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**THE DEVELOPMENT OF A QUESTIONNAIRE ASSESSING THE  
OUTCOME OF MEMORY REHABILITATION FOR PEOPLE WITH  
ACQUIRED BRAIN INJURY**

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Thesis submitted to the University of Nottingham  
for the degree of Doctor of Philosophy

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## Abstract

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**Part A:** Memory rehabilitation is a promising approach to address memory difficulties although its effectiveness with neurologically impaired individuals is yet to be established (**Chapter 1**). This thesis was conducted within the context of the pilot and main phase of a randomised controlled trial (ReMind) evaluating the effectiveness of memory rehabilitation for people experiencing memory problems following traumatic brain injury (TBI), stroke and multiple sclerosis (MS). The trial compared the effects of restitutive and compensatory memory rehabilitation strategies with a self-help control intervention on memory functioning, mood, activities of daily living and mental adjustment. The quantitative data obtained in this trial did not provide strong evidence to support the effectiveness of the intervention. The use of inappropriate outcome measures may account for the contradictory or inconclusive findings of the ReMind and other memory rehabilitation studies. **Chapter 2** provides a review of measures that were used in the ReMind trial and/or were commonly used to evaluate outcome in memory rehabilitation studies. A lack of measures that considers the aims of memory rehabilitation and the needs of neurologically impaired individuals was observed. The post-intervention interviews of participants ( $N=19$ ) in the pilot phase of the ReMind were analysed thematically (**Chapter 3**). Participants reported benefits in areas that were not covered by existing quantitative outcome measures such as insight into the nature and severity of their memory problems, confidence in their ability to manage these difficulties and qualitative improvements in the use of memory aids.

The aim of the following studies was to develop and evaluate a questionnaire responsive to the effects of memory rehabilitation following acquired brain injury. The process included two stages:

**Part B: Identification of the content of AMEDO questionnaire:** At this stage, studies were conducted within the main phase of the ReMind trial. The content areas of the questionnaire were identified based on the input and feedback of participants in each of the three memory rehabilitation programmes (Restitution, Compensation and Self-help groups). A mixed methods design was followed and information was drawn from two sources:

- 1) Real time observations of 43 sessions were performed (**Chapter 4**). The study introduced a new recording strategy by using a time sampling method to qualitatively record the content of conversations. Group activity was also evaluated. Following a quantitative content analysis method, observations were grouped into categories and their frequency was assessed in order to systematically describe and compare the content of the three programmes.
- 2) Semi-structured post-intervention interviews were conducted with 20 participants to explore their experience in the groups (**Chapter 5**). Recurrent patterns of data were identified inductively following a thematic analysis approach. Interviews from each programme were analysed separately and the emerging themes were compared and contrasted to highlight similarities and differences between the programmes. The majority of participants perceived the main benefits of memory rehabilitation to be: a) responding to their need for information on the cognitive effects of brain injury, b) enhancing their sense of self-efficacy and control over their memory difficulties, c) motivating them to adopt a more proactive attitude towards the management of these problems. The advantages of the group based approach to rehabilitation were also highlighted by most respondents.

Questionnaire items were generated to cover the key content areas that were identified in both studies: memory knowledge, awareness, emotional adjustment, active coping, control beliefs, attention, significant others (comprised Part A of the questionnaire), the use of external memory aids (comprised Part B1) and the use of internal memory aids (Part B2).

**Part C: Evaluation of the psychometric properties of Adaptation to Memory Difficulties Outcome questionnaire (AMEDO):** The final study of this thesis (**Chapter 6**) evaluated the psychometric properties of the new questionnaire. The first version of AMEDO included 45 items rated on a 4-point Likert scale (strongly disagree-strongly agree). Face validity was assessed by researchers and clinicians experienced in the area of neurological rehabilitation. The psychometric properties of AMEDO were evaluated by posting the questionnaire to a sample of people with MS and TBI identified through hospital records. It was returned by 110 people with MS and 34 people with TBI and 87 of these participants returned the second questionnaire that was sent to assess stability.

After applying the criteria of face validity, response distribution, and construct validity 15 items were retained in Part A of the questionnaire, and four items in Parts B1 and B2 respectively. The distribution of responses was acceptable for all items except for the ones assessing the use of external memory aids which displayed negative skew (ceiling effects). Principal component analysis indicated that the questionnaire captured most of the content areas it was designed to cover. Part B1 and B2 formed two distinct subscales assessing effectiveness in the use of external and internal memory aids respectively. Part A comprised three components: "Memory knowledge", "Control" and "Emotional adjustment". Evaluation of item-convergent validity confirmed the three factor solution. Internal consistency estimates for all the subscales were found to be satisfactory ( $\alpha=.74-.84$ ). Correlations between the subscales indicated that the represented constructs were related in meaningful ways. Test-retest reliability coefficients for the subscales ranged between  $r=.60$  to  $r=.82$ . The biggest discrepancies were found in the "Memory knowledge" and external memory aids (EMA) subscales whereas the "Control" and "Emotional adjustment" showed acceptable levels of stability. Differences between test-retest scores in the former subscales dropped to satisfactory levels when analyses were repeated excluding respondents who completed the 2<sup>nd</sup> questionnaire more than a month after completing the 1<sup>st</sup> questionnaire. This finding indicated that the observed differences between scores at Time 1 and Time 2 may be reflective of actual changes taking place during that interval. Finally, it was shown that scores were not significantly affected by age, diagnosis and time since injury and, therefore, the questionnaire may be relevant to a wider neurological population.

In conclusion, AMEDO is a brief and simple measure tailored to the characteristics and needs of neurologically impaired individuals. The questionnaire shows promise as an outcome measure specific to the effects of memory rehabilitation, to complement memory batteries and established generic measures. Further evaluation of the scale should confirm the stability of the questionnaire and assess its responsiveness to changes following memory rehabilitation.



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Μαμά, μπαμπά, γιαγιά, ευχαριστώ!



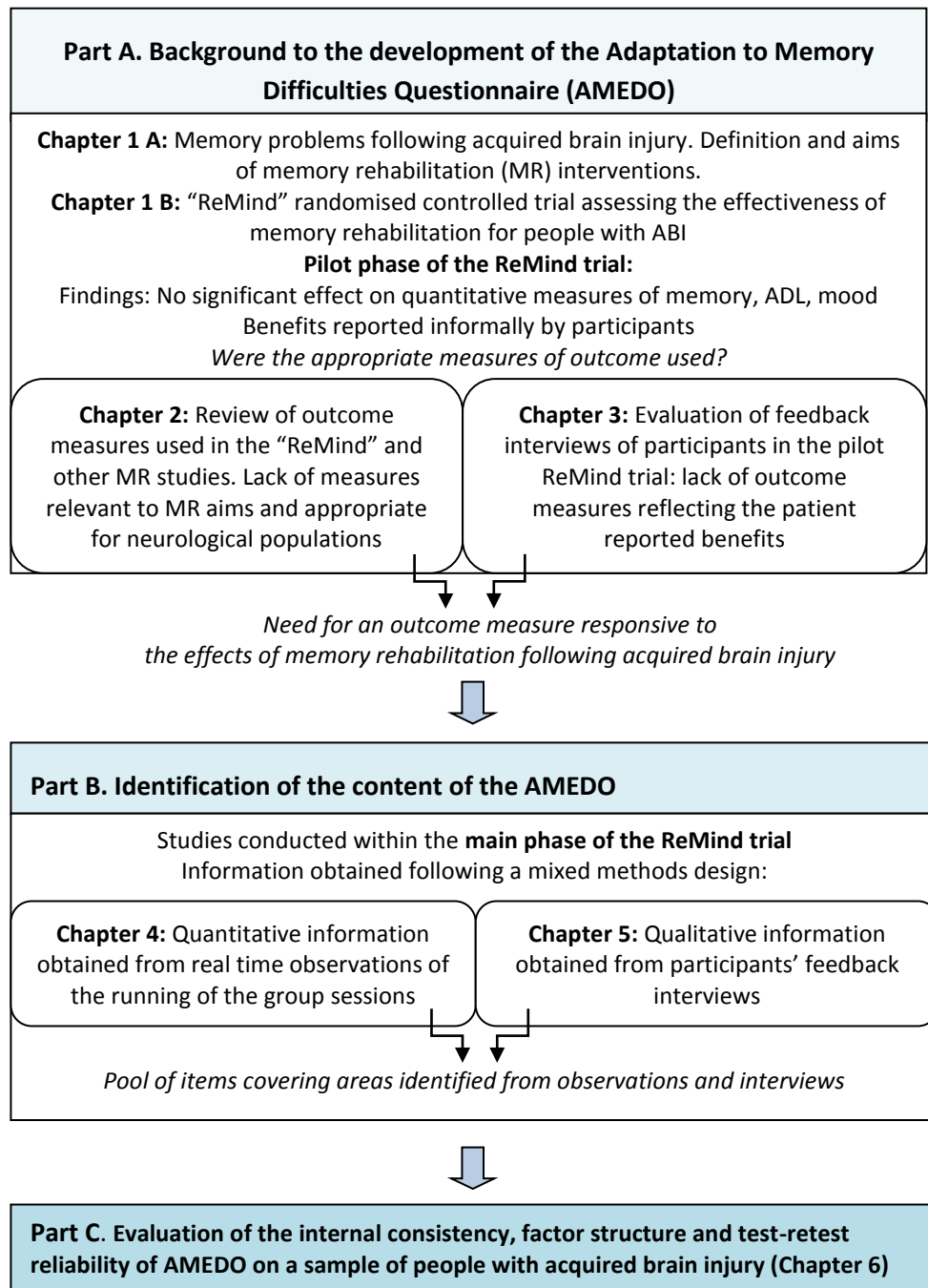
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## Part A.

### Chapter 1: Introduction to memory rehabilitation

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#### 1.1 Diagram of the structure of this thesis



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## 1.2 Author contribution

During the *pilot phase* of the ReMind trial the author checked the transcripts of feedback interviews against the original recordings and analysed them (Chapter 3). During the *main phase* of the trial, she contributed to the recruitment and baseline assessment of potential participants. She observed the activity and content of the memory rehabilitation groups. She developed a coding scheme, recorded and analysed the observations. A research assistant (Dr Alana Tooze) was employed to assess inter-rater agreement (Chapter 4). The author arranged and conducted the feedback interviews jointly with a research assistant (Miss Katherine Siu). All the interviews were analysed by the author. An independent assessor (Mr Tom Jeffcoate) was employed to verify the validity of the analysis (Chapter 5). Finally, the author developed the Adaptation to Memory Problems Outcome questionnaire, obtained ethical approval for administering it to clinical populations, collected and analysed the data as presented in Chapter 6.

### **1.3 Chapter outline**

The first part of this chapter provides a brief overview of different ways of conceptualising and categorising memory function. Information on the nature and cognitive sequelae of acquired brain injury related to multiple sclerosis, stroke and traumatic brain injury is then presented. The concept of memory rehabilitation is introduced and the World Health Organisation (WHO) classification of functioning, disability and health is used as a framework for the description of different approaches to memory rehabilitation. What follows is an overview of the principles, aims and methods of restitutive, compensatory and holistic approaches. The key findings of recent studies evaluating the effectiveness of memory rehabilitation interventions for people with acquired brain injury are presented. In the second part of this chapter, an outline of the randomised controlled trial, within which this thesis was embedded, is provided to summarize the aims, methods and main findings of the trial. Finally, the need for critical evaluation of the outcome measures used in memory rehabilitation is discussed.

### **1.4 Conceptual approaches of memory function**

#### **1.4.1 Stages of memory**

Defining memory is not an easy task as it refers to a complex combination of subsystems rather than a unitary function (Baddeley, 1995). It is well established that memory is not confined to a single brain structure but many parts of the nervous system contribute to the representation of a single event (Milner et al., 1998). One simple way of conceptualising memory is as “the ability to take in, store and retrieve information” (Wilson, 2009 p.1). Based on that definition, memory can be conceived as a process involving three main stages. The first stage is encoding which refers to the process, effortful or unconscious, by which sensory information is initially organised and converted into a representation suitable for memory storage (Colman, 2003; Skeel & Edwards, 2001). The thalamus and the frontal lobe systems are considered to have an important role in this process (Sohlberg & Mateer, 2001). Attention components, in particular, such as selection of target information, may significantly affect the successful encoding of information (Wilson, 2009). It is, therefore, no surprise that people with executive deficits (e.g. following TBI) often experience encoding difficulties (Ibid.) Once new information is



encoded, structural changes in the brain need to take place in order to allow the long-term storage of information (Skeel & Edwards, 2001). At a neuronal level, long-term memories are represented as groups of cells that are activated in a consistent pattern (Andrewes, 2004). Problems with storage are often seen in people with damage to the medial temporal structures (e.g. hippocampus) who demonstrate an abnormally rapid rate of forgetting (Sohlberg & Mateer, 2001). Retrieval is the final stage which allows the stored information to be recalled when required. Retrieval deficits are usually observed in people with frontal lobe damage (Sohlberg & Mateer, 2001). They are usually assessed by comparing the ability to recognise previously presented information (recognition) to straight recall of that information (Ibid). It has been suggested that in everyday life these stages are not isolated from each other but interact (Terry, 2009; Wilson, 2009).

### **1.4.2 Time dependent forms of memory**

In terms of the length of time for which information is stored, three broad categories have been identified: sensory memory, short-term (STM) and long-term memory (LTM). Sensory memory is a very short-term memory store which holds information processed by the sense organs for less than a quarter of a second (Colman, 2003, Wilson, 2009). Although it is an important part of the memory process, it is usually conceptualised and studied as a perceptual component (Baddeley, 2004). According to Wilson (2009), in clinical practice problems in the sensory memory system would be diagnosed as perceptual disorders rather than memory impairments. Short-term memory refers to a unitary, brief and limited capacity storage system as it can keep a maximum of 10 items (typically seven items) for up to 60 seconds (Smith & Jonides, 1998; Terry, 2009). It serves as a passive storage of information while that information either becomes encoded into long-term memory or is forgotten. The capacity of STM is widely assessed by a digit span test which measures the number of items that can be recalled in the right order after a single presentation (Andrewes, 2001). As noted by Wilson (2009), STM problems usually present as difficulties with planning, organisation, divided attention and speech processing.

Short term memory was viewed as a unitary temporary storage system (Atkinson & Shiffrin, 1968). This model was then extended by Baddeley & Hitch (1974) who introduced the concept of working memory to describe a multi-component system responsible not only for the temporary storage but also for the organisation and manipulation of incoming information in short-term memory. Working memory comprises two short-term storage

mechanisms: a) the phonological loop, which holds acoustic and verbal information, and b) the visuospatial sketchpad which stores visual and spatial information. Each of these loops employs different neural circuits (Baddeley, 2004). The model acknowledges the important contribution of attention to memory. The whole system is controlled by a central executive system which focuses and distributes attention across multiple tasks. The most recent addition to the model was the episodic buffer (Baddeley, 2000), which links short and long-term stores (e.g. arithmetic knowledge stored in LTM can be used to perform calculations in the STM). Working memory is assumed to contribute to tasks such as allocation of attention, planning, language comprehension and problem solving (Terry, 2009). Tasks that measure working memory either increase the amount of information that must be stored during a single task or require the examinee to perform two tasks simultaneously (Lezak, 2004). Visuospatial span function can likewise be tested by asking participants to remember the sequence of blocks on a board (Terry, 2009). Circuits in the prefrontal and parietal cortex are thought to be involved in working memory (Bear et al, 2001; Kolb & Wishaw, 2003).

Under specific conditions, such as rehearsal, information may be transferred into the long-term memory store. This system is more robust, as forgetting does not easily occur, it has virtually unlimited capacity and can hold information from minutes to years (Bear, 2001; Terry, 2009). Information in this system is primarily coded based on its meaning (semantic encoding) (Terry, 2009). LTM is affected in the majority of people with memory impairments (Wilson, 2009). These patients may demonstrate preserved short-term memory, an indication that STM and LTM represent separate memory systems (Ibid.).

