would tick the box 'More than once a day.'

	Not at all in the last 3 months	About once in the last three months	More than once in the last three months, but less than once a month	About once a month	More than once a month but less than once a week	About once a week	More than once a week but less than once a day	About once a day	More than once a day
Forgetting where you have put something. Losing things around the house.									
Failing to recognise places that you are told you have been before.									
Finding a television story difficult to follow.									

	Not at all in the last 3 months	About once in the last three months	More than once in the last three months, but less than once a month	About once a month	More than once a month but less than once a week	About once a week	More than once a week but less than once a day	About once a day	More than once a day
Not remembering a change in your daily routine such as a change in the place where something is kept or a change in the time something happens. Following your old routine by mistake.									
Having to go back to check whether you have done something you meant to do.									
Forgetting when it was that something happened; for example, whether it was yesterday or last week.									
Completely forgetting to take things with you, or leaving things behind and having to go back and fetch them.									

	Not at all in the last 3 months	About once in the last three months	More than once in the last three months, but less than once a month	About once a month	More than once a month but less than once a week	About once a week	More than once a week but less than once a day	About once a day	More than once a day
Forgetting you were told something yesterday or a few days ago, and maybe having to be reminded about it.									
Starting to read something (a book or an article in a newspaper or magazine) without realising you have already read it before.									
Letting yourself ramble on, to speak about unimportant or irrelevant things.									
Failing to recognise, by sight, close friends or relatives who you meet frequently.									

	Not at all in the last 3 months	About once in the last three months	More than once in the last three months, but less than once a month	About once a month	More than once a month but less than once a week	About once a week	More than once a week but less than once a day	About once a day	More than once a day
Having difficulty in picking up a new skill; for example, finding it hard to learn a new game, or to work some new gadget after you have practised it once or twice									
Finding that a word is 'on the tip of your tongue'. You know what it is but cannot quite find it.									
Completely forgetting to do things you said you would do and you planned to do									
Forgetting important details of what you did or what happened to you the day before.									

	Not at all in the last 3 months	About once in the last three months	More than once in the last three months, but less than once a month	About once a month	More than once a month but less than once a week	About once a week	More than once a week but less than once a day	About once a day	More than once a day
When talking to someone, forgetting what you have just said. Maybe saying 'What was I just talking about'?									
When reading a newspaper or magazine being unable to follow the thread of a story; losing track of what it is about.									
Forgetting to tell someone something important. Perhaps forgetting to pass on a message or remind someone of something.									
Forgetting important details about yourself; for example, your birthdate, or where you live.									

	Not at all in the last 3 months	About once in the last three months	More than once in the last three months, but less than once a month	About once a month	More than once a month but less than once a week	About once a week	More than once a week but less than once a day	About once a day	More than once a day
Getting the details of what someone has told you mixed up and confused.									
Telling someone a story or joke that you have told them once already.									
Forgetting details of things you do regularly, whether at home or at work. For example, forgetting details of what to do, or forgetting at what time to do it.									
Finding that the faces of famous people seen on television or in photographs look unfamiliar.									
Forgetting where things are normally kept or looking for them in the wrong place.									

	Not at all in the last 3 months	About once in the last three months	More than once in the last three months, but less than once a month	About once a month	More than once a month but less than once a week	About once a week	More than once a week but less than once a day	About once a day	More than once a day
Getting lost or turning in the wrong direction on a journey, on a walk or in a building where you have <i>often</i> been before.									
Getting lost or turning in the wrong direction on a journey, on a walk or in a building where you have <i>only been once or twice</i> before.									
Doing some routine thing twice by mistake. For example, putting two lots of tea in a teapot or going to brush/comb your hair when you have just done so.									
Repeating to someone what you have just told them or asking the same question twice.									

Everyday Memory Questionnaire-r

Instructions

The 13 statements listed below are about forgetting things, something everyone does to an extent. I would like you to tick the box that best indicates how often each statement has happened to you over the last month.

For example on the first statement, if you think that you forget where you put things around the house more than once a day you would tick the box 'once or more in a day.'

	Once or less in the last month	More than once in the last month but less than once a week	About once a week	More than once a week but less than once a day	Once or more a day
1) Having to go back to check whether you have done something that you should have done.					
2) Forgetting when it was that something happened; for example, whether it was yesterday or last week.					
3) Forgetting that you were told something yesterday or a few days ago, and maybe having to be reminded about it.					
4) Starting to read something (a book or an article in a newspaper or magazine) without realising you have already read it before.					

	Once or less in the last month	More than once in the last month but less than once a week	About once a week	More than once a week but less than once a day	Once or more a day
5) Finding that a word is 'on the tip of your tongue'. You know what it is but cannot quite find it.					
6) Completely forgetting to do things you said you would do, and things you planned to do.					
7) Forgetting important details of what you did or what happened to you the day before.					
8) When talking to someone, forgetting what you have just said. Maybe saying 'What was I just talking about'?					
9) When reading a newspaper or magazine being unable to follow the thread of a story; losing track of what it is about.					
10) Forgetting to tell someone something important. Perhaps forgetting to pass on a message or remind someone of something.					
11) Getting the details of what someone has told you mixed up and confused.					
12) Forgetting where things are normally kept or looking for them in the wrong place.					
13) Repeating to someone what you have just told them or asking the same question twice.					

Everyday Memory Questionnaire-r (relative/significant other version)**Instructions**

The 13 statements listed below are about forgetting things, something everyone does to an extent. I would like you to tick the box that best indicates how often each statement has happened to your relative/significant other over the last month.

For example on the first statement, if you think that they forget where they put things around the house more than once a day you would tick the box 'once or more in a day.'

	Once or less in the last month	More than once in the last month but less than once a week	About once a week	More than once a week but less than once a day	Once or more a day
1) Having to go back to check whether they have done something that they should have done.					
2) Forgetting when it was that something happened; for example, whether it was yesterday or last week.					
3) Forgetting that they were told something yesterday or a few days ago, and maybe having to be reminded about it.					
4) Starting to read something (a book or an article in a newspaper or magazine) without realising they have already read it before.					

	Once or less in the last month	More than once in the last month but less than once a week	About once a week	More than once a week but less than once a day	Once or more a day
5) Finding that a word is 'on the tip of their tongue'. They know what it is but cannot quite find it.					
6) Completely forgetting to do things they said you would do, and things they planned to do.					
7) Forgetting important details of what they did or what happened to them the day before.					
8) When talking to someone, forgetting what they have just said. Maybe saying 'What was I just talking about'?					
9) When reading a newspaper or magazine being unable to follow the thread of a story; losing track of what it is about.					
10) Forgetting to tell someone something important. Perhaps forgetting to pass on a message or remind someone of something.					
11) Getting the details of what someone has told them mixed up and confused.					
12) Forgetting where things are normally kept or looking for them in the wrong place.					
13) Repeating to someone what they have just told them or asking the same question twice.					

APPENDIX G

Beliefs about Memory Aids Questionnaire (BMQ).

Participant number:

Date information taken: ____ / ____ / 20__

Beliefs about Memory aids Questionnaire (BMQ)Instructions

We would like to know how you feel about your memory and about using memory aids. By memory aid we mean anything you use to help you remember things which could be either:

- a tool you use to help you remember things such as a mobile phone, a diary, a notice board, a to-do-list or a calendar etc.
- or something you *think or do* to help you remember such as putting things in key places, creating mental pictures or rhymes to help you remember people's names etc.

So please tell us how much you agree or disagree with the following statements by ticking the box that applies to you.

	Strongly Disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
1) My actions will have no effect on the outcome of my memory problem. *					
2) My memory is ok so I don't need to use memory aids.					
3) Using memory aids will make my memory lazy.					
4) Repeating things to myself works as well as a memory aid.					
5) Using a memory aid would make me feel like I need help.					
6) There is very little that can be done to improve my memory problem. *					

	Strongly Disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
7) Having a memory problem makes me feel like I need help.					
8) I don't have enough things to remember to need to use memory aids.					
9) The course of my memory problem depends on me.					
10) I wouldn't forget to do things if I used memory aids.					
11) There is nothing that can help my memory problem. *					
12) Using memory aids would help me to manage (have control over) my memory problem.					
13) Only older people should need to use memory aids.					
14) The negative effects of my memory problem can be prevented (avoided) by using memory aids.					
15) It's better to try to rely on my own memory than use memory aids.					
16) I can usually rely on someone to remind me so I don't need to use memory aids.					