### **1.4.3 Content dependent forms of long-term memory**

Long-term memory may be either explicit (declarative) or implicit (non-declarative). Implicit memory can be observed during performance of tasks that do not require intentional or conscious recollection of the event of learning (Andrewes, 2004). It refers to “knowing how” and allows the acquisition of perceptual, cognitive and motor skills such as riding a bike (Terry, 2009). The term explicit memory is used to describe information which can be consciously recalled and reported explicitly (Sohlberg & Mateer, 2001). This kind of memory is particularly vulnerable to neurological problems and is the main focus of memory rehabilitation (Wilson, 2009). Implicit memory, however, has also a role to play in rehabilitation particularly for people with severe memory impairments. Evidence suggests that implicit memory is often preserved in these patients even if their explicit memory is

greatly affected (Kolb & Whishaw, 2003). Clinicians may, therefore, build on different forms of implicit memory such as procedural learning and priming in order to teach the use of certain external memory aids (Wilson, 2009). Explicit memory can be further subdivided into semantic and episodic memory. Semantic memory is a store of general factual knowledge such as meanings of words and visual appearance of objects (Tulving, 1972). This kind of memory is usually preserved particularly for information acquired before memory impairment (Wilson, 2009). However, cases of people with TBI exhibiting semantic memory problems have been reported (Wilson, 1997). Memory for personal life experiences (e.g. where one spent their holidays) is called episodic or autobiographical memory (Kolb & Whishaw, 2003). Memory rehabilitation is mainly concerned with episodic memory failures which are the main source of difficulty for memory impaired individuals (Wilson, 2009).

A schematic representation of memory components is presented in Figure 1.

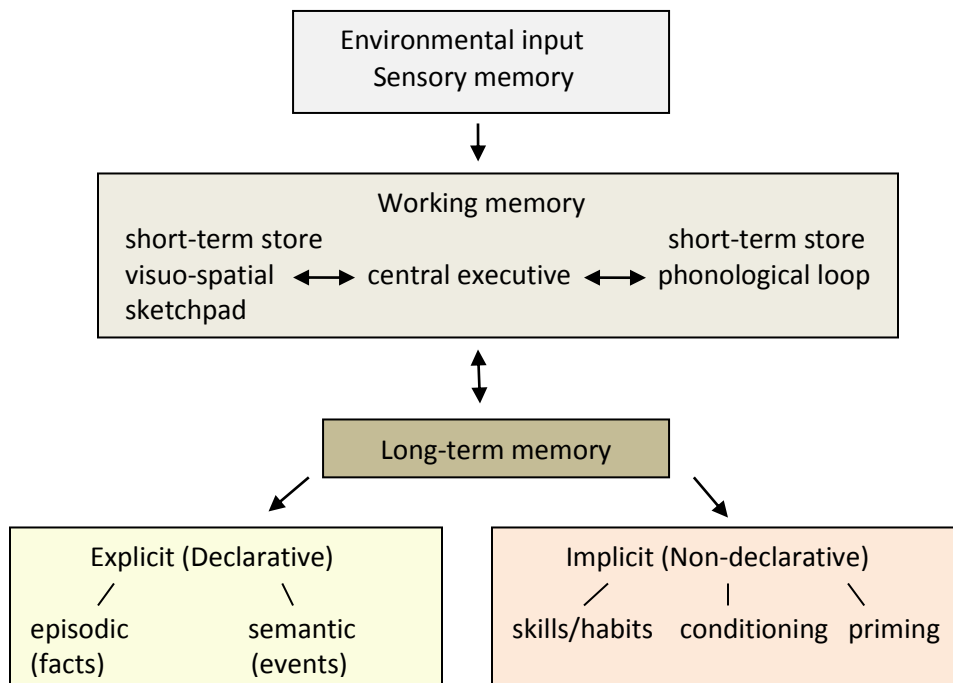


Figure 1. A schematic representation of memory components.

### 1.4.4 Modality specific memory

Despite some controversy in the literature, evidence seems to suggest that the two cerebral hemispheres are specialised in processing different types of material for memory.

A common finding is that left sided deficits are linked to verbal memory problems whereas right sided lesions interfere with visuospatial memory processes (Golby et al., 2001). Milner et al. (1991), for example, showed that patients with lesions in the left prefrontal cortex had difficulties remembering verbal material whereas right sided deficits were associated with visuospatial memory deficits. Similarly, it has been observed that verbal working memory is mediated by areas in the left parietal cortex whereas spatial working memory is implemented by mainly right hemisphere regions (Smith & Jonides, 1998). These findings have important implications for rehabilitation as clinicians can build on the preserved skills in order to compensate for the impaired functions (Skeel & Edwards, 2001; Wilson, 2009;). For example, a person with poor visual memory may be able to verbalise the visuospatial information that needs to be recalled and benefit from relevant memory aids.

### **1.4.5 Prospective memory**

In everyday life, memory does not only refer to the ability to recall past events but also to the ability of remembering to do things in the future. Prospective memory has been defined as “the ability to remember to perform an intended action” (Kinsella, 1996; p.500). The reason that it is described separately is that, although it requires the involvement of memory systems, the existing research evidence implies that it is a distinct and separate memory system or process (Baddeley, 2004). Prospective memory is considered to be a multifactorial construct that, in addition to memory, involves other cognitive processes such as executive functions and attention as well as motivation (Sohlberg & Mateer, 2001). Failures of prospective remembering can occur with disruption to any of these factors, a fact that further complicates assessment and therapeutic intervention (Raskin & Sohlberg, 2009). One way to describe prospective memory tasks is to categorise them as event based tasks, which must be carried out in association with a particular event, or time based tasks which should be carried out at a particular time or after a certain amount of time (Raskin & Sohlberg, 2009).

The importance of this facet of memory is demonstrated by the fact that failure to perform prospective memory tasks is one of the most common complaints of memory impaired individuals (Baddeley, 2004; Mateer et al., 1989; Wilson et al., 2005). It is also considered as one of the most disabling forms of memory impairment as it interferes with individuals’ social life (e.g. forgetting appointments), family life or even personal safety (e.g. forgetting to switch off the oven) (Brooks, 2004; Fleming, 2005). As stressed by

Fleming (2005), frequent prospective memory failures may be particularly embarrassing and result in brain injured people being thought as “unreliable”, limiting their career prospects (Fleming, 2005).

### **1.5 Memory decline as a result of acquired brain injury**

A number of factors may affect memory performance such as age (e.g. Schaie & Willis, 1986), mood disturbances (e.g. Fann et al., 2001) and motivation (e.g. West et al., 2003). Memory decline may also be a direct consequence of brain injury. The current thesis was concerned with memory problems that are secondary to acquired brain injury (ABI) and, more specifically, to traumatic brain injury, multiple sclerosis and stroke. In the following section further information on memory impairment in relation to these diagnostic groups is provided.

#### **1.5.1 Traumatic brain injury**

Traumatic brain injury (TBI) refers to an alteration in brain function that occurs either immediately, at the moment of impact (primary injury), or as a secondary injury due to complications (e.g. hypoxemia, hypotension and intracerebral hematoma) and is manifested as sensory, motor, behavioral and/or neuropsychological changes (Bruns & Hauser, 2003; Hannay et al., 2004). It is usually categorized as open or closed head injury depending on whether the skull is breached (Rao & Lyketsos, 2000). Estimates of the incidence of TBI vary across studies depending on the study site, the criteria for severity classification and the inclusion of deaths (Tagliaferri et al., 2006). The most commonly used indexes for categorizing the severity of head injury are post-traumatic amnesia (PTA) and the Glasgow Coma Scale (Jennett, 1996; Wilson, 1999). According to Kay & Teasdale (2001), each year in the UK about 1 million patients seek medical attention following head injury and, based on the Glasgow Coma Scale classification, 90% of these patients have a mild head injury, 5% have moderate and 5% severe head injury. TBI affects all ages but is considered to be the most common cause of death and long-term disability in young people (Ghajar, 2000). Risk factors include gender, as males are twice as likely as females to experience TBI, unemployment and lower socioeconomic and educational levels (Ponsford et al., 1995).

High rates of disability have been found in young people and adults one year after TBI (Thornhill et al., 2000). There is great heterogeneity in the pattern of impairment among patients and, except from physical impairment, people with TBI may also experience

neuropsychiatric disturbances such as cognitive deficits, personality and mood disturbances as well as behavioural problems (Hannay et al., 2004; Rao & Lyketsos, 2000). Cognitive deficits are common particularly in the domains of attention, memory and executive functioning (Hannay et al., 2004; Rapoport et al., 2005). Self-awareness and the appreciation of one's deficits might also be compromised (Gass & Apple, 1997; Sherer et al., 1998). Cognitive problems are among the most handicapping sequelae of TBI as they interfere with the person's ability to use their knowledge and skills appropriately (Hannay et al., 2004; Rapoport et al., 2005). For example, it has been shown that cognitive deficits are a better predictor of non-return to work than are physical impairments (Brooks et al., 1987).

Memory impairment is a particularly common and debilitating consequence of head injury (Thompson, 1996). Oddy et al. (1985) found that 53% of people with TBI and 79% of their relatives reported persistent memory deficits 7 years after closed head injury. Similar results were observed in a study by Masson et al. (1996) where 67% of people with severe TBI reported memory problems 5 years post injury. Recall of both verbal and visual information is usually impaired (Spikman et al., 1995) and prospective memory failures are a common complaint of people with TBI (Mateer et al., 1987). De Luca et al. (2000) suggested that memory impairment following TBI is due primarily to deficiencies in the initial acquisition of information rather than compromised retrieval. Recognition is usually found to be intact (Spikman et al., 1995). Working memory, which is associated with brain regions often damaged by TBI (e.g. prefrontal cortex), may be impaired (Christodoulou et al., 2001) with the problem becoming particularly obvious in tasks which involve time pressure in carrying a series of actions (Kinsella et al., 1996). Episodic memory may also be problematic as brain injured patients tend to be over-general in autobiographical recall (Williams et al., 1998) while procedural learning is usually preserved (Timmerman & Brouwer, 1999).

Memory impairment has important consequences for survivors of TBI as it often produces a high level of dependency and causes difficulties in many areas of social activity (Hannay et al., 2004). It has been found to be a contributing factor in failure to return to work and a predictor of failure to complete vocational training (Levin et al., 1989; Ryan et al., 1992). Warren et al. (1996) observed that the ability to cope with memory problems without depending on relatives was significantly associated with increased life satisfaction after TBI. In their study Ryan & Lewis (1988) found that people with TBI recognized

memory deficits as major hurdles in improving the quality of their lives (Ryan & Lewis, 1988).

Regarding the course of cognitive problems, the first 6-12 months subsequent to the injury are usually characterized by a rapid recovery phase (Rao & Lyketsos, 2000). After the end of the first year spontaneous recovery levels off and no major improvements are expected after the end of the second year (Hannay et al., 2004; Rao & Lyketsos, 2000). Memory deficits may be resistant to recovery and along with attention, processing speed and executive functions comprise the main permanent cognitive sequelae often observed in people with TBI (Hannay et al., 2004; Rao & Lyketsos, 2000). According to Wilson (2004), about 36% of people with severe head injury will have significant and permanent memory impairment.

### 1.5.2 Stroke

The cerebrovascular accident (CVA) or stroke refers to a “brain injury caused by an abnormality of the blood supply to a part of the brain” (Caplan, 2006, p.32). The word stroke underlines the sudden onset of the impairment as patients are “struck” suddenly and complications in brain functions begin quickly or even instantly (Ibid.). The disruption of blood flow leads to a shortage of vital nutrients (e.g. oxygen and glucose) in brain cells and is the main pathogenic mechanism of stroke (Caplan, 2006). A number of different subtypes of strokes exist which, however, can be divided into two broad groups: haemorrhagic and ischemic strokes (Ibid.). Ischemia accounts for the majority of strokes, approximately 80-85% of cases, and is caused by a blockage of the arteries leading to the brain (Tuomilehto et al., 2010). Haemorrhage is the polar opposite as it refers to bleeding inside the skull either into the brain or into the fluid surrounding the brain (Caplan, 2006). It is responsible for about 5-10% of all strokes but it occurs more often in young people and is associated with a high mortality rate (Tuomilehto et al., 2010).

Stroke is the third most common cause of death in the UK after heart disease and cancer (O’ Mahony et al., 1999). Most people affected are over 65, but anyone can have a stroke, including children and even babies (Hannay et al., 2004). It is estimated that in England and Wales about 110.000 people suffer a first stroke every year – of them around 1000 people are under the age of thirty- and another 30.000 people have a further stroke (Department of Health, 2001). Risk factors include a stressful and unhealthy lifestyle, the presence of certain medical conditions or other predisposing factors (e.g. heredity), smoking, and heavy alcohol consumption (Hannay et al., 2004). Although medical advances

have reduced mortality, about one third of stroke patients die in hospital and about 50% of the survivors are left with moderate to severe disabilities (Bamford et al., 1990). It has been suggested that having a stroke increases the chances of disability more markedly than any other condition (Adamson et al., 2004). Stroke has also been described as the most common cause of complex disability, meaning that it is associated with more individual domains of disability than other conditions (Ibid.).

Depending on the part of the brain that is affected, strokes may result in different types and severities of dysfunction (Caplan, 2006). About one-third of stroke survivors do not achieve functional independence and they have to face a range of physical, cognitive, communication (e.g. aphasia) and psychosocial problems (Hannay et al., 2004; Kase et al., 1998). Stroke has also been reported to impair self-awareness (Hartman-Maeir et al., 2003). Cognitive and emotional difficulties are common and may further result in disruption of interpersonal relationships and social isolation (Mukherjee et al., 2006). Tatemichi et al. (1994) assessed patients three months after admission for ischemic stroke and found that about one third of them experienced cognitive problems including memory, orientation, language and attention.

It has been suggested that memory problems are probably the most common cognitive impairment in this population (Doornhein & deHaan, 1998) although there is some uncertainty over its prevalence, course and implications (Majid et al., 2000). Tinson & Lincoln (1989) found that 49% of non-dysphasic stroke patients demonstrated impaired performance in a standardized memory assessment (RBMT). More recently, a study by Madureira et al. (2001) revealed memory impairment in 20% of survivors 3 months after stroke. Memory difficulties were mild in 38% of the sample, moderate in 10% and severe in 52%. The majority of memory impaired participants was older and had left sided brain lesions (Ibid.). Some evidence on the course of cognitive recovery after stroke comes from the study of Hichstenbach et al. (2003). In a two year follow up, they observed improvements for all cognitive domains in a small subset of participants. The domains in which the biggest improvement was found were attention and language whereas the least improvement was observed in memory function. The majority of patients, however, either showed no improvement or experienced further cognitive decline.



### 1.5.3 Multiple sclerosis

Multiple sclerosis (MS) is a chronic progressive disease associated with the degeneration of the myelin sheath surrounding neurons in the central nervous system (CNS) (Miller, 2001). Based on the rate of progression of the disease four clinical courses have been identified. These clinical patterns are not mutually exclusive and patients may experience changes in the pattern of their disease over time (Birnbaum, 2009). *Relapsing-remitting* is the most common clinical pattern affecting about 85% of people with MS (Murray, 2005). It is characterized by periods in which symptoms are exacerbated followed by periods where varying degrees of recovery are observed (Ibid.). Early in the course of the disease symptoms might resolve completely during the remission phase, however, as the disease progresses complete recovery is less common and deficits are permanent (Birnbaum,2009). About half of the individuals with remitting relapsing MS may start experiencing a progressive deterioration of their condition which may or may not be precipitated by occasional relapses (*secondary progressive*, Ibid.). About 20% of MS patients experience an almost continuous course of disease with some acute periods of symptom relapse (*progressive relapsing*) or without any clear-cut relapses or remissions (*primary progressive*) (Hannay et al., 2004). A smaller percentage of patients experience only infrequent relapses and may still be minimally impaired 15 years or more after diagnosis (*benign MS*) (Hannay et al., 2004). On the other hand, *malignant MS* may cause significant disability within a few years after disease onset, leading to dependency or death (Ibid.).

The estimated prevalence rate of MS in Europe for the past three decades is 83 per 100.000 with higher rates observed in northern countries (Pugliatti et al., 2006). It should be noted, however, that some heterogeneity in prevalence rates is observed between the countries as in the case of Scotland where prevalence rates were found to be higher than for the rest of the UK (Ibid.). This finding is consistent with the hypothesis that onset of the disease reflects a complex interaction between environmental factors and specific genetic susceptibility (Noseworthy et al., 2000; Rosati, 2001). The disease is between two and three times more common in women than in men, although the reason for this is unknown (Stauffer, 2006). It is considered to be the most common disabling neurological condition affecting young adults as the highest prevalence rates have been estimated for the age group 35 to 64 years (Pugliatti et al., 2006). The etiology of the disease is not known but immunological, genetic and viral factors are possible triggers (Hannay et al., 2004). At the

moment MS is incurable but disease progression can be delayed with one of several disease-modifying drugs (Goodin et al., 2002).

The lesions that MS causes in the white matter of the CNS are scattered in time and anatomically and may or may not lead to observable deficits (Hannay et al., 2004). Consequently, the disease is characterised by considerable heterogeneity in clinical manifestations and rates of disease progression. Some common symptoms include problems with balance and mobility, visual impairments (i.e. optic neuritis), sensory disturbances (e.g. numbness, tingling), muscle spasms and spasticity, bowel and bladder dysfunction and fatigue (Hannay et al., 2004). Behavioural and mood disorders are also seen in people with MS such as affective instability, depression and bipolar disorder (ibid.). Evidence suggests that cognitive deficits are particularly common in multiple sclerosis occurring approximately to 45% to 65% of patients at different stages of the disease (Benedict et al., 2006; Rao et al., 1991a). Impaired cognitive domains are usually information processing speed, mental flexibility, memory and attention (Calabrese, 2006). The prevalence and impact of cognitive problems in MS used to be underestimated by researchers and clinicians who focused their attention on physical impairments (Fischer, 2001; Hoffman et al., 2007). This could be explained by a misconception that prevailed in the past according to which cognitive impairment occurs only in late stages of the disease (Fischer, 2001). Another explanation suggested by Fischer (2001) was that the brief assessments used to evaluate disability may not be sensitive to mild cognitive impairment. The nature of cognitive impairment itself, which is usually limited to specific cognitive domains rather than global, may further hinder the detection of cognitive problems (ibid.). It has also been found that families and carers often disregard cognitive deficits attributing them to mood disturbances (Rao et al., 1991a). Over the past few decades, however, MS related cognitive impairment has been increasingly acknowledged and researched (Hoffmann et al., 2007). This interest is probably further stimulated by studies demonstrating the major impact that MS related cognitive impairment has on the patient's quality of life, employment status, social function and mood (Amato, 1995; Cutajar et al., 2000; Rao et al., 1991b). Reports from clinicians also suggest that the presence of cognitive impairment early in the course of the disease may be predictive of a more rapid progression of physical decline (Lynch et al., 2005).

Memory in particular is one of the most consistently impaired cognitive domains in MS, being evident in about 40% to 65% of patients (Calabrese, 2006; Chiaravalloti & DeLuca, 2008, Rao et al., 1993). It appears to be heterogeneous in nature with some patients

showing mild disturbances that are almost undetectable and others exhibiting striking performance deficits (Hannay et al., 2004). Deficits have been observed on working memory (Rao et al., 1993) and episodic memory (Rao et al., 1991a) but less often in semantic memory (Thornton & Raz, 1997) whereas implicit memory is usually preserved (Fischer, 2001). Verbal memory may be affected and people with MS often complain about word-finding problems (Fischer, 2001). Early research suggested that MS preferentially disrupts retrieval while sparing encoding and storage processes (Rao et al., 1989). However, later studies have suggested that encoding problems may be the basis of memory deficits in MS (DeLuca et al., 1998; Thornton et al., 2002). At a functional level, memory problems in MS patients have been identified as presenting significant obstacles to maintaining meaningful employment and to successfully completing rehabilitation and vocational training (Beatty et al., 1995). Memory impaired MS patients take part in fewer social activities than their cognitively intact counterparts and require more assistance in performing complex household tasks (Rao, 1991). Another study (Benito-Leon, 2002) showed that memory impairment in MS patients was directly related to their health related quality of life.

There is some controversy in the literature over the factors that affect the course of cognitive impairment in MS. Rao et al. (1993), did not find any associations between memory performance and disease variables such as course, duration, physical disability and medication use. These findings were partly supported by studies showing that cognitive impairment does not correlate significantly with the duration of the disease and is only weakly associated with the extent of neurological and physical disability (Lynch et al., 2005; Thornton & Raz, 1997). The course of the disease, however, seems to have an effect on cognitive problems as clinical observations suggest that cognitive deficits fluctuate in accordance with disease activity (remissions/relapses) (Fischer, 2001). Other factors that potentially affect cognitive performance include emotional disturbances (Thornton & Raz, 1997) and fatigue (Bryant et al., 2004).

### 1.5.4 Managing memory deficits

#### Physical treatments

The contribution of pharmacologic treatments in alleviating cognitive problems has received considerable research attention. Due to the heterogeneity in the pathology and manifestation of neurologic disorders no single drug exists that could be beneficial to all individuals with acquired brain injury. The majority of the evaluated drugs are psychoactive agents targeting neurotransmitter systems involved in different cognitive and behavioural processes (Whyte, 2008). That means that existing drugs do not tackle specific cognitive deficits, such as memory or attention, but more global cognitive functions. Following a critical review of the literature, Chiaravalloti & DeLuca (2008) concluded that no effective treatment has yet been identified for MS related cognitive impairment. Some evidence suggests that drug induced improvements in memory function may be possible, however, most studies suffer from methodological limitations and further research is necessary (Ibid.). Ferro & Martins (2001) were led to similar conclusions after reviewing studies on the benefits of medication for memory disturbances of vascular cause. Regarding traumatic brain injury, Whyte (2008) noted that psychoactive medication might contribute to the enhancement of learning and recovery processes although the existing evidence is incomplete. As highlighted by Whyte (2008), evaluating the effectiveness of pharmacologic treatment in clinical practice is complicated by variables such as the simultaneous occurrence of spontaneous recovery and day to day changes in performance.

Stem cell implantation as an alternative to drug therapies is a new promising area of research which might lead to new ways of supporting natural neurogeneration (Wilson, 2010). Although treating cognitive impairments pharmacologically may not be feasible in the foreseeable future, some biological factors have been identified as being particularly beneficial for cognitive function. Research findings highlight the potential of nutrition and diet to promote neuronal survival and growth and indirectly facilitate neuronal communication and memory formation (Parrott & Greenwood, 2008). Physical activity may as well support neuronal health and, in combination with diet, contribute to the maintenance and enhancement of cognitive vitality (Kramer et al., 2008).

#### Memory rehabilitation

An alternative approach to managing the consequences of brain injury is rehabilitation. Rehabilitation refers to a wide range of interventions which aim to enable people who

have suffered an injury or a disease to reduce the impact of their problems in everyday life, function as independently as possible and participate effectively in their valued activities (Hart & Evans, 2006; Wilson, 2009). According to Wilson (2009) rehabilitation should be understood as a process which requires the collaboration of patients, clinicians, family as well as members of the wider community. One important component of rehabilitation focuses on cognitive problems. Cognitive rehabilitation involves non pharmacological and non-surgical interventions that aim to restore or improve the functioning of cognitive systems and support brain injured people and their families in accepting and managing the residual cognitive deficits (Prigatano, 2005a; Wilson, 1999). Over the last 30 years there has been an increased interest in the potential of cognitive rehabilitation to alleviate cognitive deficits and improve individuals' well-being. The following section provides information on different approaches to the implementation of memory rehabilitation interventions as well as evidence on their effectiveness.

### 1.6 Approaches to memory rehabilitation

Different and often conflicting approaches in the implementation of cognitive rehabilitation have been developed and evaluated. Their goals and outcomes can be better understood within the framework proposed by the World Health Organisation which is further described below.

#### 1.6.1 The International Classification of Functioning, Disability and Health (ICF)

The World Health Organisation classification systems were developed to provide a conceptual framework for the description of health and disease. The International Classification of Functioning, Disability and Health (ICF-WHO, 2001) is the latest revision which replaced the WHO Classification of Impairments, Disabilities and Handicaps (ICIDH-WHO, 1980). In the modified version, the terms “disability” and “handicap” were abandoned and the focus was shifted from the “consequences of the disease” to the “components of health”. Moving from a purely medical model of disease and a negative definition of health, ICF was designed to classify not only limitations in functioning but also positive experiences such as working or studying. ICF comprises two main parts each with two components: Part one, *Functioning and Disability*, includes a) *body functions/structures* and b) *activities/participation*. The second part, *Contextual factors*, comprises *environmental factors* and *personal factors*. Each component can be expressed in both positive and negative terms to describe either health or disease. For example, in order to indicate non-problematic aspects of health, the components of the first part can be summarised using the term “*Functioning*” whereas the term “*Disability*” is used to summarise impairments, activity limitations and participation restrictions.

As this thesis was concerned with health problems (i.e. memory dysfunction) the *Disability* components are further described. *Pathology* or *disease* refers to abnormalities or changes in structure and/or function of an organ (e.g. stroke). *Impairments* are the manifestations of dysfunction in anatomical parts of the body (body structures) or in physiological and psychological functions (body functions) such as disorders of memory. The term *activity limitations* refers to difficulties in executing activities as a result of underlying impairments (e.g. memory failures), including taking care of oneself, learning and applying knowledge, communicating, maintaining interpersonal relationships etc. *Participation restrictions* are problems an individual may experience at a societal level, in the context of work, interpersonal interactions or leisure activities. To provide a specific example, an individual having sustained a stroke (pathology) may be diagnosed with a

verbal memory deficit (cognitive impairment) which results in him/her experiencing difficulties in remembering peoples' names (activity limitation) which, in turn, undermines his/her social life (participation restriction).

The second part of the ICF provides a classification of the *contextual factors* which are conceptualised as the "background" of an individual's life. *Environmental components* represent the "physical, social and attitudinal environment in which people live and conduct their lives" and are organised from the individuals' immediate to their general environment (WHO 2001, p.16). *Personal factors* are also components of contextual factors and they may include gender, age, coping styles, lifestyle, social background and psychological assets. They are currently not coded specifically in the ICF because of the large social and cultural variance associated with them. It is suggested, however, that they should be taken into consideration as part of the overall model because they are believed to influence -facilitate or hinder- the outcome of an intervention (Peterson, 2005). According to the ICF model, contextual factors interact with all components of disability to determine the level and extent of an individual's functioning.

The ICF aspires to provide the public, researchers, clinicians and policy makers with a common language for describing health and health related states. Its purpose is not to classify people by providing a diagnosis but to consider the functional impact of that diagnosis and offer a multi-perspective appreciation of a person's life. Non-medical factors such as personal character (internal influence) and emotional support provided by family and friends (external influences) are recognised as affecting health outcomes (Tate, 2004). The relationship between the health condition and contextual factors is perceived as dynamic and reciprocal, determining an individual's functioning within a specific domain. Consequently, interventions at one level may indirectly affect and modify other components. Although some controversy exists regarding the classification of certain deficits, the ICF is considered to be an important development in rehabilitation psychology research and practice (Peterson, 2005). It can be used as a model in order to understand the consequences of a health condition, set intervention goals and evaluate rehabilitation outcomes (Lincoln & Nair, 2008; Powell, 1998).

A schematic representation of the ICF components is shown in Figure 2.

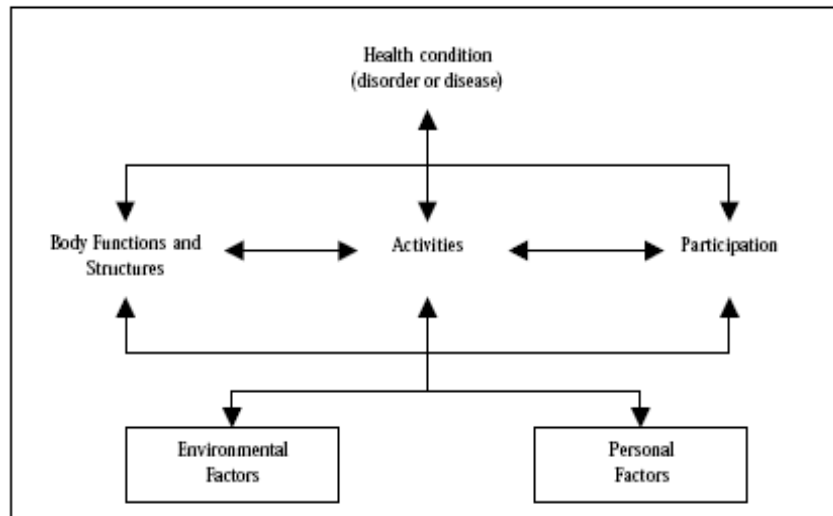


Figure 2. Interactions between the components of ICF (ICF-WHO, 2001; p18).

A distinction is often drawn on whether rehabilitation efforts should aim at restoring impaired cognitive function or at enabling brain injured individuals to adapt to the presence of a cognitive deficit and participate in valued activities. This distinction has been a source of considerable debate in cognitive rehabilitation literature with interventions focusing on either of the two or a combination of the two approaches.

### 1.6.2 Restorative approaches

Restorative interventions stem from the belief that the brain has an inherent capacity to regenerate and recover from the damage that leads to cognitive impairment (Winocur, 2008). As seen in the previous section, some amount of neural recovery or reorganisation occurs spontaneously following brain injury and varies with a number of factors such as aetiology, age, the affected neural circuits and the time post injury (Kolb & Gibb, 2008). According to the cognitive reserve hypothesis, differences in recovery may also be influenced by premorbid characteristics such as level of education and intelligence (Kesler et al., 2003). Another variable that is thought to affect brain plasticity is environmental stimulation. Restorative interventions assume that repeated use of the affected cognitive process will facilitate spontaneous neural recovery and strengthen the underlying neural connections (Anderson et al., 2010). It has been suggested that the strength and duration of neuroplasticity depend on the relevance and intensity/frequency of environmental input (Kolb & Gibb, 2008). Memory rehabilitation programmes that emphasise this approach typically involve the repetitive practice of memory drills. These may be paper



and pencil or computerised exercises and memory games such as learning strings of numbers or lists of words.

Regarding the outcome of restorative approaches, there is work suggesting that partial restoration of function may be achieved in cognitive domains such as attention (Ponsford, 2008; Sohlberg & Mateer, 2001;) neglect (Antonucci et al., 1995) and language (Leon et al., 2008). Memory function, however, appears to be more resistant to restorative efforts as, up to date, limited evidence exists that repetitive practice can lead to direct and lasting improvement of memory (Glisky, 2005; Wilson, 2009, Robertson & Murre, 1999; Sohlberg & Mateer, 2001). According to Sohlberg & Mateer (2001), if any improvement is noticed following memory drills this is probably related to increases in attention ability particularly for memory problems that are secondary to attention deficits. Prospective memory function for example, which has shown to be more responsive to restorative intervention, is suggested to implicate attention and executive function components (Raskin & Sohlberg, 2009). Even when some degree of neuroanatomical reorganisation is achieved, this improvement does not necessarily translate to observable improvement in performance (Dixon et al., 2008). Therefore, the generalisability of any observed benefits from the training situation to real life problems is questionable. Furthermore, as noted by Wilson (2009), the vast majority of restorative programs fail to address the emotional and social consequences of brain injury (Wilson, 2009).