	Strongly Disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
17) People won't take me seriously if they see me using a memory aid.					
18) I wouldn't have to rely on other people as much if I used a memory aid.					
19) I would feel stupid if I had to use a memory aid in public.					
20) Writing things down just isn't me.					
21) I will never get my memory back if I rely on memory aids now.					
22) There is a lot I can do myself to control my symptoms.					
23) What I do can determine whether my memory problem gets better or worse.					
24) Having a memory problem makes me feel less of a person.					
25) Nothing I do will affect my memory problem. *					
26) I have the power to influence my memory problem.					

	Strongly Disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
27) Having a bad memory makes me feel stupid.					
28) Using a diary just doesn't fit my lifestyle.					
29) Using memory aids will fix the cause of (cure) my memory problem.					
30) People would think less of me if they knew I needed to use memory aids.					
31) Using a memory aid is a lot of effort.					
32) Using a memory aid would just be an unpleasant reminder of my memory problem.					

BMQ sub-themes:

Personal control beliefs items: 1, 9, 22, 23, 25, 26.

Treatment control beliefs items: 6, 10, 11, 12, 14, 18.

Lifestyle fit items: 8, 16, 20, 28, 31.

Inappropriate beliefs items: 2, 3, 4, 15, 21, 29.

Threat appraisals items: 5, 7, 13, 17, 19, 24, 27, 30, 32

Nb * indicates item reverse coded.

APPENDIX H

Memory Strategies Questionnaire

Participant number:

Date information taken: ____ / ____ / 20__

Memory Strategies Questionnaire¹

The following questionnaire asks about the kind of aids or strategies you use to help you remember things. Please think back over the last month and answer each question by ticking the box that best shows how often you have used each strategy.

	Never	Once a Week	2 times a week	3 times a week	4 or more times a week
1. I use a diary to remind me of what I need to do.					
2. I use a list of things I need to do.					
3. I use reminder notes.					
4. I plan my daily routine in advance so I will not forget things.					
5. I repeat things I need to do several times to myself in order to remember.					
6. I use external reminders, like a notice board, in my house to help me to remember to do things.					
7. I rehearse things in my mind so I will not forget to do them.					
8. I lay things I need to take with me by the door (or get someone to do this for me) so I will not forget them.					

	Never	Once a Week	2 times a week	3 times a week	4 or more times a week
9. I use Post-It (sticky notes) reminders and place them in obvious places.					
10. I create mental pictures to help me remember to do something.					
11. I use things in piles so I know which ones to do first and which can wait.					
12. I lay in bed at night and think of things I need to do the next day so I won't forget to do them.					
13. I try to do things at a regular time so I won't forget to do them.					
14. I use reminders on my mobile phone so I won't forget to do things.					
15. I ask someone I can rely on to tell me things.					
16. I make up rhymes and create mental pictures to remember people's names.					
17. I put certain things in the same place (or get someone to do this for me) so I can find them, e.g. keys or spectacles					

	Never	Once a Week	2 times a week	3 times a week	4 or more times a week
18. I use a diary of what has happened to remember what I have done in the past.					
	Never	Less than half the time I go	Half the time I go	Almost every time I go	Every time I go
19. I use a list whenever I go shopping.					

Are there any other strategies that you use to remember things, that you have not been mentioned within this questionnaire? If so, what are these strategies?

¹ Adapted from the Prospective Memory Questionnaire (Hannon et al., 1995)

Everyday instances of forgetting

The statements listed below are about the things that TK forgets. For everyday of the week I would like you to tick how often each statement has happened to TK.

For example if on Monday TK forgets where he has put his door keys on three occasions that day, you would put three ticks in the box which corresponds to the statement 'lost door keys' on Monday 13th.

Week Commencing: Monday 10th June 2011.

	Monday 13 th June	Tuesday 14 th June	Wednesday 15 th June	Thursday 16 th June	Friday 17 th June	Saturday 18 th June	Sunday 19 th June
Forgotten to attend a Doctors appointment							
Forgotten to attend a Dentist appointment							
Forgotten to attend a hospital appointment							
Forgotten to attend ██████████							
Forgotten to make an appointment, for example the Doctors, Dentist. If other please state.							

	Monday 13 th June	Tuesday 14 th June	Wednesday 15 th June	Thursday 16 th June	Friday 17 th June	Saturday 18 th June	Sunday 19 th June
Needed to be reminded to attend appointment at the Doctors, hospital, Dentist. If other please state							
Needed to be reminded to attend ██████████							
Needed to be prompted (by friend) to attend ██████████							
Forgotten to pay credit card bill							
Forgotten to pay water, gas electric bills.							
Forgotten to pay any other bills Please state.							
Forgotten to pass on a message.							

	Monday 13 th June	Tuesday 14 th June	Wednesday 15 th June	Thursday 16 th June	Friday 17 th June	Saturday 18 th June	Sunday 19 th June
Forgotten about a social event with friends or an event you had planned to do together.							
Needed to be reminded/prompted about a social event with friends or an event you had planned to do together							
Lost door keys							
Lost mobile phone							
Any thing else that TK has forgotten that are not mentioned above. Please state:							

APPENDIX J

Socio-demographic data sheet.

Participant number:
Date information taken: ____ / ____ / 20__

Socio-demographic data

DATE OF BIRTH- ____ / ____ / 19__

AGE- years months

GENDER- Male Female

INPATIENT or OUTPATIENT- Location-

TIME PERIOD/ DATE of ACQUIRED BRAIN INJURY-

TYPE/LOCATION of BRAIN INJURY-

EDUCATION HISTORY-

EMPLOYMENT HISTORY-

APPENDIX K

National Qualifications Framework data.

The National Qualifications framework

Qualifications by level across the NQF; QCF and FHEQ

Level	Examples of NQF qualifications	Examples of QCF qualifications	Examples of FHEQ level qualifications
Entry	<ul style="list-style-type: none"> - Entry level certificates - English for Speakers of Other Languages (ESOL) - Skills for Life - Functional Skills at entry level (English, maths and ICT) 	<ul style="list-style-type: none"> - Awards, Certificates, and Diplomas at entry level - Foundation Learning Tier pathways at entry level - Functional Skills at entry level 	
1	<ul style="list-style-type: none"> - GCSEs grades D-G - BTEC Introductory Diplomas and Certificates - OCR Nationals - Key Skills at level 1 - NVQs at level 1 - Skills for Life 	<ul style="list-style-type: none"> - BTEC Awards, Certificates, and Diplomas at level 1 - Functional Skills at level 1 - OCR Nationals - Foundation Learning Tier pathways - NVQs at level 1 	
2	<ul style="list-style-type: none"> - GCSEs grades A*-C - BTEC First Diplomas and Certificates - OCR Nationals - Key Skills level 2 - NVQs at level 2 - Skills for Life 	<ul style="list-style-type: none"> - BTEC Awards, Certificates, and Diplomas at level 2 - Functional Skills at level 2 - OCR Nationals - NVQs at level 2 	
3	<ul style="list-style-type: none"> - A levels - GCE in applied subjects - International Baccalaureate - Key Skills level 3 - NVQs at level 3 - BTEC Diplomas, Certificates and Awards - BTEC Nationals - OCR Nationals 	<ul style="list-style-type: none"> - BTEC Awards, Certificates, and Diplomas at level 3 - BTEC Nationals - OCR Nationals - NVQs at level 3 	
4	<ul style="list-style-type: none"> - NVQs at level 4 - BTEC Professional Diplomas, Certificates and Awards 	<ul style="list-style-type: none"> - BTEC Professional Diplomas Certificates and Awards - HNCs - NVQs at level 4 	<ul style="list-style-type: none"> - certificates of higher education - higher national certificates

Level	Examples of NQF qualifications	Examples of QCF qualifications	Examples of FHEQ level qualifications
5	<ul style="list-style-type: none"> - HNCs and HNDs - NVQs at level 5 - BTEC Professional Diplomas, Certificates and Awards 	<ul style="list-style-type: none"> - HNDs - BTEC Professional Diplomas, Certificates and Awards - NVQs at level 5 	<ul style="list-style-type: none"> - diplomas of higher education - Foundation Degrees - higher national diplomas
6	<ul style="list-style-type: none"> - National Diploma in Professional Production Skills - BTEC Advanced Professional Diplomas, Certificates and Awards 	<ul style="list-style-type: none"> - BTEC Advanced Professional Diplomas, Certificates and Awards 	<ul style="list-style-type: none"> - bachelors degrees - bachelors degrees with honours - graduate certificates and diplomas - Professional Graduate Certificate in Education
7	<ul style="list-style-type: none"> - Diploma in Translation - BTEC Advanced Professional Diplomas, Certificates and Awards 	<ul style="list-style-type: none"> - BTEC Advanced Professional Diplomas, Certificates and Awards 	<ul style="list-style-type: none"> - masters degrees - integrated masters degrees - postgraduate certificates - postgraduate diplomas
8	<ul style="list-style-type: none"> - specialist awards 	<ul style="list-style-type: none"> - Award, Certificate and Diploma in strategic direction 	<ul style="list-style-type: none"> - doctoral degrees

http://www.direct.gov.uk/en/EducationAndLearning/QualificationsExplained/DG_10039017

APPENDIX L

National Qualifications framework data.