### **1.6.3 Compensatory approaches**

An alternative approach suggests that instead of seeking to restore function the ultimate goal of cognitive rehabilitation should be “to facilitate meaningful and measurable improvements in patients’ everyday functioning” (Anderson et al., 2010, p.50). In order to tackle the functional consequences of impairments in everyday life compensatory interventions have been developed. According to Backman & Dixon (1992), deficits are manifested as a mismatch between individuals’ skills and the extent to which they are able to adapt to environmental demands placed on them. The authors suggested four mechanisms by which individuals may reduce this mismatch and overcome their losses: a) increasing time, effort or training in order to maintain or recover the affected skill (*restoration*), b) developing a new or an existing skill to replace the declining or defective one (*substitution*), c) adjusting one’s goals and expectations to be in accordance with the new situation (*accommodation*) and d) modifying the environment and adjusting expectations of others (*assimilation*). Based on these principles described by Backman &

Dixon, Wilson & Watson (1996) developed a practical framework for understanding the mechanisms by which compensation can be achieved in cognitive rehabilitation. Substitution of the affected function with intact or residual skills and environmental reorganisation were identified as the core mechanisms of compensation and, based on that, compensatory strategies can be broadly classified as: external memory aids, internal memory aids and environmental restructuring. As highlighted by Wilson (2000), these methods are not mutually exclusive and they can be combined in order to achieve optimum outcomes.

### External memory aids

Compensation may be achieved by teaching people how to bypass the cognitive deficit by using their intact skills. This process corresponds roughly to the *substitution* principle described by Backman & Dixon and it is the most widely used and researched in memory rehabilitation. It involves the use of *external* memory strategies which rely more on external objects and parts of the environment than one's memory processes. Different systems for the classification of external memory aids (EMA) have been proposed. Wade and Troy (2001) identified two broad categories of EMA: a) *cueing strategies* which work as reminders of when something should be done but do not provide further information on what it is to be remembered (e.g. alarms, mobiles etc.) and b) *recording strategies* which offer a stored representation of information for future use (e.g. diaries, Dictaphones). An increasing range of EMA is available, as technological developments have allowed the use of electronic devices such as paging systems, computers and mobile phones. Evans et al. (2003) reported that non-electronic EMA were the most commonly used compensation strategies as reported by about 80% of respondents. Among these, calendars, wall charts, notebook lists and appointment diaries were the most popular EMA. Electronic MA were not used by many participants while the most popular among them were alarms.

The effectiveness of non-electronic memory aids has been the subject of many studies with mainly positive results. The study of Schmitter–Edgecombe et al., (1995) showed that notebook training can significantly reduce self-reported memory failures. Zencius et al., (1991) found the use of memory notebooks to be superior to memory retraining strategies (e.g. verbal rehearsal, acronyms) in improving prospective memory performance in a group of TBI patients. The benefit was most apparent for people with more severe memory difficulties for whom retraining techniques were found to be ineffective. McKerracher et al., (2005) evaluated a modified notebook which incorporated a weekly timetable and a

daily to do list. They observed that it improved performance on a series of prospective memory tasks and participants' ability to conduct the tasks independently. Improvements in prospective memory tasks following application of note-taking strategies were also demonstrated in two studies conducted by Fleming and colleagues (Fleming et al., 2005; Fleming et al., 2008). Most importantly, Fleming et al., (2005) found that the gains were preserved at a 2 month follow-up and were followed by a small improvement in participants' level of community integration.

Despite the scepticism of users, technological memory aids are increasingly researched and promising compensation strategies. In a series of case studies, van Hulle & Hux (2006) showed that a combination of alarms and written reminders helped TBI patients to become independent in taking their medication. The Neuropage, a popular paging system, has been extensively evaluated in a series of studies over the last 20 years by the research team of Wilson and colleagues. Neuropage was found to be a cost-effective device, reducing everyday memory and planning problems. In a randomised controlled trial, Wilson et al. (2001) showed that more than 80% of participants using the Neuropage were significantly more successful in carrying out activities such as taking medication and keeping appointments than controls. A more recently developed paging device called Voice Organiser was also found to be effective in reducing memory lapses in two prospective memory tasks (Van den Broek et al., 2000). This device has an advantage over systems such as the Neuropage as it is simpler in use and does not require external programming by a company. Mobile phones have also received research interest as, due to their widespread use in all age groups, they may be one of the first compensatory devices to be considered by rehabilitation professionals (Leong et al., 2006). Their alarm and reminder functions demonstrated effectiveness in facilitating prospective memory (Stapleton et al., 2007) and their use has been linked to improved attendance rates in primary care (Leong et al., 2006).

A general comment that can be made on the above studies is that the effectiveness of EMA has mainly been illustrated in prospective memory tasks. Taking into account the fact that prospective memory incorporates components of attention and executive function it is possible that EMA facilitate compensation for deficits in all these three cognitive domains (Sohberg & Mateer, 2001).

### Environmental restructuring

This approach refers to methods of structuring and rearranging the environment in order to allow individuals to avoid or minimise reliance on their memory function. Different strategies can be employed such as adhering to routines, leaving items to be remembered in easily visible places and keeping environments well organised. For example, remembering to take medication or finding the keys may be facilitated by placing these objects in a fixed part of a room. This strategy could be complemented with an external memory aid, such as post it notes, in order to remind people to look at that place. Suitably structured environments may be particularly beneficial for people with severe memory problems, reducing the load placed on their memory. Changing the layout of a room and/or providing different forms of visual cues like labels on doors and wall or floor signs may prove particularly helpful for these individuals. Wilson & Kapur (2008) stressed the importance of the clinician obtaining a clear picture of a patient's environment in order to intervene and modify environmental features if needed. Distal environmental cues such as the layout of a building, shopping centre or town, may also contribute to improving everyday memory functioning (Wilson, 2009).

### Internal memory aids

Internal memory aids (IMA) facilitate the mental manipulation of information to be recalled and, therefore, encourage people to use their residual skills more effectively. According to Wilson & Kapur (2008), almost all IMA facilitate learning more than rote rehearsal. Based on the memory modality that is employed, IMA may be categorised into *verbal* and *visual* mnemonics (Wilson, 2009). Verbal IMA include simple and widely used mnemonics, such as rhymes, as well as more complicated methods such as first letter mnemonics, where the first letters of words in a sentence correspond to the information to be recalled. The story making method, which involves combining the target items into a story, was evaluated in a RCT by Chiaravalloti et al. (2005). An increase in new learning, as measured by a list learning task, was observed in participants with moderate to severe learning impairment but not in those with mild impairment. However, self-reported improvements in memory were noted in all participants as compared to a control group. Visual imagery, or the transformation of information to be learned into a picture, is one of the most widely researched IMA. Thoene & Glisky (1995) found it to be superior to other approaches for face-name learning. A study by Kaschel et al. (2002) found the use of imagery mnemonics significantly improved delayed recall compared to a control group

which received different memory rehabilitation strategies. Making associations between verbal and visual stimuli, for example names and faces, is has been found to be more effective than drill and practice exercises (Doornhein and De Haan, 1998). However, these benefits were limited to the practiced tasks and did not generalise to other situations.

Errorless learning and the method of vanishing cues, capitalise on the usually spared implicit memory ability of memory impaired individuals. The vanishing cues strategy involves gradual withdrawal of the cues provided to people to allow successful recall. This method has been shown to be beneficial for teaching computer skills to amnesic people (Glisky et al., 1994). Errorless learning is based on research showing that memory impaired individuals learn better when they are prevented from making mistakes during the learning process (Wilson et al., 1994). Elimination of errors can be achieved following a number of strategies such as breaking down the task into small steps, avoidance of guessing and correcting mistakes as soon as possible (Sohlberg et al., 2005). In a review of studies on errorless learning, Clare & Jones (2008) concluded that the method is advantageous over conditions in which errors are allowed, at least for certain types of tasks (e.g. face name associations). Nevertheless, the degree to which these benefits generalise to novel situations needs to be answered by future research (Ibid.).

### Issues related to the choice and application of memory aids

Not everyone benefits from the same strategy and the choice of memory aids should be informed by individual abilities, needs and preferences (Wilson, 2009). Memory aids may be targeting different stages of information processing depending on whether the problem is related to encoding, retrieval or storage (Skeel & Edwards, 2001). For example, people who show a greater difficulty with encoding may need to consider organising their environment so that distracters are minimised and adequate attention is paid to the information. External aids such as notebooks, alarms and pagers may be particularly beneficial for individuals with retrieval problems. Exploring peoples' modality specific memory abilities (i.e. sensory, verbal, visual) can also inform choosing the most appropriate strategy (Skeel & Edwards, 2001). People with verbal memory strengths may benefit from digital voice reminders or by reading out loud the information to be remembered. It is, therefore, highly important that training in use of aids is preceded by thorough neuropsychological assessment in order to identify specific strengths and weaknesses. Interestingly, the literature review revealed that, over the past decade, there has been a relevant paucity of research focusing on the evaluation of single memory

strategies. This probably reflects the fact that the majority of rehabilitation programs employ a variety of internal and external memory aids in order to respond to participants' specific needs and abilities. In one of the few studies that have detected improvements in memory function (i.e. verbal learning task, face-name associations), a training approach combining external and internal aids was employed and was found to be superior to a drill and practice approach (Berg, Koning-Haanstra & Deelman, 1991).

Despite their apparent simplicity, the application of memory aids is not always a straightforward process. McKerracher et al. (2005), highlighted that patients' limited awareness of deficits which may lead to them disregarding the need for compensation. As a result, these individuals may either refuse to adopt compensatory strategies or exhibit low motivation and persistence when putting the strategies into practice. Kapur et al. (2004) suggested that "metamemory skills" training may be needed in order to enable people to realise their problems, identify the situations where aids are required and chose the right aid for the particular circumstances. Resistance to the use of compensatory strategies may also be linked to the belief that external memory aids minimise or inhibit natural recovery (Wilson & Watson, 1996). As noted by Prigatano (2000), people may believe that by exclusively relying on their memory capacity, they may improve it. Providing some basic information on how memory works might reassure people that the use of aids will not attenuate their cognitive functions (Kapur et al., 2004).

A certain level of preserved cognitive processes is needed in order to successfully apply aids. People need to be able to plan, organise their efforts, concentrate and remember to put the aids into practice. This means that people with severe cognitive impairments, who need aids the most, may experience the greatest difficulty when using them (Wilson, 2009). Another reason for avoiding the use of MA may stem for peoples' feelings of embarrassment about their condition (Wilson, 2005). Training programmes that incorporate psychotherapeutic interventions may be particularly helpful in dealing with issues of denial and low self-confidence. According to a study by Evans et al. (2003), younger age and premorbid use of memory aids seem to predict better use of compensatory strategies whereas very severely impaired individuals with widespread deficits appear to compensate less well. Further research, however, is necessary in order to acquire a better understanding of how personal and neuropsychological characteristics affect compensation outcome.

### Aiming for restoration or compensation?

Compensatory approaches have been suggested by many rehabilitation professionals as the treatment of choice, a view which is supported by the majority of research evidence in the area (Ben-Yishay, 2000; Robertson, 2002; Wilson, 2009). As suggested by Prigatano (1995), "If a memory compensation helps the patient to be realistic and independent in daily activities and fosters greater social integration then it can be credited as a success even if the underlying memory function remains impaired" (p.607). Sohlberg et al., (2007) reviewed the available literature on external memory aids and found that the majority of studies supported the effectiveness of EMA in helping people with memory impairments complete everyday activities. Following two systematic reviews of cognitive rehabilitation Cicerone et al. (2000) recommended compensatory memory training (i.e. internal and external memory aids) as a practice standard, particularly for individuals with mild memory impairment. Cappa et al., (2005) came to the same conclusions after conducting a systematic review on behalf of the European Federation of Neurological Societies. Following a systematic review focusing on the effectiveness of memory rehabilitation for people with stroke, Nair (2007) noticed that results appeared to follow a general trend: compensatory strategies were more beneficial than restorative approaches or lack of treatment.

It has to be noted, however, that the absence of evidence in support of restitution-oriented interventions does not prove the absence of any effect (Evans, 2006). Hildebrandt et al., (2006) argued that methodological limitations, such as the intensity of the administered intervention, may account for the lack of effect observed in most studies. Hildebrandt et al. compared an intensive restitution oriented treatment focusing on learning word lists to a group focusing on teaching compensatory memory strategies and a control group receiving similar training to the restitution group but with lower intensity. They found that the high intensity restitution group showed greater improvements than the other two. Furthermore, there was some evidence for generalisation of the effects to other tasks such as prospective memory tasks. Despite the encouraging findings, it remains to be clarified whether memory improvement reflects restoration of function or a change in the learning strategies employed by participants. What needs to be taken into consideration is that restoration and compensation are not totally independent and unrelated processes. Behavioural changes are based on learning which occurs as a result of repetitive activation of cognitive processes (Sohlberg & Mateer, 2001; Wade, 2010).

Advances in neuroimaging techniques may help clarify the effects of training on functional reorganisation and contribute in guiding rehabilitation goals (Levin, 2006).

According to Prigatano (2000), rehabilitation should aim at “facilitating recovery during the first few years after injury and preventing long-term deterioration” (p.124). Restorative approaches may be set as a treatment priority in the early days following brain injury in an attempt to enhance the rate of recovery. After natural recovery has stopped or slowed down intervention objectives may need to be revised and rehabilitation efforts focus on teaching people how to cope with their residual disabilities (Wilson, 2009).

### **1.6.4 Holistic approaches**

Prigatano (1995) criticised modern memory rehabilitation approaches for overemphasising cognitive strategies while disregarding contextual factors. Holistic programmes are concerned with the person as a whole rather than focusing exclusively on cognitive problems. This approach, pioneered by Ben-Yishay and Prigatano, is based on the belief that it is not possible to isolate cognitive impairment from the individuals’ psychosocial function and personal characteristics (Sohlberg & Mateer, 2001). In accordance with the ICF descriptive framework, holistic programmes take into account all the three levels of functioning in order to address the totality of peoples’ experience of illness.

One of the issues that receive considerable attention in holistic programmes is the way cognitively impaired individuals perceive and appraise their difficulties. Ben-Yishay (2000) identified the “awareness and understanding stage” as a critical clinical landmark in the rehabilitation process. According to the author, during this stage participants are expected to achieve a better understanding of the nature of their cognitive problems and how they affect various aspects of everyday life. Awareness, or self-awareness as it is often termed, is defined as “the capacity to perceive the ‘self’ in relatively ‘objective’ terms while maintaining a sense of subjectivity” (Prigatano & Schacter, 1991, p. 13). Impaired self-awareness is a common sequel of acquired brain injury with a particularly high prevalence in people with traumatic brain injury (Bach & David, 2006). It has been recognised as one of the greatest obstacles in brain injury rehabilitation (e.g. Bach & David, 2006; Prigatano, 2005b; Schonberger et al., 2006). Impaired self-awareness may lead to unrealistic expectations and undermine participants’ motivation and engagement with rehabilitation (Fischer et al., 2004; Ownsworth & Clare, 2006; Paulsberg, 1995). Because of this, managing awareness problems has been an integral component of many holistic



rehabilitation programmes (e.g. Cheng & Man, 2006; Prigatano & Fordyce, 1986). These programmes involve interventions such as providing information to both patients and their families about brain injury as well as employing psychotherapeutic techniques to help participants come to terms with their disabilities (Anderson, 2010; Solberg & Mateer, 2001). In the study of Ownsworth & McFarland (1999), a combination of diary-use training with training promoting self-regulation and self-awareness resulted in more diary entries and fewer memory complaints than a diary only approach.

Memory problems often result in emotional distress including feelings of fear, loss, anger and increased anxiety (Wilson, 2004). Relaxation therapy and group work may contribute to the management of these problems and are commonly included in holistic rehabilitation programmes (Prigatano, 2000). Personal factors such as coping styles, attitudes and beliefs, may also interact with peoples' ability to engage and benefit from memory rehabilitation (Prigatano, 1995). The importance of health beliefs such as locus of control and self-efficacy in influencing rehabilitation outcome is increasingly appreciated by rehabilitation professionals (Dawson & Winocur, 2008; Sohlberg & Mateer, 2001). Sohlberg & Mateer (2001) stressed the need to enhance peoples' confidence in their ability to manage their cognitive problems and increase their sense of self-efficacy.

Regarding the effectiveness of holistic rehabilitation programmes existing evidence is encouraging. Prigatano et al., (1994) showed that participation in a holistic rehabilitation programme may be related to increased productivity. The researchers compared a group of TBI patients who were admitted to a holistic rehabilitation programme with an historical control group of TBI patients. Before enrolling in the programme, the control group had received different forms of rehabilitation which were not further specified by the authors as detailed records of these patients were not available. It was shown that a greater number of participants receiving the intervention got involved with voluntary or gainful employment compared to the controls. These improvements were associated with increased awareness and acceptance of the problems and good working alliance with the rehabilitation staff. Evidence from research with TBI groups suggest that rehabilitation programmes which incorporate both individualised cognitive and psychosocial interventions achieve the greatest overall improvement in functioning (Cicerone et al., 2000). Cicerone et al. (2000) proposed that peoples' capacity to acknowledge and adapt to cognitive deficits may moderate the effectiveness of these programmes. An updated review from the same authors (Cicerone et al., 2005) further supported the effectiveness of holistic programmes for improving community integration and social participation

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following stroke or TBI. More recently, Cicerone et al. (2008) compared a holistic programme to a standard neurorehabilitation consisting primarily of individual discipline specific therapies (e.g. occupational therapy) that targeted specific deficit areas. The holistic programme was found to be superior to standard neurorehabilitation in improving self-efficacy for the management of symptoms, perceived quality of life and community integration.

### **1.7 Evaluation of memory rehabilitation in people with acquired brain injury: the “ReMind” randomised controlled trial**

This thesis was conducted within the context of the “ReMind” randomised controlled trial evaluating the effectiveness of memory rehabilitation for people with memory problems following traumatic brain injury, stroke or multiple sclerosis (das Nair & Lincoln, 2012). The following section provides a brief overview of the aims, methods, chronology and findings of the trial in order to set the background for the subsequent chapters. A more detailed description of the methods of the study is provided in Chapter 3 p.63.

#### **1.7.1 Background and aim of the RCT**

Systematic reviews of memory rehabilitation interventions following stroke, multiple sclerosis and traumatic brain injury have indicated that there is insufficient evidence to support or refute the effectiveness of such interventions (e.g. Carney et al, 1999; das Nair & Lincoln, 2007). Positive results have been reported by single case or small group studies, however, conclusions cannot be reached due to the lack of well-conducted randomised controlled trials.

The ReMind randomised controlled trial was conducted in order to address this gap in the literature. The aim of the trial was to compare the effectiveness of compensation and restitution memory rehabilitation strategies with a self-help control intervention on memory functioning, mood, independence in activities of daily living and adjustment. A summary description of the RCT is given in Table 1. The trial was conducted in two phases: a pilot and a main trial. A chronology is presented in Table 2.

Table 1

*Summary description of the ReMind RCT*

<b>Overall design</b>	single-blind randomised controlled trial
<b>Random allocation:</b>	random allocation in cohorts of four to compensation, restitution or self-help groups
<b>Groups</b>	
<b>Location:</b>	University of Nottingham/Derby City hospital
<b>Format:</b>	multi-week, group-based rehabilitation programmes
<b>Number of sessions:</b>	1 introductory individual session and 10 group sessions (1 session per week)
<b>Length of each session</b>	1 ½ hours with a 10-15 minute break
<b>No of participants in each group:</b>	4
<b>Target population:</b>	<i>Diagnosis:</i> People with brain injury due to TBI, MS, Stroke <i>Age:</i> 18 years of age and older <i>Level of memory impairment:</i> overall profile score of <3 on the Rivermead Behavioural Memory Test- Extended version or <25 <sup>th</sup> percentile on the Doors and People test
	<ol style="list-style-type: none"> <li>1) <b>Focus of restitution programme:</b> training in use of internal memory aids, attention training techniques, repeated practice and extended rehearsal</li> <li>2) <b>Focus of compensation programme:</b> training in use of external memory aids and ways of adapting to memory problems</li> </ol>
	<b>Shared goals of restitution and compensation (intervention groups):</b>
	<ol style="list-style-type: none"> <li>a) increase knowledge about brain damage and memory functioning</li> <li>b) encourage the use of memory aids</li> <li>c) develop and enhance participants' ability to cope with memory problems</li> <li>d) provide peer support</li> </ol>
	<ol style="list-style-type: none"> <li>3) <b>Goals of self-help control programme:</b> emotion focused programme, memory training not offered, encourage participants to discuss emotional issues related to impairments, practice relaxation exercises (e.g. Jacobson's Progressive Muscular Relaxation)</li> </ol>
<b>Outcome evaluation:</b>	
<i>a) quantitative measures:</i>	
-memory functioning: Everyday Memory Questionnaire, Rivermead Behavioural Memory Test-Extended version,	
-use of memory aids: Internal and External Memory Aids Questionnaires	
-mood: General Health Questionnaire-12, Wimbledon Self Report Scale	
-independence in activities of daily living: Nottingham Extended Activities of Daily Living Scale	
<i>b) post-intervention qualitative interviews with participants</i>	
<b>Follow-up assessment points:</b> 5 and 7 months after randomization	
<b>Feedback interviews:</b> 7 months after randomisation	

Table 2  
*Time course of the ReMind studies*

<b>Pilot phase RCT</b>	
<b>Recruitment:</b>	May 2004- April 2006
<b>Group sessions:</b>	July 2004-July 2006
<b>1<sup>st</sup> follow-up:</b>	October 2004- November 2006
<b>2<sup>nd</sup> follow-up/ Interviews:</b>	December 2004- February 2006

<b>Main phase RCT</b>	
<b>Recruitment:</b>	January 2007- April 2008
<b>Group sessions:</b>	May 2007- August 2008
<b>1<sup>st</sup> follow up:</b>	September 2007-October 2008
<b>2<sup>nd</sup> follow-up/Interviews:</b>	November 2007- January 2009

### 1.7.2 Findings

#### Pilot study

Improvements over time were noted in both intervention groups, compared to the self-help group, on the Everyday Memory Questionnaire and the Internal Memory Aids Questionnaire but they did not reach statistical significance. Based on the quantitative data, there was no evidence to suggest that memory rehabilitation improved everyday memory or other functional outcomes either immediately post-intervention or at long-term follow up. However, improvements were informally reported by participants during the group sessions. The results are presented and discussed in a PhD thesis (Nair, 2007).

#### Main phase

When the studies of the current thesis were conducted, the results of the main phase of the RCT were not yet available. Data analyses were completed in August 2011. A detailed account of the results is presented in a research paper (Nair & Lincoln, 2012). In order to increase the sample size, data from the main RCT were combined with the data obtained in the pilot study. In sum, 72 people were randomised to one of the three programmes of the ReMind study (mean age 47.7, *SD* 10.2; 32 men). The results indicated

there were no statistically significant differences between the restitution and compensation treatment programmes and the self-help programme in self-reported memory problems in daily life (Everyday Memory Questionnaire). However, both restitution and compensation based memory rehabilitation programmes appeared to lead to an increased use of internal memory aids at both five months ( $p=.006$ ) and seven months ( $p=.049$ ). The authors suggested that this trend might be explained by the fact that internal memory aids had not been taught as part of clinical practice whereas participants may have previously been taught to use some external memory aids and therefore the effect of the intervention on these was smaller. There were no statistically significant differences between the groups on measures of mood, adjustment and activities of daily living.

A number of factors might affect the outcome of cognitive rehabilitation making the interpretation of these findings a difficult task. Possible reasons for the lack of effect of memory rehabilitation were considered and discussed by the authors (see Nair, 2007; Nair & Lincoln, 2012). Failure to find statistically significant differences between the intervention and the self-help groups could mean that the interventions were ineffective. Alternatively the results may reflect an implementation failure rather than genuine ineffectiveness. In both studies, however, observations of the actual running of the group sessions confirmed that the programmes were delivered according to the predefined protocol. The sample size may have been inadequate and lacked power to detect measurable differences between the groups. Small but still clinically valuable differences may have been present which would require larger trials to detect. Furthermore, the intensity of the intervention may have been inadequate. It has to be noted, however, that the rehabilitation programmes evaluated in this study were developed keeping in mind their applicability to clinical settings.

Before drawing any conclusions on the outcome of an intervention, the way this outcome was assessed needs to be considered. The findings of the ReMind trial engender questions regarding the quality and appropriateness of the measures used to evaluate outcome. As noted by Streiner & Norman (2008) it is often difficult to dissociate the characteristics of outcome measures from those of the intervention itself. The use of appropriate measures has been highlighted as one of the main determinants of the outcome of complex interventions such as cognitive rehabilitation (e.g. Craig et al, 2008). Poor quality measures may provide an inaccurate appraisal of the effects of an

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intervention leading to spurious conclusions. As noted earlier, benefits were informally reported by participants during the pilot phase of the ReMind study. It is possible that participants did experience some meaningful changes which, however, were not picked up by the assessment tools used in the trial. The inconsistency in the findings of previous memory rehabilitation studies may also be partly explained by the types of measures employed.

In order to further assess this possibility, the following chapter will provide a critical appraisal of the outcome measures used in the ReMind trial. Outcome measures commonly used in memory rehabilitation studies will also be reviewed in order to explore their ability to evaluate outcome in memory rehabilitation for people with acquired brain injury.

## 2: Measurement of outcome in memory rehabilitation

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### 2.1. Chapter outline

The chapter starts with a brief consideration of the challenges in assessing the outcome of cognitive rehabilitation interventions. A number of criteria for selecting appropriate measures of outcome are outlined. Using these criteria as a guide, information is provided on the content and psychometric properties of the outcome measures used in the ReMind trial. Outcome measures identified as widely used in memory rehabilitation studies are also reviewed, highlighting strengths and limitations. The review is divided in standardised measures of memory performance and self-report questionnaires of memory failures. Questionnaires of mood and participation are also briefly considered. Reasons for which these measures may not be responsive to the effects of memory rehabilitation are discussed.

### 2.2. Challenges in evaluating complex interventions

Outcome refers to “the effectiveness of activities in relation to the achievement of the intended goal” (Bowling, 2009; p.13). Health service outcome, in specific, was described by Bowling (2009) as “the effects of health services on patients’ health as well as patients’ evaluations of their health care” (p.130). Assessing the outcome of rehabilitation is not an easy task as many variables may interfere with a person’s long-term adaptation (Sohlberg & Mateer, 2001). Wade (2003) outlined a number of difficulties that complicate the process of outcome evaluation in rehabilitation. In pharmacological interventions, the active ingredients are known and they are expected to affect all participants in the same way and within a specific time frame. Cognitive rehabilitation, on the other hand, involves complex interventions which consist of a number of components that interact or act independently (Campbell et al., 2007). Their implementation requires changes in participants’ thoughts and behaviours and is directly affected by personal and contextual factors (Wade, 2003). Consequently, it is likely that individual differences will be observed regarding when and how people experience the effects of rehabilitation. This complexity may lead to difficulties in isolating the specific mechanism of action or “active ingredient” and consistently replicating the intervention (Lewin et al., 2009). While medical interventions are primarily focused on specific body functions and structures (impairment)

rehabilitation interventions are usually multifocal, interested in altering individuals' levels of activity and participation. Therefore, rehabilitation professionals may need to use a selection of tests tapping different areas of interest in order to obtain a comprehensive and rounded description of the effects of an intervention.

The scientific integrity of the outcome measures needs to be ensured in order to reach safe conclusions on the effects of the intervention. The following section reviews the psychometric properties that should be considered before selecting instruments to assess outcome.

### **2.3. Criteria for selection of outcome measures**

In order to choose the most appropriate measures of outcome, methodological and statistical criteria need to be considered. The test or scale should be judged in relation to three basic psychometric properties: reliability, validity and responsiveness to change.

Validity refers to the extent to which an instrument really measures what it purports to measure and it is assessed through a number of processes. First of all, the measure needs to appear relevant and plausible in a particular setting, and the instructions and questions phrased using concise, clear and unambiguous language. Lezak (2004) stressed the importance of *face validity* in neuropsychological assessment, as people with impaired cognitive abilities may reject tasks that are too confusing for them. The extent to which a measure covers a representative sample of what it is intended to measure is referred to as *content validity* (Anastasi & Urbina, 1997). As noted by Sohlberg & Mateer (2001), realistically a measure cannot fully capture all the relevant aspects of a construct and, therefore, more than one measure would be required in order to acquire a comprehensive appreciation of the construct. Similarly to face validity, the evaluation of content validity is based on subjective judgments made by experts. Further evidence would be, however, needed in order to support the value of the measure in relation to the theoretical construct it is supposed to measure.

*Construct validation* requires an on-going process where specific hypotheses are formed based on the theoretical construct and examined against data collected through the measure. For example, the measure is expected to correlate with similar variables (*convergent validity*) whereas low correlations should be seen between the measure and other unrelated constructs (*discriminant validity*) (Bowling, 2009). In this way, the scientific integrity of both the theory of the construct and the instrument is examined (Sohlberg & Mateer, 2001). Users may also be interested in the degree to which data obtained from



the instrument are consistent with other observable criteria (*concurrent validity*) or in whether these data can predict future performances, such as which patients will benefit the most from rehabilitation (*predictive validity*). The ability of an instrument to predict behaviour and functional outcomes is often referred to as *ecological validity* and will be further discussed later in this chapter. As has been highlighted by many authors (e.g. Anastazi & Urbina, 1997), validity is not a stable property of a measure but it should be established in relation to the particular use the measure is intended for. For example an instrument may be valid for use as a diagnostic tool for healthy elderly people, but be inappropriate for use as a measure of outcome for neurologically impaired individuals.

Reliability indexes provide an indication of the degree to which variation in test scores reflects true differences in the assessed characteristics rather than chance error (Anastazi & Urbina, 1997). *Internal reliability* refers to the consistency of responses to all the items in a test and is indicative of the extent to which items measure the same construct (Strauss et al., 2006). Score consistency may also be judged on the degree of agreement between two or more raters of the same test administration (*inter-observer reliability*). Another method of assessing reliability is by re-administering the instrument to the same people after a time interval long enough to ensure that respondents will not remember their first answers and short enough to assume that no changes in the assessed characteristics have taken place (*test-retest reliability, or stability*). Lezak (2004) commented on the difficulty of establishing the stability of test performance of people with brain injury due to fluctuations in their level of mental efficiency. Spontaneous recovery and adjustment may occur in these populations affecting performance in various ways. As an alternative, Lezak suggested that reliability should be established in healthy control groups. Reliability tends to increase with the number of items and, therefore, the reliability of test batteries that rely on summed or average scores may appear to have satisfactory levels of reliability which, however, does not correspond to the reliability of component subtests (Streiner & Norman, 2008).

Establishing a measure's stability is essential in order to be sure that any observed variation over time is associated with real changes in peoples' performance and not to other variables. However, a test that is not responsive to performance fluctuations is not useful as a measure of outcome in rehabilitation. Measures of outcome in cognitive rehabilitation need to be able to detect clinically meaningful change. In the literature the terms "*sensitivity*" to change and "*responsiveness*" are used interchangeably; however, some authors draw a distinction between the two. According to Liang (2000), sensitivity to

change refers to the ability of a measure to detect change even if that change is not relevant or meaningful to the researcher. Responsiveness, on the other hand, refers to the ability of a test or scale to assess changes which are clinically important or meaningful to the decision maker. Some authors suggest that responsiveness can be considered a form of construct validity while others argue it should be treated as a third basic psychometric property of equal importance to reliability and validity (Streiner & Norman, 2008). Evaluating the sensitivity of an instrument in rehabilitation can be challenging as the representativeness of the chosen intervention and the extent of expected effects may be difficult to pre-specify.

Repeated assessment of patients with the same instrument is often required in rehabilitation in order to assess the effects of an intervention. In this case, it is possible that improvements occur simply as a result of practice with the test material. Cognitive assessments and especially measures of memory and learning may be particularly vulnerable to practice effects (Lincoln & Nair, 2008; Strauss et al., 2006). Explicit or implicit learning might take place and affect performance (Strauss et al., 2006). In order to control for this bias the use of alternative or “*parallel*” versions of the same instrument needs to be considered although it is not always possible to eliminate practice effects (Ibid.) and parallel versions do not always exist.