Standard Occupational Classification 2010 (SOC2010)

General nature of qualifications, training and experience for occupations in SOC2010 major groups.

Major group	General nature of qualifications, training and experience for occupations in the major group
1) Managers, directors and senior officials	A significant amount of knowledge and experience of the production processes and service requirements associated with the efficient functioning of organisations and businesses.
2) Professional occupations	A degree or equivalent qualification, with some occupations requiring postgraduate qualifications and/or a formal period of experience-related training.
3) Associate professional and technical occupations	An associated high-level vocational qualification, often involving a substantial period of full-time training or further study. Some additional task-related training is usually provided through a formal period of induction.
4) Administrative and secretarial occupations	A good standard of general education. Certain occupations will require further additional vocational training to a well-defined standard (<i>e.g.</i> office skills).
5) Skilled trades occupations	A substantial period of training, often provided by means of a work based training programme.
6) Caring, leisure and other service occupations	A good standard of general education. Certain occupations will require further additional vocational training, often provided by means of a work-based training programme.
7) Sales and customer service occupations	A general education and a programme of work-based training related to Sales procedures. Some occupations require additional specific technical knowledge but are included in this major group because the primary task involves selling.
8) Process, plant and machine operatives	The knowledge and experience necessary to operate vehicles and other mobile and stationary machinery, to operate and monitor industrial plant and equipment, to assemble products from component parts according to strict rules and procedures and subject assembled parts to routine tests. Most occupations in this major group will specify a minimum standard of competence for associated tasks and will have a related period of formal training.
9) Elementary occupations	Occupations classified at this level will usually require a minimum general level of education (<i>i.e.</i> that which is acquired by the end of the period of compulsory education). Some occupations at this level will also have short periods of work-related training in areas such as health and safety, food hygiene, and customer service requirements.

HOW TO USE

Google Calendar

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Participant 2 Lines 542-610.

Not needing to use memory aids because person is ok
Doesn't need them

After BI people will see you differently—friends don't want to know you.

Idea of being thought of as dumb, especially if you have to use things/aids to help you to remember.

Being laughed at/joked about by friends—feel low

When you go somewhere again memory is triggered.

Repetition/rehearsal i.e. doing things over and over again helps you remember

Everyone is different—has different problems

Do what is best for you

Write down what goals you want to achieve so you can mark them off

R: Can you think of any reasons why people might not want to use any memory strategies?

Pt2: Coz they know about the task they have to do, they can't be arsed changing their future if they know the task and they make good money so they go back to what they were doing no point in retraining memory and getting something else.

R: Ok can you think of any other reasons?

Pt2: When you like use book and pen and paper in front of people some people can understand what you've been through like your close friends but how many close friends do you have when you come out of here, none coz you've been in serious damage, none of your friends want to know you, everyone will think your dumb, they will say "what's that man, carrying notepad" or wait there while I go get a notepad before I come out. That's what they'll say and how does that make you feel? It makes you fell low don't it. If you go play snooker and your mate scores and who won last night and you can't remember, you can't take notepad and book oh yeah John won last night, so and so won last night, this is the score, but as soon as I'll come back to that building like, before yeah who won last night, I got bit confused but now I come back I remember, doing it over and over again that puts the memory back in your head.

R: Any other possible reasons?

Pt2: For some people they can't speak so they can't do any sort of memory strategies that you lot have come across, because Jane her spelling ok but she can't speak at all so it's the kind of position that you're in to do what you can do. If her brains ready then do what you can do but if you're not that bad and you want to get on with, in life, then don't do many things just write down the main things what you want to achieve then once you done them tick them off.

Negative social evaluations

Repetition/rehearsal helps

Planning, preparing of things need to do

Selective with what you note down—not everything

Audio reminder—as it just bleep it's a discrete reminder so no one knows why

Socially acceptable to say 'got to go' when phone bleeps but to be reminded that u have to go home that's different similar to when he talks about everyday strategies.

Idea of being thought of as dumb and rejected if highlight that you need something to remind you

Social acceptance—being thought of as ridiculous by other people for using aids

'Outside' --- general public/other people out of rehab service---views/perceptions of you being thick so don't want to carry aids with you

Double handicap – if you have difficulty writing and can't read your own writing people laugh at you even more

Feeling useless—what am I here for?

Have to keep moving on

R: Ok can you tell me about the last time you used your phone, when you set an alarm to remind you?

Pt2: When I go home at night times or in the evening I write down the information that I need on my phone then set time and day. I don't write everything down I just write appointment days, what stuff that I need look at something and then my phone bleeps and I look at my phone and say yeah yeah I got to go I got to go. I don't say oh yeah my phone bleeps it's my reminder I got to go I make it like I got to go home, or I've got to go home go to take my tablets that's it. Not say something about it then I'd look dumb oh yeah I got to go do something at home. They're not going to come knocking on your door they'll say you're that dumb you have to carry your phone bleeper just to go home. You understand?

R: Ok can you tell me your views of using the memory strategies that you have mentioned please?

Pt2: If you feel happy like then do it but if you think people will laugh at you then there's no point in doing it then it's going to make you look more ridiculous then you'll feel ridiculous.... Already coming to these memory classes then when you go like outside you don't want to have to carry booklet around with you and feel bit thick. Most can't read or write themselves so when you write something down it's still hard for me to say... you can probably read it yourself but when you can't spell can't even see it your handwriting so crap people will laugh at you even more that makes it more difficult in life and you think what the hell am I here for cant get on with nothing. But things that you know about achieving carry on with them but if you can't get back into them do something you can get into you can't just end life here there's no point.

Negative social evaluations

Negative social evaluations

Negative social evaluations

Other people's perceptions

Going from a memory aid makes you look dumb to people rejecting you completely

Idea that people will laugh at u behind your back

Society/people's opinions make using memory aids difficult

You can use memory aids until memory is capable of remembering/memory improved so no need to use them.

R: How do you feel about the memory strategies that you use?

Pt2: They're positive, there are certain things that you can't.... it's the people that you meet out there. You can't carry dictaphone, notepad and book you know not even a little one and you know it might be important but if you can't remember it everyone will think you're dumb, that your thick that you can't remember things what's the point in me talking to you no more, I don't want to talk to you that's what people will say, they won't say it to your face. But it's the people you meet out there that make it difficult carrying memory strategies around but you yourself can do it until you're capable of remembering yourself.