Other issues that should be taken into account in test selection are the practical ones of administration time and costs. Tests and scales should ideally be as short and simple as possible, and their results easy to communicate particularly when they are intended to be relayed to cognitively impaired individuals (Wade, 2003). Another consideration is whether to use an instrument specifically tailored to the area or population of interest or another generic instrument. One of the arguments in favour of generic scales is that they allow comparisons across different conditions and interventions (Streiner & Norman, 2008). Furthermore, it is more likely that a generic scale will be more widely used and, therefore, its validity and reliability will be more extensively researched (Ibid.). On the opposite side of the argument, generic scales include questions that may be irrelevant or inappropriate for a specific population. For example, the Cognitive Failures Questionnaire (Broadbent et al., 1982) considers cognitive problems that may not be applicable to individuals who only experience memory difficulties. Unless more items on memory are added, increasing considerably the length of the questionnaire, the few relevant items may fail to detect changes following a memory rehabilitation programme. Streiner & Norman (2008)

recommended the use of a well-established generic scale in combination with a specific one as the best option.

### **2.4. Commonly used measures of outcome in memory rehabilitation**

In a survey aimed at identifying the most commonly used outcome measures for rehabilitation in the UK, Turner-Stokes & Turner-Stokes (1997), found that a very wide range of measures were used in clinical practice many of which were poorly validated. Carney et al. (1999) noted that about 25% of the measures used to evaluate the outcome of cognitive rehabilitation in TBI populations were “clinic-specific” and highlighted the lack of an established set of outcome measures. The lack of consensus on outcome measures and the difficulties that this poses for comparing across studies and establishing the effectiveness of cognitive rehabilitation has been emphasised by researchers (Cicerone, 2000; 2005; Lincoln & Nair, 2008). Similarly, a review of studies on memory rehabilitation revealed great heterogeneity in the measures used to evaluate outcome. In addition to widely used and well validated measures many researchers utilised unpublished “clinic-specific” measures, tailored to specific training programs with questionable psychometric properties and generalisability in different contexts. Therefore, a comprehensive review of the outcome measures used in memory rehabilitation is not feasible here and is out of the scope of the present study. In addition to the outcome measures used in the ReMind trial, a brief description of outcome measures most commonly used in memory rehabilitation studies will be provided, considering their strengths and limitations. This review is divided in two parts, one focusing on “objective” performance based outcome measures and one on “subjective” self-report methods of collecting information.

### **2.5. Objective neuropsychological memory measures**

Objective neuropsychological tests are designed to evaluate the nature and severity of specified cognitive impairments. In this section a number of standardized memory measures are reviewed. They are classified into: a) laboratory memory tests, which comprise laboratory developed memory tasks, and b) measures developed with ecological validity in mind.

### **2.5.1. Laboratory memory tests**

#### Wechsler memory scale-third edition (WMS-III; Weschler, 1997)

The WMS-III and its predecessors are considered to be the most commonly used tests of memory functioning (Strauss et al., 2006). The third edition was validated on a wider age range (16-89 years) and includes 11 subtests, six of which are considered primary and five optional. The subtests can be combined to obtain summary scores for: a) immediate and delayed auditory memory, b) immediate and delayed visual memory, c) auditory recognition, d) working memory, e) immediate memory that includes both visual and auditory components, f) delayed memory that includes both visual and auditory components. According to the manual, the comparison of summary scores offers the potential to evaluate processes of encoding, consolidation and retrieval. For example, low delayed performance relative to immediate performance may indicate weaknesses or deficits in the ability to retain information. Similarly, when auditory delayed performance is lower than the auditory recognition delayed performance some type of retrieval deficit may be present. This is because retrieval through recall is considered to be more demanding than retrieval through recognition (WMS-III, 1997).

According to the technical manual (WMS-III, 1997, 2002), the internal consistency and stability coefficients of subtests and indices are adequate to high and inter-rater reliability is excellent. Among its advantages is the fact that it has been widely used and researched and its sensitivity to memory disturbances has been demonstrated in a variety of clinical populations (Lezak, 2004; Strauss et al., 2006). It is, however, rather lengthy for assessing outcome as the administration time for the whole battery requires at least two hours. In memory rehabilitation the battery is rarely used as a whole but instead specific subtests are administered to assess the memory components of interest (Skeel & Edwards, 2001).

#### California Verbal Learning test (CVLT- II; Delis et al, 2000)

This is a list learning task that assesses both recall and recognition of verbal material. The items are vegetables, animals, ways of travelling and furniture. The order with which respondents recall the items may give an indication of whether they used semantic associations as a learning strategy (i.e. grouping items from the same categories). Various scores can be obtained including measures of immediate recall, percentage of information retained over time, recall versus recognition etc. Short forms and parallel forms are also included. Internal consistency and test-retest reliability were found to be high (Delis, 2000). In the study of Higginson et al. (2000), the long delay free recall task was found to

be an ecologically valid test correlating significantly with a scale assessing activities of daily living in multiple sclerosis. The test, however, has been criticised for not being a "pure" measure of learning ability but rather a measure of the interaction between verbal memory and concept apprehension (Lezak, 2004).

### The Rey-Osterrieth Complex Figure test (ROCT; Osterrieth, 1944; Rey, 1941)

People are presented with a complex line drawing and are asked to copy it and then draw it from memory. A delayed reproduction trial may also be used. This measure has gained popularity possibly because it provides information not only on visual memory performance but also on a number of other cognitive processes such as perceptual, organisation and problem solving functions. Various scoring systems have been proposed some of which take into account qualitative aspects of performance (e.g. organisation, symmetry etc.). This can be considered either as a strength or limitation of this measure depending on the aim of the assessment and the experience of the administrator. The variability in the scoring criteria means that scoring may be open to subjective interpretation which undermines the ability of the measure to be used as a quantitative assessment of impairment. On the other hand, qualitative information can be used to reveal aspects of respondents' learning and recall strategies (Mayes & Warburg, 1992; Strauss et al., 2006). For example, people who use an organisational strategy to group features of the figure into meaningful units may show an advantage in recalling the figure compared to participants who rely on isolated elements of the drawing (Strauss et al., 2006).

Meyers & Meyers found satisfactory levels of test-retest reliability (1995). There is conflicting evidence on the ability of ROCT memory recall and recognition trials to discriminate between healthy and brain injured groups (e.g. Ashton et al, 2005). Ashton et al. 2005, argued that perceptual organisation skills may interfere with memory performance and suggested clinicians to use the test in conjunction with other tests of learning and memory. Another potential pitfall is that subtle motor or perceptual problems may confound the outcome (Lezak, 2004). In the study of Ryan & Ruff (1988), ROCT was one of the outcome measures used to assess the efficacy of a memory retraining programme for head injured patients. Participants' performance on the ROCT improved following the programme, however, this effect was restricted to participants who demonstrated mild residual deficits.

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### Doors and People test (D&P; Baddeley et al, 1994)

The battery includes four subtests assessing visual recognition (Doors), visual recall (Shapes), verbal recognition (Names) and verbal recall (People). It yields a single age-scale overall score as well as separate measures of visual and verbal memory, recall, recognition and forgetting. According to the manual, the inter-rater reliability is excellent ( $r=.98$ ); however, no information is provided on test-retest reliability and practice effects. Some evidence of test-retest reliability was provided by Wilson et al. (2000) who studied the performance of people with severe head injury on the verbal and visual recognition tests. No changes over time were found on the verbal recognition tasks whereas an average increase of one item over the 20 sessions was found on the visual recognition trial. Among its strengths is that it has been validated on neurologically impaired individuals (e.g. Hunking et al., 2000). It is relatively short as it takes about 35-45 minutes to complete. The materials and situations in the battery approximate everyday memory tasks, however, further evidence is needed to support its ecological validity (Strauss et al., 2006).

### Prospective memory measures

Despite the fact that prospective memory (PM) failures are among the most frequently reported by brain injured people, a limited number of studies used PM clinical measures to evaluate outcome. This may be related to the fact that standardised measures directly tapping prospective memory functions became available only in the past decade. *The Memory for Intentions Screening Test (MIST; Raskin, 2004)* is one of the two available standardised prospective memory measures. It is a paper-and-pencil test requiring verbal or action responses in four time-based and four event-based prospective memory tasks. It was developed for use with people with TBI and it is reported to have satisfactory validity and reliability (Fleming et al., 2005). The administration time is about 30 minutes and one parallel form is available. The measure, however, is not commercially available and the existing evidence on its scientific and clinical value is limited (Fish et al., 2010). In the study of Fleming et al. (2005), people with TBI showed improvements on the MIST following a prospective memory rehabilitation programme.

The value of standardized tests lies mainly in their use for screening or diagnostic purposes. They may provide clinicians with some information on the function of different memory components which can be used in rehabilitation planning. For example, differences in performance on the verbal and visual tasks may indicate lifelong strengths

and weaknesses or acquired memory deficits. It is acknowledged, however that other cognitive abilities (e.g. attentional abilities, receptive and expressive language abilities, perceptual organizational abilities, vocabulary and articulation) may account for these differences in performance (Weschler, 1997). Furthermore, by looking at performance discrepancies that are inconsistent with normal expectations, the identification of malingers may be facilitated. For example, a much better performance on a difficult memory test compared to a usually easier task may warrant further investigation.

Although a certain overlap exists, many authors have stressed that measures aimed at case description may not be appropriate for outcome evaluation (Lincoln & Nair, 2008; Mayes & Warburg, 1992; Wilson, 2009). Although their scoring systems may permit the classification of people into broad diagnostic categories, they may not be sensitive to subtle changes in ability (Lincoln & Nair, 2008). Most importantly, these measures examine the nature and severity of memory impairment but not how this impairment affects peoples' everyday lives. Furthermore, they provide minimal or no information on the compensatory strategies employed by memory impaired individuals. As discussed in the previous section, rehabilitation efforts, particularly in the post-acute stages, focus on developing participants' ability to cope with or compensate for memory deficits rather than tackling impairment itself. Even when impairment is addressed by an intervention, the ultimate aim is not to improve test performance but to reduce disability and improve social participation. However, the highly structured and specific tasks included in these measures are not always representative of typical real life situations. For example, someone's ability to memorize and reproduce an abstract design may be a poor estimate of this person's ability to perform everyday household activities. The need to overcome this problem led to the development of ecologically valid measures which include tasks more likely to occur in natural contexts. These measures aim at predicting the memory problems that are likely to occur in everyday life.

### **2.5.2. Ecologically valid tests**

Rivermead Behavioural Memory test (RBMT-RBMT-E; Wilson et al., 1985; Wilson et al., 1999)

This is one of the most commonly used outcome measures in memory rehabilitation. The development of RBMT was not guided by a specific theory or model of memory but was shaped by clinical experience with memory impaired patients. It was designed to a) predict everyday memory problems in people with acquired brain injury and b) monitor

change over time. It comprises tasks that mimic everyday memory situations and were found to be troublesome for memory impaired people. These subtests involve: remembering names, routes, appointments, recognising pictures and faces, delivering a message, remembering the date, and orientation. In the original validation study the developers found high correlations between participants' scores on the RBMT and their everyday memory failures as registered in therapists' observations (Wilson et al., 1989). As noted by Strauss et al., (2006), it is the first formal psychometric test assessing prospective memory (i.e. message and appointment tasks). However, the existence of a purely prospective component has been questioned (Efklides, 2002; Kixmiller et al, 1997). Various studies have assessed the inter-rater and parallel form reliability yielding satisfactory results (Strauss et al., 2006).

It has been tested in groups of non-progressive brain injured individuals and people with progressive neurological diseases such as MS (e.g. Cutajar et al, 2000). According to the authors, RBMT scores are not significantly influenced by self-reported anxiety and depression. Its ecological validity has been documented in a number of studies. Lincoln & Tinson (1989) found that RBMT was more closely related to subjective ratings of everyday memory problems than other more traditional standardised measures (i.e. logical memory, digit span, paired associate learning). A long term follow up study of memory impaired people showed that RBMT scores ,both at the end of rehabilitation and at follow up, were good predictors of independence (defined as in paid employment and/or living alone and/or in full time education) (Wilson, 1991). Further evidence on the ecological validity of the battery was provided in the study of Higginson et al., (2000). They found strong associations between three RBMT subtests (names, belonging and story delayed), functional status and significant others' subjective memory ratings. However, as some of the RBMT tasks were not administered due to ceiling effects, the ecological validity of the whole battery was not evaluated.

Rivermead Behavioural Memory Test has not proven sensitive enough to detect mild memory problems in brain injured people. For this reason a revised, more difficult version, the RBMT-E was developed by doubling the amount of material to be remembered. This version was used in the ReMind trial to evaluate outcome. The scores from the subtests can be summed and converted to an overall profile score ranging from 0 (impaired) to 4 (exceptionally good memory). It was found that those brain injured individuals who scored in the normal or near-normal range on the original RBMT appeared to have memory deficits on the RBMT-E (Wilson et al., 1999). Among its advantages is its brevity as its



administration time is about 30 minutes. The developers argued that due to its relevance to everyday situations the RBMT-E is also a face valid test, a property which may make it more appealing to some people with brain injury. Furthermore, substitutive versions of the route and message subtests were developed in order to facilitate the use of the RBMT-E with people with restricted mobility (Clare et al., 2000). Floor effects have also been observed in some subtests, which led to the development of the RBMT-3 (Wilson et al., 2007; as cited in Wilson, 2009). RBMT-3 includes improved visuospatial recognition subtests as well as the “novel task” subtest which assesses the ability to learn a new skill (Wilson, 2009). This latest version became available fairly recently and has not been used in any of the memory rehabilitation studies reviewed for this thesis.

According to Wilson (2009), the main aim of the RBMT tests is to give an indication of the problems that need to be tackled in memory rehabilitation. They do not, however, allow the precise specification of the nature and extent of a person’s memory problems. It is therefore suggested by Wilson (2009) that the test be used in combination with other neuropsychological batteries in order to acquire a comprehensive picture of an individual’s strengths and weaknesses. An additional caveat that needs to be considered when assessing the outcome of memory rehabilitation is that the RBMT tasks may not be sensitive to the use of memory strategies. Jennet & Lincoln (1991) used RBMT to evaluate the effectiveness of a group memory training programme. Although the number of memory aids used by participants was increased, this improvement was not reflected in RBMT performance. An explanation suggested by the authors was that RBMT provides limited opportunities for using internal memory aids. A similar pattern of results was observed in the study of Evans & Wilson (1992). The observed increase in the use of memory aids after the memory rehabilitation programme was not followed by a relevant improvement in RBMT scores. Tam & Man (2004) also noticed clinical improvements following a computer assisted retraining programme which again were not tapped by RBMT.

### Cambridge Prospective Memory Test (CAMPROMPT; Wilson et al., 2005)

As seen earlier, the RBMT includes some prospective memory items, however, the scoring system does not allow the computation of a separate prospective memory index. Furthermore, RBMT assesses only one aspect of prospective memory as it does not include time-based prospective memory tasks. The Cambridge Test of Prospective Memory (CAMPROMPT) was developed in order to fill in an important gap in memory research as,

according to the authors, it was the first standardised test assessing prospective memory which was designed with ecological validity in mind (Wilson et al., 2005). It consists of three event based and three time based prospective memory tasks. In between the tasks participants are engaged with distractor paper-and-pencil tasks such as a general knowledge quiz and a word-finder puzzle. One of its advantages is that it permits the use of memory aids to facilitate recall (a paper and pencil are provided to participants). In this way, rehabilitation professionals may obtain valuable information regarding whether and how participants use memory strategies. The normative sample consisted of healthy and neurologically impaired individuals. In the initial validation study the RBMT was found to correlate significantly with the CAMPROMT total scores and the event-time based total score but not with the time-based total score. According to the developers this finding indicates that the CAMPROMT is a more comprehensive test of prospective memory. It is relatively quick to administer (30 minutes), test-retest reliability was found to be acceptable and a parallel version is available. Although it shows promise as a clinical instrument Fish et al., (2010) cautioned that convincing evidence on its ecological validity is still limited.

Although RBMT and CAMPROMT appear to be more naturalistic measures further evidence is needed regarding their ability to measure activity limitation rather than impairment. What these tests seem to disregard is the role of the environment in the expression of disability. The testing situation itself is artificial, designed to minimise or eliminate any confounding variables such as distracters in order to optimise performance (Heinrichs, 1990). On the other hand, memory impaired people may have structured their environment in a way that offers them enough cues and means of compensation that would allow them to respond to everyday life demands. These tests may, therefore, lead to an overestimation or underestimation of peoples' ability to perform everyday memory tasks. Although CAMPROMPT allows the use of external memory aids that are available during the assessment procedure, it does not offer a comprehensive account of participant's means of compensation. Individuals' perspective on the degree to which these problems interfere with their everyday life is completely disregarded. Furthermore, contextual factors such as coping styles, motivation and family support are not considered by these tests (Evans, 2010).

Despite their acknowledged limitations, the majority of cognitive rehabilitation studies rely on standardized assessments for evaluating outcome (Cicerone, 2005). This approach

has been criticized by many rehabilitation professionals as the ability of these measures to tap improvements at the level of activity and participation is questionable (Lincoln & Nair, 2008; Wilson, 2000). It has been suggested that standardized measures should be complemented with information on relevant functional outcomes. Such information may be provided by self-report questionnaires which will be further described in the following session.

### **2.6. Self-report questionnaires**

One method of obtaining information about functional outcome is to conduct direct observations. Observations may take place either within the rehabilitation service or in a participants' house in order to assess how participants cope within a familiar context and how family members support these coping efforts. Direct observations, however, require a great amount of clinicians' time which may make them impractical and costly and in some cases unfeasible (Sohlberg & Mateer, 2001). An alternative approach is to use self-report measures such as questionnaires which are most commonly used in rehabilitation.

#### **2.6.1. Memory questionnaires**

Wilson (1999) used the term "behavioural assessment" to refer to information gathered via self-report measures (i.e. questionnaires, checklists, and diaries), direct observation, and interviews (Wilson, 1999). As noted by Wilson (2009) the term highlights the interplay between a person's behavior and environmental factors, something that is disregarded by standardized assessments. In contrast to objective measures, behavioural assessments are part of the treatment process itself as they contribute in the formation of intervention goals and in monitoring participants' progress as well as in evaluating the final outcome. They can be valuable tools, allowing rehabilitation professionals to obtain information on: a) how memory deficits affect participants' everyday life, b) the specific memory failures that participants experience as most distressing and should therefore be set as a priority in rehabilitation, c) the mechanisms of compensation employed by participants (Wilson, 1999). Being essentially measures of metamemory, they explore respondents' beliefs regarding their memory providing, in this way, information on respondents' perceptions and understanding of their problems. When used at the beginning of a neuropsychological intervention, they offer a non-threatening way of exploring cognitive difficulties. Asking for participants' views may also increase their motivation to actively engage in the rehabilitation process. Many questionnaires have versions intended for patients' family

members or other people able to report on their memory problems. In this way, it is possible to obtain a different, and often more objective, perspective on an individual's memory difficulties. Furthermore, in most cases, completion of the questionnaires does not require the presence of the clinician reducing, in this way, assessment time and costs. In the following section some questionnaires frequently used to evaluate outcome memory rehabilitation studies are briefly reviewed.

### Internal and External Memory Aids Questionnaires

These questionnaires were used in the ReMind study to assess the frequency of use of internal and external memory aids. They are unstandardised questionnaires based on the Memory Aids Questionnaire (Wilson & Moffat, 1984). Participants were asked to indicate on a 4-point scale ranging from "very often" to "never" the frequency with which they were using a specific memory aid (higher scores indicating higher use).

### Memory Assessment Clinics Rating Scales (MAC-S; Crook & Larrabee, 1990)

MAC includes two subscales: a) 21 items assess individuals' ability to remember specific types of information (e.g. "meanings of words that you rarely use") and b) 24 items evaluate the frequency of memory failures (e.g. "fail to recognise people who recognise you"). All items were rated using a 5-point Likert scale. It was validated in a large sample of healthy elderly people without memory or depression problems (N=1106). Factor analysis yielded five "*ability to remember*" factors: Remote Personal Memory, Numeric Recall, Everyday Task Oriented Memory, Word recall/Semantic memory and Spatial and Topographic Memory, and five "*frequency of occurrence*" factors: Semantic Memory, Attention/Concentration, Orientation in Daily Tasks, General Forgetfulness and Facial Recognition. Satisfactory levels of test-retest reliability were reported in a later study by Crook & Larrabee (1992). Although it was developed to assess memory complaints in older adults, the validation study did not find a significant association with age. The authors considered this finding as an indication that items tap everyday memory problems common to all age groups. Kaschel et al., (2002) investigated the effectiveness of imagery based mnemonic strategies for people with TBI. Significant improvements were apparent in verbal memory tests (i.e. logical memory task from RBMT; appointments) which were paralleled by positive changes in relatives' ratings (MAC-F) but were not reflected in participants' self-reports.

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### Memory Functioning Questionnaire (MFQ; Gilewski & Zelinski, 1988)

MFQ is a 64-item scale assessing different aspects of everyday memory functioning on a seven-point Likert scale. It was developed for examining memory complaints of older people and was validated in healthy volunteers (Gilewski et al., 1990). Factor analysis yielded four underlying factors: frequency of forgetting, seriousness of forgetting, retrospective functioning and use of mnemonics. Internal consistency estimates were found to be high and the factor structure was found to be invariant across age groups and at retest 3 years later. Age appeared to account for some variance in total scores although authors suggested that the effect was insignificant. Findings on the validity of the measure are contradictory. Zelinski et al. (1990) reported a modest but significant relationship between the MFQ and objective memory tests (i.e. word list, story recall) in two groups of elderly adults after controlling for variables such as depression and education. However, scores on MFQ were not related to prospective memory tasks (subtests from RBMT). Contrary to these findings, Brown et al. (1991) failed to find a relationship between the MFQ and objective memory tests in a group of people with neurological problems. In a study by Kinsella et al. (1996) none of the four subscales correlated significantly with traditional memory assessments (i.e. verbal learning, digit span, prospective memory task) for either control or TBI participants. Nevertheless, significant correlations were found between prospective memory tasks and MFQ subscales, particularly the retrospective functioning factor. Furthermore, only items comprising the retrospective functioning factor discriminated between TBI memory impaired individuals and healthy controls. No differences between the two groups were observed in the frequency or seriousness of forgetting factors, a finding that was attributed to respondents' limited insight.

Another potential caveat, highlighted by Lezak (2004), is the questionnaire's complexity which may make it unreliable for use in people with severe cognitive impairment. One section of the questionnaire focuses on frequency of forgetting during reading either a novel or a newspaper/magazine article. Participants are required to choose among five different frequencies of forgetting including: "three or four chapters before the one you are currently reading" or "the chapter before the one you are currently reading". It is suggested, however, that people with cognitive problems may find it difficult to discriminate between these items. Its considerable length led Zelinski & Gilewski (2004) to the development of a 10-item version. As noted by Tate (2010), the psychometric properties and clinical utility of this latest version have yet to be proved. Despite its disadvantages, the questionnaire proved to be sensitive to improvements in memory

performance (Chiaravalloti et al., 2005). Chiaravalloti et al. (2005) compared a group of people with MS practicing the story method technique to a control group engaging in non-specific control tasks such as reading a story. Significant improvements on the MFQ and an objective verbal learning test (Hopkins Verbal Learning Test) were observed. The two groups did not differ in depression and anxiety levels at either baseline or follow-up assessments.

### The Everyday Memory Questionnaire (EMQ-28; Sunderland et al., 1983)

EMQ is one of the most frequently used questionnaires in memory rehabilitation and was used as an outcome measure in the ReMind trial. EMQ consists of 28 statements assessing the frequency of memory failures related to faces, places, actions, speech, reading, writing and learning new tasks. Responses are given on a 9 point scale ranging from “not at all in the past 3 months” to “more than once a day”. The use of response categories that refer to specified time period has been recommended over the use of more vague categories such as “often”, “rarely” and “sometimes” (Aldridge & Levine, 2001). The scale was originally intended to investigate the effects of closed-head injury and therefore items included memory failures that pilot work had shown to be prevalent following head injury. An attempt was also made to cover a wide range of everyday memory failures that would not be specific to certain groups of respondents (e.g. household activities that may be more prevalent in women). Tate (2010) commented that some of the items may describe other cognitive difficulties that could be related to memory disorder (e.g. finding television stories difficult to follow).

Based on data from a group of elderly people, Sunderland et al. (1986) reported moderate test-retest reliability (never greater than  $r=0.6$ ). Cornish (2000) provided evidence on satisfactory internal consistency and a clear factor structure comprising five components: conversational monitoring, spatial memory, retrieval, task monitoring and memory for activities. Similarly to other self-report questionnaires, findings regarding concurrent validity with objective memory tests are mixed. Sunderland et al. (1983) found that relatives' ratings on the EMQ correlated with a greater number of objective memory tests than reports from head injured patients. This finding was supported by a later study of Sunderland et al. (1986) on a sample of elderly people which confirmed the low correlation of EMQ with objective tasks. Schwartz & McMillan (1989) noticed that differences between controls and head injured people on the EMQ were greater when excluding people who were not definite memory impaired cases based on the RBMT. In

that case, both relatives' and self-ratings were found to correlate significantly with RBMT scores. Lincoln & Tinson (1989) also reported high correlations between the RBMT and the EMQ but only for specific RBMT subtests (e.g. Appointment and Route), whereas very low correlations were found for the Faces subtest. This latter finding seems to support the hypothesis that there is a closer correspondence between the EMQ and verbal memory tasks than visual memory tests (Sunderland et al., 1983; Sunderland et al., 1986).

There is conflicting evidence on sensitivity to effects of treatment. Jenett & Lincoln (1991) found that the number of memory aids used by participants increased following rehabilitation; however, this improvement was not reflected in the EMQ. The researchers suggested that improvements in performance could have been counterbalanced by a more accurate appraisal of the severity of memory problems. In contrast, Schmitter-Edgecombe et al., (1995) found that a group of TBI patients who received training in using a notebook strategy reported fewer everyday memory failures on the EMQ than the controls. In a group of people with MS, Allen et al. (1998) found significant improvements in recall of lists following training in the story method. A borderline significant reduction in memory failures as reported in the EMQ was also observed. The findings of the above studies suggest that the questionnaire's responsiveness to the effects of memory rehabilitation needs to be supported by further evidence.

Concern has been raised over the number of response categories used in the EMQ as they may be more than the respondents' ability to discriminate (Streiner & Norman, 2008). Furthermore, a three month time period may be an interval too long to allow accurate recollection. Bowling (2010) noted that time periods between three and seven days are considered as the most valid and reliable frames to use. Clinical evidence suggests that cognitively impaired people may find the questionnaire lengthy and the wording of the items confusing (Royle & Lincoln, 2008). In the ReMind study a simplified version developed by Royle & Lincoln was used. In this version responses are given on 5-point scale ranging from "once or less in the last month/never" to "once or more a day". This version was validated on a sample consisting of healthy individuals and people with stroke and multiple sclerosis. Results showed good internal consistency and discriminatory validity, however, further evidence is needed on concurrent validity and test-retest reliability.

Although questionnaires are the most frequently used method for the evaluation of prospective memory, only a few of them focus exclusively on prospective memory.

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The Prospective Memory Questionnaire (PMQ; Hannon, Adams, Harrington & Fries-Dias, 1995). It consists of 52 questions that can be grouped in four subscales: frequency of forgetting, short-term habitual intentions (e.g. I forgot to put a stamp on a letter before emailing it), long-term episodic intentions (e.g. I forgot to return books to the library by the due date), internal cued intentions (e.g. I forgot what I wanted to say in the middle of a sentence) and strategy use (e.g. I rehearse things in my mind so I will not forget to do them). Items are rated on a 9-point Likert type scale. It has been validated in healthy adults and a small sample of adults with brain injury (N=15). It has shown to be an internally consistent instrument with satisfactory test retest reliability (Hannon et al, 1995). In contrast to other similar questionnaires, PMQ assesses strategy use which may be an important tool for rehabilitation. Raskin & Sohlberg (2009) assessed the effectiveness of a prospective memory intervention for people with brain injury. Although significant improvements were found in performance of “objective” prospective memory tasks and in a self-report everyday memory questionnaire, these changes were not tapped by the PMQ.

### Comprehensive Assessment of Prospective Memory (CAPM; Shum & Fleming, 2008)

The CAPM was designed for use with people with TBI and comprises 93 items, each item rated on a 5-point Likert scale. The main advantage of this questionnaire is that it considers not only the frequency of failures but also respondents’ perceived amount of concern as well as a number of possible reasons for these failures (e.g. motivation). It also includes some items related to strategy use. A significant other’s version is available to be completed by a person familiar with the patient’s functional status. Roche et al. (2002) found that only the significant others’ ratings discriminated between a healthy control and a TBI group as TBI patients underestimated their frequency of forgetting. In the normative sample, a group of healthy individuals, internal consistency and temporal stability were found to be within acceptable ranges (Chau et al., 2007). Fleming et al. (2005) used CAPM to evaluate a prospective memory training intervention. Although a significant improvement was observed in objective prospective memory assessment, these were not reflected on the CAPM. As noted by Tate (2010) CAPM’s correspondence with other, objective and subjective, measures needs to be further researched.

Despite advantages, the use of questionnaires is linked with certain problems. First of all, the accuracy of individual’s self-reports can be affected by a number of factors. These include impaired self-awareness and unrealistic expectations about recovery as well as



limited willingness to admit and/or report deficits (e.g. Allen & Ruff, 1990; Beatty & Monson, 1991). Furthermore, there is evidence indicating that self-appraisal of memory functioning is related to the affective state of the respondent, with changes in reported memory problems following improvements in mood (e.g. Antikainen et al., 2001; Randolph et al., 2004).

A paradox that is linked with most memory questionnaires is that they require memory impaired people to accurately report on the frequency of their memory problems. As noted by Hickox & Sunderland (1994), inaccurate self-report may occur simply because respondents do not remember their everyday memory failures. Streiner & Norman (2008) stressed that this problem may be particularly obvious in progressive disorders such as MS where symptoms tend to fluctuate over time and cautioned that questionnaire developers often vastly overestimate peoples' ability to recall past events. In order to overcome the constraints imposed by memory the use of diaries and checklists completed on a regular basis has been adopted. These systems can be complemented with the use of memory aids that remind individuals to record memory failures. It has been suggested that this approach can provide more accurate estimates as the interval between forgetting and reporting is reduced (Hickox & Sunderland, 1992). Ownsworth & McFarland (1999) found a significant association between scores on a daily checklist and performance on WMS-R subtests (i.e. digit span, visual and verbal paired associates). Furthermore, the checklist was found to discriminate between different diary interventions in the degree of memory improvement reported during the treatment phase. The main problem with these recording systems, however, is that they are highly individualized and, therefore, do not allow comparison across studies.

The majority of memory questionnaires have been developed for use with healthy elderly populations without taking into account the characteristics of neurological populations. Kinsella et al. (1996) proposed that the basis for memory failures in the elderly is distinct and/or is confounded by ageing factors. Therefore, the relevance and appropriateness of these questionnaires for use with brain injured people is called into question. As seen earlier, the wording and response format may be too complicated for people with cognitive problems and the resulting confusion may be a source of response bias (e.g. agreeing with all statements). The length of the questionnaires may also induce response bias through the effect of fatigue and lack of motivation (Waltz, 1991). Another potential drawback is that the content of some questions may limit their ability to detect change following memory rehabilitation. Items such as "losing the thread of thoughts in

public speaking (CFQ) or “finding television stories difficult to follow” (EMQ) may reflect cognitive decline which cannot be addressed by interventions specifically targeted to memory deficits.

### 2.6.2. Questionnaires of mood

Questionnaires assessing mood are often included as secondary outcome measures of cognitive rehabilitation. The ICF classifies some emotional dysfunctions as impairments occurring as a direct consequence of brain injury. Cognitive rehabilitation, however, is primarily concerned with mood problems that occur in response to cognitive impairments and disabilities. It has been suggested that within the context of rehabilitation, emotional disorders such as anxiety, depression and low self-esteem could be perceived as emotional disabilities that interact with cognitive disabilities (Lincoln & Nair, 2008).