Negative social evaluations

Inappropriate belief

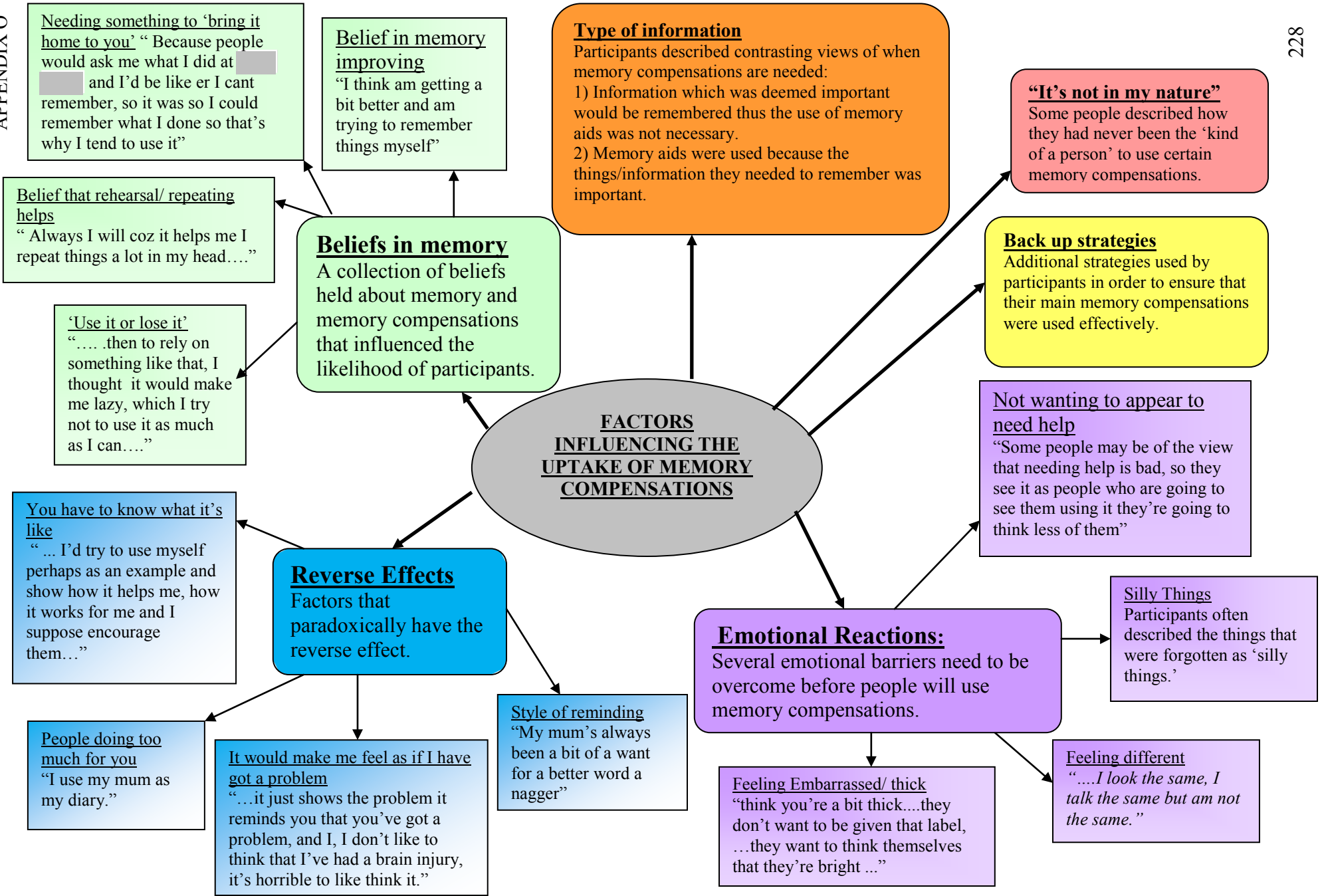


Table of the total number of participants representing each master and sub-theme.

	Participant 1	Participant 2	Participant 3	Participant 4	Participant 5	Participant 6	Participant 7	Participant 8
Emotional Barriers preventing acceptance of memory compensations								
Not wanting to appear to need help				X	X		X	
Feeling embarrassed/ thick	X	X	X		X	X		
Silly Things		X		X		X	X	
Feeling Different	X				X	X	X	X
Reverse Effects								
You have to know what it's like				X	X	X		
Style of reminding	X	X	X	X		X		
People doing too much for you						X		X
"It would make me feel as if I have got a problem"						X	X	

	Participant 1	Participant 2	Participant 3	Participant 4	Participant 5	Participant 6	Participant 7	Participant 8
Beliefs about Memory								
Needing something to ‘bring it home to you’	X		X		X	X	X	X
Belief in memory improving	X		X					X
Belief in rehearsal/repetition helps	X	X					X	
‘Use it or lose it’		X	X					
“It’s not in my nature”	X	X				X	X	X
Type of information								
Don’t need to use memory aids for important information as this type of information is remembered it because it is important.		X		X	X			
Memory compensations are used to remember things/information because it is important to the individual.			X					X
Back up strategies		X	X	X	X		X	X

APPENDIX Q

Additional examples of verbatim quotes for each master and sub-theme.

Additional examples of verbatim quotes for each master and sub-theme.

Emotional barriers preventing acceptance of memory compensations

Not wanting to appear to need help

“Erm..... well some people may be of the opinion themselves that needing help is bad, so they can see it as people who are going to see them using it they’re going to think less of them. But it’s not necessarily true, but it’s the way that the world can be perceived and of course they don’t want people to think less of them so they won’t use the help that they might need, coz they don’t want other people to think that they need help.” (Participant Four: Lines 376-380)

“To view something like a memory strategy as an outside help, like for instance my phone it helps me to remember things, some people don’t want to admit they need help.” (Participant Four: Lines 395-397)

“But people just generally don’t want to admit that they need help so they’ll avoid using strategies coz it’s a form of help.” (Participant Four: Lines 412-413)

“To be fair I think you’ve got to use memory strategy’s, things like and diary when you can do them when you’re on your own, rather than doing things that everybody can see, unless you’re that kind of person that doesn’t care I think you’d find it quite hard to do something in front of people.” (Participant Five: Lines 384-387)

“I think instead of people looking at you thinking ‘why do you need that for’. So at least you can look at it in your own privacy and not worry about what other people think.” (Participant Five: Lines 397-399)

“some people can be quite nasty aren’t they or some people have got horrible attitudes or haven’t got time to have an understanding or anything, so you know some people might not want to show they’ve got memory problems...” (Participant Seven: Lines 452-455)

“They might be embarrassed but you don’t know do you. You.... suppose don’t want it to be seen as a weakness do you.” (Participant Seven: Lines 462)

“You know if you’re having to..... well some people are funny with them coz like a diary can show they’ve got a bit of a weakness you know something wrong and so keep it covered up.” (Participant Seven: Lines 466-468)

“Yeah showing a sign of weakness and being different from everybody else, but you know sometimes it can be not a nice feeling you know it can make you feel vulnerable.”
(Participant Seven: Lines 475-476)

Feeling embarrassed/ thick

“Coz people might think they’re thick, I don’t know. Probably might think if they used some kind of like urm pen and paper to write things down. That’s the way people are, think of a cruel mind, yeah so you got the good and you got the bad you know what I mean so yeah” (Participant One: Lines 443-446)

“I don’t just go round carrying notepad and book, everybody who you meet start to write it down in your note book ‘Oh yeah what was the football score, let me write it down’ that’s ridiculous people would be like.....the man next to you will laugh at you saying ‘Why do you need these things, notepad book and pen?’ ...” (Participant Two: Lines 399-402)

What they’ll say is ‘Can you remember that dumb kid there’ (pointing motion with hand), that’s what they’ll say ‘Can you remember that dumb kid’ that’s what they’ll remember that’s why I don’t carry no book.” (Participant Two: Lines 407-409)

“... When it comes to you, you pull a notepad in front of them they’ll say ‘you’re that dumb I can’t take you on’...” (Participant Two: Lines 443-444)

“Then my phone bleeps and I look at my phone and say yeah yeah I got to go I got to go. I don’t say oh yeah my phone bleeps it’s my reminder I got to go I make it like I got to go home, or I’ve got to go home go to take my tablets that’s it. Not say something about it then I’d look dumb oh yeah I got to go do something at home. They’re not going to come knocking on your door they’ll say you’re that dumb you have to carry your phone bleeper just to go home.” (Participant Two: Lines 578-584)

“Like using a diary, some people might say ‘what are you using that for, cant you remember?’ I’d say to them ‘No I can’t’ I’m not embarrassed I do use it. I’d always tell them the truth. But some people are frightened to tell the truth.....” (Participant Three: Lines 582-586)

“... if someone thought that they were a bit thick for using a diary they may not start using a diary where as you obviously need that diary, need to use it.” (Participant Five: Lines 394-396)

Age related embarrassment

“... Why do you need these things, notepad book and pen? I can remember these things and I’m 50 years older, your half my age and you got memory difficulties’ they’d find it very funny. They won’t laugh at you in front of your face but when they go home they’ll tell their kids ‘I met a man today he’s half my age and he’s got memory problems.’”

What would that look like when those kids see you they'll laugh at you not to your face but behind you...." (Participant Two, Lines 402-407)

"Everyone's different, even with people who've had a brain injury, everyone's like with me am only 19 I'm not going to feel as comfortable using a diary as say someone 45 would, but they wouldn't perhaps know how to use phone, but a phone would be brilliant for me..." (Participant Six: Lines 637-639)

'Silly things'

"...saw someone out there and they pull out pen and paper for simple things I would laugh at them and say what you doing if you can't remember things that are that easy then you aint going to get nowhere in life." (Participant Two: Lines 370-372)

"Depends what things they writing down, if it was silly things then I'd laugh at them at what you've got to write that down for, you've got to wake up at this time." (Participant Two: Lines 391-392)

"If you pull out a notepad for simple things, what they not going to take you seriously when you need a notepad, they say what for?" (Participant Two: Line 445-446)

"I forget silly little things like if someone was to tell me tomorrow could I do this at such and such time." (Participant Four: Lines: 20-21)

"Er it's more like silly little things like forgetting to turn my straighteners off, or forgetting times, or if I've got to do something for my Mum." (Participant Six: Lines 3-4)

R: "What do you mean by stupid things? Pt6: *"Come on I bet you remember to turn things off or you remember whether you've got an appointment or..... before I would, before I'd remember it would just come naturally to me, but now it's like er I don't know, it's just now remembering what am doing that day..."* (Participant Six: Lines 542-547)

"...I can go like things like to the bank and put my card in and I won't remember I've took my card out..... silly things so that annoys me sometimes coz I go all panicky" (Participant Seven: Lines 109-110)

Feeling different

"...like I'm a lot different to how I was before a lot different.... Like I would do everything on my own like I didn't have appointments like I do now obviously, but my Mum was never like this with me before. It's changed my life you become a different person. As much as you say try and think that you're normal am not like my Mum or other people." (Participant Six: Lines 158-162)

“...different days you just wake up and you feel different. I go into my own little world sometimes.” (Participant Six: Line 211)

“I don’t know coz, I think she remembers it so why shouldn’t I remember it, it’s my appointment and why can’t then I think ah if I’ve got to do this tomorrow why wouldn’t I remember it. It just... makes you feel a bit like a kid, so I don’t know, horrible thing isn’t it.” (Participant Six: Lines 248-250)

“I don’t really bother with people no more since, er, I don’t see anybody else that am not, I’ not my old normal self, going out and all that, it seems like am a different person I do keep myself to myself. Like I come here alright but I like my company.” (Participant Seven: Lines 384-387)

“I’ve pretty much become a recluse.” (Participant Eight: Line 499)

Reverse Effects

You have to know what it’s like

“First thing I’d do id I’d try not to force it upon anyone ‘use memory strategies use them’ and I’d try to use myself perhaps as an example and show how it helps me, how it works for me.” (Participant Four: Line 429-431)

“...not to say ‘use memory strategies now or else’ because that’s not going to get me anywhere.” (Participant Four: Line 432)

“If don’t think there’d be a problem if they could look at you and you would say that it works for me this is how it helps then I think they’d naturally then want to use them. I think if I came and said I use a diary and it really helps, it reminds me of what I’ve done, I can look back and it reminds me. I think if people can see some reason behind it then they’ll do it.” (Participant Five: Lines 373-377)

“Yes if say someone told me something that had worked for them if they told me, if they showed them that its worked for me, it’s helped me, and then they’ll think that if its worked for them and other people then they’ll think it could work for me as well couldn’t it.” (Participant Six: Lines 627-630)

Style of reminding

“Yeah she does yeah and like er at the same time she’ll like even though she doesn’t need to ask coz I know ‘Have I taken my tablets?’ and like yeah course I’ve taken my tablets and erm she like asks me erm like if I’ve paid my bills. Well there’s my pile of letters all in front of me so if it’s in front of me then yes.” (Participant One: Lines 327-330)

“...well my parents don't say much about it, but my sister knows where am coming from so she tells me to do things like to write it down and everyday she comes into my bedroom says 'Have you had your medication, have you had your medication?' like every morning... Mum used to knock on door and say 'Have your medication.'”
(Participant Two: Lines 288-291)

“...if I haven't wrote it down someone else has, if it's the social worker I don't like them writing it down for me I like to do it myself.” (Participant Three: Lines 378-379)

“My mum's always been a bit of a, want of a better word a nagger. She'll go on about something repetitively in the end and in the end I'll just forget about it because I'm fed up of hearing about it.” (Participant Four: Lines 87-89)

“Claire my fiancéshe's not going to go round and mention every reminder to me. I got my reminder and it doesn't bother her that I do, in fact she looks at it kind of positively coz at least I remember to do things, but she won't turn round and say 'have you done it?' and sort of if you like get on at me about it, where as with my Mum she'll be like 'have you done this yet? Have you done that yet...?’” (Participant Four: Lines 301-306)

People doing too much for you

“Oh it affects my Mums life more, because she has to remember everything for me, it's like my appointments if I got a letter for an appointment she'll have to remind me that I got to go to it and er..... yeah it affects my Mums life not mine, I use my mum as my diary.” (Participant Six: Lines 24-27)

“She has to remind me like when people are coming out to see me or am going today I didn't know I was coming to Commonsides and she said like its 'Wednesday today so you've got to be ready for ... 10' yeah is it 10, yeah. So my Mum reminds me of most things.” (Participant Six: Lines 40-43)

“... my Mum puts my timetable up and she puts my appointment letter up, like I have been trying to remember more, but I think its coz I got my Mum to do that I don't.”
(Participant Six: Lines 115-116)

“...but I never look at it so it's got pointless writing things in it anymore. Coz Mum will just go 'You've got an appointment at the hospital tomorrow' or 'You've got to do this tomorrow' or things like that.” (Participant Six: Lines 138-140)

“I think if I didn't feel she was there for me as much I'd start thinking 'Oh shit I've got to er I've got to I've got to look and do it for myself'” or I think if I lived on my own it would make a big difference, I think I'd be more responsible and take the time I'd have to take control of my own life.” (Participant Six: Lines 183-186)

"I have someone round me someone who takes care of these things for me." (Participant Eight: Line 11)

R "How does having someone to rely on influence you in using memory aids? Pt 8
"Like I said it probably makes me lazier, yeah." (Participant Eight: Lines 318-320)

"No because I use her, number one, I er don't use the mobile, diary you know."
(Participant Eight: Line 487)

"It would make me feel as if I have got a problem"

"Because obviously they'd say 'Can't you remember that?' I don't know, I'd feel I don't know it would make me feel like I have got a problem if like I don't know if I had a diary to remember me, it shows that I have got a memory problem and sometimes I don't want to think that I have." (Participant Six: Lines 460-463)

"Yeah, because it makes you feel like you have got a problem and it reminds you that you have had a brain injury and it makes you feel different." (Participant Six: Lines 565-566)

"...it just shows the problem it reminds you that you've got a problem, and I, I don't like to think that I've had a brain injury, it's horrible to like think it." (Participant Six: Lines 569-571)

"...a diary can show they've got a bit of a weakness you know something wrong and so keep it covered up.... but I don't care anymore you know, I used to when I first started, but now it doesn't. It used to bother me that I... you know get... you know and I'd get frustrated and I could get... I'd get quite upset and you know this isn't me, now I've got over it, it's part of me now that's how I deal with it." (Participant Seven: Lines 467-471)

Beliefs about Memory

Needing something to 'bring it home to you'

"...coz they were like rabbiting on to me like I couldn't understand a word they were saying to me so I thought ok I'd record it." (Participant One: Lines 301-302)

"...I repeat things a lot in my head as well, like I know if I have an appointment, I have an appointment I have an appointment. I had an appointment with Carole, I think well that's a different method I used I wrote that down actually coz I forgot the first appointment and so when she phoned me and I wrote it down so I could remember that appointment urm" (Participant One: Lines 467-471)

"Well it's er how can I put it, when you get used to something. It's getting used to it at first er before could rely on my memory to do it but now I can't and they've proved that to me, so the OT's proved it to me that I can't and I got to write things down to help to

remind me. That's reasonable and I've accepted that.” (Participant Three: Line 499-502)

“So I've started to try to write down in there what I've done at Commonside and what I've done in like, where I've been if I went to the pictures or went out for a drink I'll write it in my diary so I can remember what I did, when I went to pictures, that's when I did this at Commonside. Because people would ask me what I did at Commonside and I'll be like er I can't remember so it was so I could remember what I done so that's why I tend to use it.” (Participant Five: Lines 120-125)

“Just when people said things here like what did we do in class and am thinking I haven't got a clue.” (Participant Five: Lines 162-163)

“Like with my mobile phone for instance I kept asking where's it at, it drove my Mum mad, she'd say 'Look on the chair look on the chair,' so now one of the strategies that I use is to keep it in one place, so I don't have to keep looking for it, it's easier to remember so that's what I keep trying to put it in one place always in one place so I nowhere to look for it and it has worked, it does work it's just the case of doing it.” (Participant Five: Lines 268-273)

“.... but then one day I realised they were important. Coming here and just listening to things I though yeah ok. So when mum asked what I did here I couldn't remember, but now I can tell you and can join in conversations” (Participant Five: Lines 490-493)

“I had a postal order I lost you know, I bought a £5 postal order and I put this postal order somewhere and I couldn't I couldn't I don't remember where I put it, everywhere I thought all the places that and I never found it till like 6 weeks after and I'd put it in the tea pot ornament thing in the kitchen, I don't remember putting it in there (laughs) and I don't. R: How did that make you feel? Pt7: That was getting me agitated but then.....R: How has this influenced you in the use of memory strategies/memory aids? Pt7: Yeah it has more now, like I say they're the ones that am starting to use” (Participant Seven: Lines 197-208)

“... I had to have my locks changed a couple of months ago coz I couldn't find my front door key..... and what it was, it was in my house and so I had all my locks changed and it was in my house coat pocket and I don't even remember where I'd put it, I don't know, so I place my keys so I know where everything is.” (Participant Seven: Lines 268-271)

“...I think to myself like I'm 19 now I do need to take control more and I've accepted that I have had a brain injury and I do need to write in a diary or whatever, my Mum can't do it forever, when am 40 years old or something, I have accepted it's just doing it now.” (Participant Six: Lines 682-685)

Belief in memory improving

“Just ... just like that as well um stuff like that. It is getting better I think that's my opinion.” (Participant One: Lines 4-5)

“It frustrates me, it frustrates me, especially when I think that like my memory is alright and others can see that it’s not. So it frus... and that am adamant that am right and adamant that am with my memory that that like that urm” (Participant One: Lines 9-11)

R: How does this influence your use of memory strategies? Pt1: *“Urm, sometimes, er I think my memory’s getting better”* (Participant One: Line 24) R: So do you use any memory strategies? Pt1 *“Urm I was, but I seem to like urm gradually like not doing it any more, I was before.”* (Participant One Lines 22-32)

R: *“So why you don’t use your mobile in the same way now then?”* Pt1: *“..... well I don’t think I need, I don’t need it that’s what I think. I don’t use it as often.”* (Participant One: Lines 190-193)

“I haven’t used it in a while to be truthful. I I think am getting a bit better and am trying to remember things myself.” (Participant Three: Lines 84-85)

“I’ve always made my own mind up to do something and I still try and do that but er memory strategies I can’t... I really don’t forget things that that much now only switching things off and things if I have left the door open, have I left the fridge door open. That all I got to remind myself.” (Participant Three: Lines 310-314)

Belief that rehearsal/repetition helps

“Well ur, what I what I tend to do now is like er, like I try to everything won’t fit in my brain, it’s like erm, the most important things I just let it go over and over in my head.” (Participant One: Lines 151-152)

“I keep repeating it to myself in my head, but not out aloud, its like recording just keep going over and over things again in my head.” (Participant One: Lines 156-157)

“Always I will coz it helps me I repeat things a lot in my head as well, like I know if I have an appointment, I have an appointment I have an appointment....” (Participant One: Lines 465-466)

“Not everything, but like I’ll write it down er I’ll put the piece of paper there and I’ll forget about that piece of paper even though it’s there, ok so like what happens is that like er I keep repeating it in my head appointment, appointment, appointment, so I look up that I got an appointment and that’s when I look at the piece of paper, the date and time.” (Participant One: Lines 485-488)

“If I’m the night before carry on repeating in my head then the next day remember things that I’ve said in my head last night then it will pass otherwise then I’ll completely forget.” (Participant Two: Lines 68-70)

“Yeah I rehearse thing in my head over and over again until I can remember them the next day. If I don’t then I’ll write them down.” (Participant Two: Lines 78-70)

“...writing things down that are important to you and carry on looking at them over and over again.” (Participant Two: Line 461-462)

“What you look at every day and you’ll remember it after about 5 or 6 times throw it away when you think your capable of remembering it, next day you probably won’t but after that you will, say yeah I know, I know you throw paper away otherwise I Don’t think carrying no booklet or pad..... Carry on reading and reading, dictaphone, putting into your head till it goes in and then delete it carry on saying things to your head over and over then hopefully it will stay in your head what you need to remember I wouldn’t write it down, anything down.” (Participant Two: Lines 526-532)

“Doing it over and over again that puts the memory back in your head.” (Participant Two: Line 561)

“I keep repeating in my head that I’ve got to do this and things like that.” (Participant Seven: Lines 514-515)

Use it or lose it’

“I didn’t like it because I’ve always relied on my own memory and my own thought and my own peace of mind and then to rely on something like that, I thought it would make me lazy, which I try not to use it as much as I can.” (Participant Three: Lines 23-25)

“It is because I want it to, I’m making myself think. It’s like wearing these glasses am supposed to wear them to help me see, but the Dr’s told me that the optic nerves at the back of my head aren’t damaged, the more I use the glasses the lazier it makes them, so it’s the same with my memory, I try to remember things myself and not rely on other things to remind me....” (Participant Three: Lines 70-74)

“It.... in a way it doesn’t. I do use them I do use them but I try not to use them as much as I did the day before or the time before because I want to try and remember things.” (Participant Three: Lines 348-350)

“..... no, I don’t the only thing I can do really is not use as many aids as I’ve used and hopefully my memory will come back to normal. For important things I’ve still got to jot things down and write things down but if I can remember it I will but if I check but er I do try to remember things well.... I the last thing I want is dementia, but I do er try and remember things.” (Participant Three: Lines 411-415)

“It makes me feel lazy to tell you the truth coz if I can’t remember it I shouldn’t have to write things down. I want to try to remember things I want to get back to a normal way, but at the moment I have to jot things down and I will do I will jot things down. It is the only way really.” (Participant Three: Lines 486-489)

“It’s not in my nature”

Everybody’s different though, like everybody different attitudes and different personalities some people carry diaries all their life and they don’t mind writing things down like.” (Participant Two: Lines 536-538)

“Probably sometime, yeah, like say ‘do yourself a diary’ I don’t want to do a diary coz that’s not am not comfortable doing a diary and that’s not what I want to do. But for some people it is, we all just do it different ways.” (Participant Seven: Lines 654-657)

“What people want to do, what they want. Everyone’s different aren’t they, you know if people want to use a diary then if that’s best for them.” (Participant Seven: Lines 668-669)

“...think it’s a little bit too much pen and paper.... that’s a woman’s thing really” (Participant One: Line 292)

“I can’t see myself carrying around a booklet 24/ 7 with pen and pencil.... na.” (Participant Two: Lines 144-145)

“I don’t like writing things..... If I was to... I have been using it I have got things written down in it but, I just it’s not in my nature to go and look in the draw and go oh look at my diary today.” (Participant Six: Lines 336-338)

“Because its, I couldn’t be arsed like to look at it and things..... I don’t know..... Just the thought I don’t know of writing a diary and looking at it, I definitely wouldn’t find that for me. May be some people would but it’s not for me.” (Participant Seven: Lines 401-403)

“....I just put my letters up and some people help them and they might write theirs on the board like have a black board or something, they could do however they’re comfortable doing it and what’s best for them. Some people might do a diary and that mighten they, but am not comfortable in doing that.” (Participant Seven: Lines 498-501)

“I’m not one to walk around with a list” (Participant Eight: Line 137)

“....make them use it what’s comfortable in their life, I wouldn’t get them to carry a book or diary round if they’re not comfortable and then their life style. I’d go back to them and say what do you want if for...” (Participant Two: Lines 483-485)

“What they, what’s best for them like, say some people might write in their phone and they’re comfortable doing that and think it’s a good idea for them or but that’s what’s best for them.” (Participant Seven: Lines 505-507)

Type of information**Don't need to use memory aids for important information as this type of information is remembered because it is important.**

"The things that are important to my life I can get on with them coz you know when you get time schedules and anything important times I can remember them times like when I have to go in and go out and things like that." (Participant Two: Lines 118-120)

"Things that make my life better, like bringing money to make my life better my kids life better then obviously I remember them things off the top of my head." (Participant Two: Lines 206-208)

"I remembered this morning that I got it, because what just, it became something important something different. Instead of a change in routine it became something that actually was different." (Participant Four: Lines 214-216)

"Something like this had some level of value behind it some level of importance and it just it stuck in my mind, it became more important that sticking to the routine...." (Participant Four: Lines 221-222)

"If it's really important I tend to.... I'm not too bad I tend to remember the really important things." (Participant Five: Lines 72-73)

Memory compensations are used to remember things/information because it is important to the individual.

"It's only important things that I write down at the moment. If I can't remember things then really it's my own fault. But important things I do write down, I do." (Participant Three: Lines 85-87)

"Well I mean very important things like dates, dates the social workers coming to see me, dates of hospital appointments, house money I've got coming in, income support and what day that comes in and I'll write it down on my calendar, its due on the, say its due today so I've wrote that day on my calendar and then I know that moneys gone into my bank account." (Participant Three: Lines 92-96)

"I've started putting them in there because probably put them somewhere and I'd forget so I do this for important things next to my bed." (Participant Seven: Lines 129-130)

Back up strategies

"...o'clock but I know that the dates that I have to wake early and times when I have to wake up because I have to look at the sheet the night before and type it down in my phone." (Participant Two: Lines 12-14)

“I get that.... Yes strategies. If I haven't, I'll tell people if I haven't got somewhere by such a time to tell me.” (Participant Three: Lines 463-464)

“I have a to-do list which is for things that aren't necessarily for a set time go onto and I have a reminder which goes off at about 4 o'clock at 4 saying look at your to-do list, check that you have got nothing to do right now.” (Participant Four: Lines 70-73)

“If I forget my phone (laughs) if I've left it lying around, I'll write myself a note and or if I want something to keep reminding me then I'll make a note put it somewhere obvious like on the fridge door. So, when every time I go and get something out of the fridge it's there instead of it just goes off, look at it, turn it off and forget about it anyway.” (Participant Four: Lines 96-100)

“Well I've already got it on my calendar, so it's an extra prompt, just extra thing really, so I can look on my calendar that it's so and so's birthday so I can get them a card but then it also comes up on my phone to remind me. So its for things like that really. It's an extra prompt.” (Participant Five: Lines 210-213)

“..... I have to tell somebody if I'm going somewhere, I'll say remind me I've got to go to so and so, or if I'm putting something somewhere I've got to say I'm putting that in there coz otherwise I'd forget where I'd put it, things like that.” (Participant Seven: Lines 11-13)

“With letters, like if I got important letters and things like that then I'll stick them on the fridge so I can remember or somebody else will tell me to remind me.” (Participant Seven: Lines 17-18)

“Erm, I probably have my own strategies as well as saying to them 'Oh remind me' so they know as well or 'Am putting this there' so I've got two in case they're not there or if they've forgotten, then I've got my own strategies but I do try and tell them as well.” (Participant Seven: Lines 290-294)

“I wouldn't like to have strategies, I'd just have one strategy for organising my life. Like with my mobile, the diary and computer I just think you know, what I am doing just going over the same thing over and over and I I just want to get on with life.” (Participant Eight: Lines 572-576)

“Because it's just confusing. I end up using one at the expense of the other and you end up spending more time writing notes than carrying them out...” (Participant Eight: Lines 586-587)

APPENDIX R

Kolmogorov- Smirnov Test for normality: SPSS output.

Kolmogorov-Smirnov Test for normality: SPSS output

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The distribution of PersonalBeliefs is normal with mean 21.828 and standard deviation 3.362.	One-Sample Kolmogorov-Smirnov Test	.335	Retain the null hypothesis.
2	The distribution of TreatmentBeliefs is normal with mean 22.241 and standard deviation 2.958.	One-Sample Kolmogorov-Smirnov Test	.347	Retain the null hypothesis.
3	The distribution of LF is normal with mean 10.655 and standard deviation 3.707.	One-Sample Kolmogorov-Smirnov Test	.053	Retain the null hypothesis.
4	The distribution of InappBeliefs is normal with mean 15.276 and standard deviation 4.116.	One-Sample Kolmogorov-Smirnov Test	.226	Retain the null hypothesis.
5	The distribution of ThreatAppraisal is normal with mean 23.948 and standard deviation 6.191.	One-Sample Kolmogorov-Smirnov Test	.137	Retain the null hypothesis.
6	The distribution of MSQtotal is normal with mean 31.121 and standard deviation 15.83.	One-Sample Kolmogorov-Smirnov Test	.395	Retain the null hypothesis.
7	The distribution of TotalEMQcl is normal with mean 23.172 and standard deviation 13.989.	One-Sample Kolmogorov-Smirnov Test	.611	Retain the null hypothesis.
8	The distribution of TotalEMQso is normal with mean 29.647 and standard deviation 14.949.	One-Sample Kolmogorov-Smirnov Test	.606	Retain the null hypothesis.
9	The distribution of EMQdifference is normal with mean 6.765 and standard deviation 15.826.	One-Sample Kolmogorov-Smirnov Test	.473	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

APPENDIX S

Multiple Regression: SPSS output.

Multiple Regression SPSS output

Multiple regression for MSQ total as the dependent variable and lifestyle fit; treatment control beliefs and inappropriate beliefs as the independent variables.

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.673 ^a	.453	.422	12.03275	.453	14.885	3	54	.000

a. Predictors: (Constant), Treatment Beliefs, Inapp Beliefs, LF.

b. Dependent Variable: MSQ total.

APPENDIX T

Pre and Post intervention BMQ results.

Participant number: 1 study 3

Date information taken: __26__ / __1__ / 2011 (PRE-INTERVENTION)

Beliefs about memory aids questionnaire (BMQ)Instructions

We would like to know how you feel about your memory and about using memory aids. By memory aid we mean anything you use to help you remember things which could be either:

- a tool you use to help you remember things such as a mobile phone, a diary, a notice board, a to-do-list or a calendar etc.
- or something you *think or do* to help you remember such as putting things in key places, creating mental pictures or rhymes to help you remember people's names etc.

So please tell us how much you agree or disagree with the following statements by ticking the box that applies to you.

	Strongly Disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
1) My actions will have no effect on the outcome of my memory problem.				X	
2) My memory is ok so I don't need to use memory aids.		X			
3) Using memory aids will make my memory lazy.				X	
4) Repeating things to myself works as well as a memory aid.		X			
5) Using a memory aid would make me feel like I need help.				X	
6) There is very little that can be done to improve my memory problem.		X			

	Strongly Disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
7) Having a memory problem makes me feel like I need help.					X
8) I don't have enough things to remember to need to use memory aids.		X			
9) The course of my memory problem depends on me.		X			
10) I wouldn't forget to do things if I used memory aids.			X		
11) There is nothing that can help my memory problem.			X		
12) Using memory aids would help me to manage (have control over) my memory problem.				X	
13) Only older people should need to use memory aids.				X	
14) The negative effects of my memory problem can be prevented (avoided) by using memory aids.				X	
15) It's better to try to rely on my own memory than use memory aids.				X	
16) I can usually rely on someone to remind me so I don't need to use memory aids.		X			

	Strongly Disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
17) People won't take me seriously if they see me using a memory aid.				X	
18) I wouldn't have to rely on other people as much if I used a memory aid.				X	
19) I would feel stupid if I had to use a memory aid in public.				X	
20) Writing things down just isn't me.				X	
21) I will never get my memory back if I rely on memory aids now.				X	
22) There is a lot I can do myself to control my symptoms.		X			
23) What I do can determine whether my memory problem gets better or worse.		X			
24) Having a memory problem makes me feel less of a person.				X	
25) Nothing I do will affect my memory problem.		X			
26) I have the power to influence my memory problem.		X			

	Strongly Disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
27) Having a bad memory makes me feel stupid.				X	
28) Using a diary just doesn't fit my lifestyle.				X	
29) Using memory aids will fix the cause of (cure) my memory problem.		X			
30) People would think less of me if they knew I needed to use memory aids.				X	
31) Using a memory aid is a lot of effort.			X		
32) Using a memory aid would just be an unpleasant reminder of my memory problem.				X	

Participant number: 1 study 3

Date information taken: __6__ / __7__ / 2011 (POST INTERVENTION)

Beliefs about memory aids questionnaire (BMQ)Instructions

We would like to know how you feel about your memory and about using memory aids. By memory aid we mean anything you use to help you remember things which could be either:

- a tool you use to help you remember things such as a mobile phone, a diary, a notice board, a to-do-list or a calendar etc.
- or something you *think or do* to help you remember such as putting things in key places, creating mental pictures or rhymes to help you remember people's names etc.

So please tell us how much you agree or disagree with the following statements by ticking the box that applies to you.

	Strongly Disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
1) My actions will have no effect on the outcome of my memory problem.		X			
2) My memory is ok so I don't need to use memory aids.		X			
3) Using memory aids will make my memory lazy.			X		
4) Repeating things to myself works as well as a memory aid.		X			
5) Using a memory aid would make me feel like I need help.		X			
6) There is very little that can be done to improve my memory problem.		X			

	Strongly Disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
7) Having a memory problem makes me feel like I need help.				X	
8) I don't have enough things to remember to need to use memory aids.		X			
9) The course of my memory problem depends on me.	X				
10) I wouldn't forget to do things if I used memory aids.				X	
11) There is nothing that can help my memory problem.		X			
12) Using memory aids would help me to manage (have control over) my memory problem.				X	
13) Only older people should need to use memory aids.				X	
14) The negative effects of my memory problem can be prevented (avoided) by using memory aids.				X	
15) It's better to try to rely on my own memory than use memory aids.		X			
16) I can usually rely on someone to remind me so I don't need to use memory aids.		X			

	Strongly Disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
17) People won't take me seriously if they see me using a memory aid.					X (only for paper based aids not present aid as its discrete)
18) I wouldn't have to rely on other people as much if I used a memory aid.				X	
19) I would feel stupid if I had to use a memory aid in public.		X (not present aid as its private)			
20) Writing things down just isn't me.					X
21) I will never get my memory back if I rely on memory aids now.			X		
22) There is a lot I can do myself to control my symptoms.				X	
23) What I do can determine whether my memory problem gets better or worse.				X	
24) Having a memory problem makes me feel less of a person.				X	
25) Nothing I do will affect my memory problem.		X			
26) I have the power to influence my memory problem.			X		

	Strongly Disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
27) Having a bad memory makes me feel stupid.				X	
28) Using a diary just doesn't fit my lifestyle.					X
29) Using memory aids will fix the cause of (cure) my memory problem.		X			
30) People would think less of me if they knew I needed to use memory aids.				X	
31) Using a memory aid is a lot of effort.		X (not present aid)			
32) Using a memory aid would just be an unpleasant reminder of my memory problem.				X	

Everyday Memory Questionnaire-r (Pre intervention)

Instructions

The 13 statements listed below are about forgetting things, something everyone does to an extent. I would like you to tick the box that best indicates how often each statement has happened to you over the last month.

For example on the first statement, if you think that you forget where you put things around the house more than once a day you would tick the box 'once or more in a day.'

	Once or less in the last month	More than once in the last month but less than once a week	About once a week	More than once a week but less than once a day	Once or more a day
1) Having to go back to check whether you have done something that you should have done.					X
2) Forgetting when it was that something happened; for example, whether it was yesterday or last week.					X
3) Forgetting that you were told something yesterday or a few days ago, and maybe having to be reminded about it.					X
4) Starting to read something (a book or an article in a newspaper or magazine) without realising you have already read it before.					X

	Once or less in the last month	More than once in the last month but less than once a week	About once a week	More than once a week but less than once a day	Once or more a day
5) Finding that a word is 'on the tip of your tongue'. You know what it is but cannot quite find it.					X
6) Completely forgetting to do things you said you would do, and things you planned to do.					X
7) Forgetting important details of what you did or what happened to you the day before.					X
8) When talking to someone, forgetting what you have just said. Maybe saying 'What was I just talking about'?					X
9) When reading a newspaper or magazine being unable to follow the thread of a story; losing track of what it is about.					X
10) Forgetting to tell someone something important. Perhaps forgetting to pass on a message or remind someone of something.					X
11) Getting the details of what someone has told you mixed up and confused.					X
12) Forgetting where things are normally kept or looking for them in the wrong place.					X
13) Repeating to someone what you have just told them or asking the same question twice.					X

Everyday Memory Questionnaire-r (Post intervention)**Instructions**

The 13 statements listed below are about forgetting things, something everyone does to an extent. I would like you to tick the box that best indicates how often each statement has happened to you over the last month.

For example on the first statement, if you think that you forget where you put things around the house more than once a day you would tick the box 'once or more in a day.'

	Once or less in the last month	More than once in the last month but less than once a week	About once a week	More than once a week but less than once a day	Once or more a day
1) Having to go back to check whether you have done something that you should have done.	X				
2) Forgetting when it was that something happened; for example, whether it was yesterday or last week.			X		
3) Forgetting that you were told something yesterday or a few days ago, and maybe having to be reminded about it.					X
4) Starting to read something (a book or an article in a newspaper or magazine) without realising you have already read it before.					X

	Once or less in the last month	More than once in the last month but less than once a week	About once a week	More than once a week but less than once a day	Once or more a day
5) Finding that a word is 'on the tip of your tongue'. You know what it is but cannot quite find it.					X
6) Completely forgetting to do things you said you would do, and things you planned to do.	X				
7) Forgetting important details of what you did or what happened to you the day before.				X	
8) When talking to someone, forgetting what you have just said. Maybe saying 'What was I just talking about'?				X	
9) When reading a newspaper or magazine being unable to follow the thread of a story; losing track of what it is about.					X
10) Forgetting to tell someone something important. Perhaps forgetting to pass on a message or remind someone of something.					X
11) Getting the details of what someone has told you mixed up and confused.					X
12) Forgetting where things are normally kept or looking for them in the wrong place.	X				
13) Repeating to someone what you have just told them or asking the same question twice.				X	

APPENDIX V

Publications and conferences.

Publications & Conferences

Publications:

Baldwin, V., Powell, T., & Lorenc, L. (2011). Factors influencing the uptake of memory compensations: A qualitative analysis. *Neuropsychological Rehabilitation, 21*, 484-501.

Baldwin, V., Powell, T., & Lorenc, L. (2010). Factors influencing the uptake of memory compensations: A qualitative analysis. Abstracts of the 7th Symposium on Neuropsychological Rehabilitation, Krakow, Poland. *Brain Impairment, 11*, 210-211.

Conferences:

Baldwin, V., Powell, T., & Lorenc, L. (2011). An exploration of the role of beliefs about memory aids in predicting the use of memory compensations following acquired brain injury (ABI). Oral presentation at the Division of Clinical Psychology Annual Conference.

Baldwin, V., Powell, T., & Lorenc, L. (2011). Factors influencing the uptake of memory compensations: A qualitative analysis. Poster presentation at the Headway Annual Conference.

Baldwin, V., Powell, T., & Lorenc, L. (2010). Factors influencing the uptake of memory compensations: A qualitative analysis. Oral presentation at the 7th Satellite Symposium on Neuropsychological Rehabilitation, Krakow, Poland.

Baldwin, V., Powell, T., & Lorenc, L. (2010). Factors influencing the uptake of memory compensations: A qualitative analysis. Poster presentation at the IPA and Grounded Theory (Qualitative Research Methods) conference, University of Birmingham. (Awarded 2nd place).

Baldwin, V., Powell, T., & Lorenc, L. (2009). Factors influencing the uptake of memory compensations. Oral presentation Psychology Postgraduate Affairs Group, Cardiff, UK.