*The Beck Depression Inventory* (BDI; Beck & Steer, 1987) and the *General Health Questionnaire* (GHQ; Goldberg & Williams, 1988) were identified by the author as most commonly used outcome measures of mood in studies of memory rehabilitation. The BDI includes 21 items covering depressive symptoms such as sadness, pessimism, social withdrawal, body-image distortion, weight loss etc. It has proven validity, reliability and sensitivity to change with psychiatric populations (Wade, 1992). Although its validity with neurological populations has been questioned due to the inclusion of somatic symptoms, the questionnaire has shown to be responsive to improvements in mood following memory rehabilitation of MS patients (Allen et al., 1998; Jonson et al., 1993). However, in a more recent study of memory rehabilitation in MS (Chiaravalloti et al. 2005), reduction of memory complaints in the treatment group was not associated with improvements in BDI.

*The General Health Questionnaire* is a self-administered screening questionnaire suitable for use in community and non-psychiatric clinical settings. It was intended for use as a “case detector” and it is not suitable for clinical diagnoses (Goldberg & Williams, 1988). The GHQ-12 was used to assess mood in the ReMind study. It is a short version of the GHQ-60 and it is considered to be the most widely used screening instrument for common mental disorders (Werneke, 2000). The items that were selected from the original questionnaire cover feelings of strain, depression, inability to cope, anxiety-based insomnia and lack of confidence. Each of the items asks whether the respondent has recently experienced a particular symptom or behaviour, rated on a 4-point scale as follows: not at all, no more than usual, rather more than usual and more than usual. The

GHQ-12 yields a total score with a higher score indicating greater severity of the condition. The advantage of the short version is that it does not include most of the items that are affected by somatic symptoms. GHQ-12 was therefore considered to be more appropriate for use in people with neurological disabilities. It has been extensively tested for reliability and validity with good results (Daradkeh et al., 2001, Garyfallos et al., 1991; Hardy et al, 1999; Trait et al., 2003). Goldberg & Sartorius (1997) showed that its validity is not influenced by demographic factors such as gender, age of subject, or educational level. Goldberg & Williams noted that physically ill people tend to score highly on the GHQ and are over-represented among false positive misclassifications. This is probably because it contains items concerning activity and somatic or cognitive disorder (Coughlan & Storey, 1988).

In the ReMind study mood was also assessed with the Abbreviated Wimbledon Self-Report Scale (Coughlan & Storey, 1988). This questionnaire is short and quick and has been developed as an alternative to BDI and GHQ scales. It has been validated in neurological patients, including patients with MS, TBI and stroke. According to the authors, it is suitable for use with neurological patients and patients with substantial physical illness as it taps the subject's emotional states with no reference to somatic complaints or ability to perform activities. It consists of 10 adjectives and phrases describing feelings (e.g. I feel helpless) which the participant rates for frequency of occurrence on a 4-point scale: 0 = "not at all", 3 = "most of the time". The items were selected by the authors to reflect the range found in other measures of mood state as well as psychiatric case-notes and textbooks. The minimum score possible on this measure is 0 (emotionally well-adjusted) and the maximum score 40 (low mood). Caseness is defined as a cut-off score of 11 or above. Demographic factors such as age and sex have not been found to have a significant effect on the scores. It has also manifested good inter-rater and test-retest reliability (Coughlan & Storey, 1988; van Baalen et al., 2006).

### **2.6.3. Questionnaires assessing Activity and Participation**

The Nottingham Extended Activities of Daily Living (EADL; Nouri & Lincoln, 1987) scale was used in the ReMind trial. The scale was developed to assess stroke patients' levels of independence at performing activities which extend beyond basic self-care. The 22-item NEADL has four subsections: Mobility (6 items), Kitchen (5 items), Domestic (5 items) and Leisure (6 items). Guttman scaling was used to arrange items hierarchically within

subsections in order of their difficulty level. Responses are made on a 4-point scale and are then dichotomised: 1 (independent: “done on my own” or “done with difficulty”) or 0 (dependent: “done with help” or “not done”). Each subsection is separately scored and a total score can be yielded ranging from 0 (more dependent) and the maximum score 22 (more independent). One of its advantages is that it assesses what patients have actually done, not potential functioning. Its strengths are that it is brief and easy to understand and has been shown to be valid and unidimensional (Lincoln & Gladman, 1992) with good test–retest reliability (Nouri & Lincoln, 1987). It was selected for the ReMind study because patients’ ability to live independently is one of the main targets of neurorehabilitation. Moreover, its sound psychometric properties and widespread use allow comparison with other studies.

A limited number of studies have evaluated the outcome of cognitive rehabilitation at the level of participation (Lincoln & Nair, 2008; Wade, 2003). This may be related to the fact that the measurement of participation is often a challenging task. Considerable controversy exists regarding what constitutes participation and how it should be measured, which the revised WHO classification has not managed to resolve (Tate, 2010). Few scales have been developed as pure measures of handicap not overlapping with quality of life, and only a small number of them address both external/objective and individuals’ perspectives (Ibid.). Many factors can affect participation and, therefore, it might be difficult for rehabilitation professionals to isolate the effects of cognitive rehabilitation (Lincoln & Nair, 2008; Wade, 2003). In the few studies where measures of participation were included, this was done in order to evaluate the effects of holistic rehabilitation interventions. As seen earlier, these programmes follow a comprehensive integrated approach incorporating physical, cognitive and psychotherapeutic interventions and therefore are aiming at a more generalized effect. In two studies evaluating the effectiveness of holistic rehabilitation for people with TBI, Cicerone et al. (2004; 2008) found significant improvements in a measure of community integration (Community Integration Questionnaire (CIQ); Willer et al., 1993). It was also observed that those participants who improved on the CIQ showed greater improvement on overall neuropsychological functioning, particularly on measures of attention and executive function (Cicerone, 2004). CIQ was originally developed for people with TBI and was designed to assess home integration, social roles and productive activity. It is a brief measure, taking less than 15 minutes to administer, and has been found to have good

internal and test-retest reliability (Tate, 2010). It has, however, been criticized for failing to capture qualitative changes in functioning (Ibid.)

None of the reviewed studies focusing on memory rehabilitation evaluated outcome at the level of participation and, therefore, relevant scales will not be further discussed here.

In sum, the review indicated that the measures commonly used to assess outcome in memory rehabilitation may not reflect the aims of neurological rehabilitation and/or the needs of people with neurological disabilities. These limitations may undermine the ability of these measures to tap meaningful improvements following memory rehabilitation. An alternative way of evaluating the effects of interventions is to use qualitative methodology in order to explore patient perceived benefits. In the following chapter the post-intervention interviews of participants in the pilot phase of the ReMind were examined to assess whether they did experience benefits which were not reflected in the quantitative outcome measures.

### **3: Participants' perceptions of the outcome of the pilot ReMind study**

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The patient-perceived effects of the ReMind trial were explored by examining the post-intervention interviews of participants in the pilot phase of the study. This chapter starts with a review of previous memory rehabilitation studies that have considered participants' feedback. The Methodology section presents a brief overview of different approaches to interviewing. Additional information on the design and methods of the ReMind trial as well as the aims and content of the programmes is also provided. What follows is a description of the process that was applied to qualitatively analyse the interviews according to the thematic analysis approach. The Results section presents the main identified themes, the number of interviews in which they appeared as well as illustrative quotes. The Discussion section focuses on the benefits represented by the identified themes and whether these could be reflected by existing outcome measures. This chapter concludes with the rationale and methodology guiding the development of a new measure assessing memory rehabilitation outcomes.

#### **3.1. The role of qualitative methods in the evaluation of memory rehabilitation interventions**

Randomised controlled trials using standardised and widely used measures are considered to be the most robust method of evaluating the efficacy of an intervention (Rennie, 1996; Campbell et al., 2007). Their study design allows researchers to control for confounders in order to minimise bias. It is recognised, however, that relying exclusively on quantification may lead in missing important information on the effects of the intervention particularly when these effects had not been predicted by the researchers and/or were not tapped by the outcome measures used in the study. The use of qualitative alongside quantitative methods (i.e. mixed methods designs) is becoming increasingly popular particularly in the evaluation of complex interventions which include components that may be difficult to capture with quantitative methods alone (e.g. Lewin et al., 2009). Methods of obtaining qualitative data, such as post-intervention interviews, are an opportunity for participants to describe, in their own words, the strengths and limitations of an

intervention and the ways it affected their everyday life. They, therefore, allow researchers to assess whether their own assumptions make sense to participants and incorporate participants' perspectives into their findings. In this way, they may facilitate researchers in developing a better understanding of how the intervention works or why it has not worked and how it can be improved (O'Cathain et al., 2007).

Despite the growing awareness of the role that qualitative research can play in the evaluation of interventions none of the memory rehabilitation studies reviewed in the previous chapter incorporated qualitative methodology. Whenever some form of qualitative data were obtained this was mainly done in an informal way, as part of case studies descriptions. Fleming et al. (2005) reported the results of three case studies of TBI patients who completed a prospective memory rehabilitation programme. The programme, which aimed at teaching compensatory strategies and increasing self-awareness, ran for 8 weeks with 1-2 hours of individual sessions each week. Improvements were found on a formal prospective memory measure (Memory for Intentions Screening Test) and a community integration questionnaire. However, these improvements were not reflected on a self-report prospective memory questionnaire (CAPM). Qualitative feedback was also obtained and briefly described by the authors. Participants reported that the programme was beneficial in increasing their self-awareness and improving everyday memory. Quemada et al. (2003) evaluated the effectiveness of a memory rehabilitation programme aimed at teaching memory aids, promoting awareness and problem solving skills. Emotional support was also offered to some participants. Twelve people with TBI participated in the programme which lasted for 6 months with 50 minute every day sessions. Comparisons between baseline and post-treatment scores showed modest improvements in some scales of the California Verbal Learning test (CVLT). No significant changes were found, however, on the Rey Complex figure test, the RBMT or the EMQ. Despite the lack of effect on the outcome measures, qualitative information indicated that participants achieved meaningful functional gains such as managing to perform everyday tasks without supervision. The authors, however, provided no details on how this qualitative information was obtained and whether it came from participants themselves, clinicians or family members.

Seeking participants' feedback was one of the approaches used by Evans & Wilson (1992) to evaluate the effectiveness of memory group for people with brain injury. Five participants attended the memory group which was based on the Rivermead Memory Group described by Wilson & Moffat (1992). Increasing patients' knowledge about

memory processes, offering training in the use of memory aids and reducing emotional consequences of memory problems were the main goals of the group. The outcomes measures were a memory aid questionnaire, a mood questionnaire (HADS), and RBMT. Patients' views on the programme were obtained informally throughout the 11 month period as well as at the end of the program using a participant satisfaction questionnaire. Although some reduction in the levels of anxiety and depression was observed, variation was noted in the pattern of use of aids and no major improvements were found in RBMT scores. According to the authors, the qualitative feedback provided a more positive picture of the programme as participants appeared to value the knowledge they obtained on memory functioning and memory aids well as the benefits of the group format. Only a brief description of this feedback was, however, presented and the only information provided on how the data were analysed was that they were "summarised".

The value of the qualitative data presented in the above studies is undermined by the fact that the authors did not explicitly elucidate how information was acquired and analysed. It appeared that feedback was obtained in an informal context without adhering to qualitative research procedures. Only a brief summary of the results was provided, undermining the purpose of qualitative research as an in-depth exploration of participants' views and experiences. Although some form of qualitative information was presented, this did not fit the criteria to represent a truly qualitative component. These projects were based on quantitative methodology treating participants' feedback as supplementary data that provided only a glimpse of another perspective.

Interestingly, what the above studies appear to have in common is a discrepancy between the qualitative information and the quantitative measures of outcome. Benefits were reported by participants that were not reflected in the psychometric tests or self-report questionnaires used in the studies. The authors of the studies did not suggest any possible explanations for the observed discrepancy. Another problem in interpreting the findings was the lack of control groups which did not allow differentiating between the effects of rehabilitation from alternative explanations. One possibility could be that the interventions were ineffective and participants' views reflected inaccurate self-appraisals or attempts to please the researchers. Alternatively, it could be argued that the benefits that participants experienced were not tapped by the outcome measures used in the studies. As seen in the previous chapter, the content and characteristics of commonly used outcome measures may turn them irresponsive to the effects of memory rehabilitation. This hypothesis is worthy of further exploration.



In sum, there is currently a lack of qualitative studies that would allow participants to express in their own words their views on the effectiveness of memory rehabilitation. It appears that little attention has been paid in investigating the subjective experience of participants in a memory rehabilitation programme. The qualitative exploration of participants' feedback would allow evaluating whether they perceived effects that were not reflected in the quantitative outcome measures. New insights about the way the outcome of memory rehabilitation is assessed may be obtained.

The present study examined the post-intervention interviews of participants in the pilot phase of the ReMind study in order to assess whether participants perceived any effects to have resulted from the programme.

### **3.2. Methodology**

#### **3.2.1. Interviews**

Waltz (1991) defined interviews as “a verbal interchange in which one individual the interviewer attempts to elicit information from another, the respondent, through direct questioning” (p.310). Information may be obtained not only via face-to face interaction but also by other means such as telephone, post or email (Coolican, 2004). Interviews are a particularly flexible tool for research. As they are not necessarily tied to any theory or philosophical tradition they are used in various types of qualitative research including ethnographic, phenomenological and grounded theory studies (Waltz, 1991). Moreover, the data that are generated can be represented in different ways following different epistemological orientations (e.g. positivist) (Breakwell et al., 2006). Interviews can be used as the primary or only approach in a study, or in combination with other data collection procedures in a mixed methods approach (Robson, 2002; Breakwell et al., 2006). For example, interviewing has long been used to complement survey research and participant observation (Fontana & Frey, 2000). Interviews can be used at any stage in the research process. They are useful in the initial phases of a study, in order to identify areas or issues for further exploration but they are also employed as part of the piloting and validation process of measurement scales (Breakwell et al., 2006).

Questioning methods are typically classified according to the degree of standardisation involved. Standardisation refers to “the control that is exercised regarding the development, content, administration, scoring and interpretation of a measure” (Waltz

1991, p.312). Structure can be imposed either through the standardisation of the questions and their sequence or through the fixed nature of the responses allowed (Breakwell et al., 2006). Interviews can range across a continuum from unstandardised (unstructured) interviews to highly standardised (structured). According to one classification system interview methods can be loosely grouped into four categories: unstructured interviews, semi-structured, structured but open-ended and fully structured interviews (Coolican, 2004).

In the completely unstructured interview respondents are encouraged to talk about whatever they wish related to a broad topic introduced by the interviewer (Robson, 2002). The role of the interviewer is directive only to the extent of keeping the respondent on the topic with minimal prompting. Completely unstructured interviews have been compared to a conversation where respondents tell their stories in their own words in a relaxed atmosphere without having to answer pre-set questions which may be confusing or upsetting (Coolican, 2004). This is the primary advantage of this approach, as it allows the respondents to express their perceptions and opinions and take control over the amount of information they wish to disclose. Although the conversational style of interviewing encourages social interaction between the interviewer and the interviewee, it depends on the interviewer's skills, increasing the likelihood of interviewer bias (Bowling, 2009). Furthermore, unstructured interviews do not allow systematic comparisons across respondents or coders (Waltz, 1991). In the absence of pre-determined topics of discussion there is also a risk of potentially missing important themes if they are not mentioned spontaneously by the respondent.

In order to avoid the problems associated with the completely unstructured approach, the interview session can use a "semi-structured" or "guided" procedure. When using semi-structured interviews the researcher begins with a rather loose interview schedule of general topics to be covered and possibly key questions to ask in relation to these topics. However, the order and the wording of the questions are left to the discretion of the interviewer and may be changed to fit the characteristics of each respondent. Questions are open-ended which means that they have no fixed answers but allow participants to respond in their own words.

The structured interview has predetermined questions with fixed wording usually in a pre-set order (Robson, 2002). In the fully structured interview respondents are asked to choose an answer from predetermined possible response alternatives. In fact this approach is rather an interview-based survey questionnaire yielding information which is

quantified. What differentiates the fully structured from the structured but open-ended interview approach is that the latter uses open-ended questions. In this context the interview is presented in the same form to all respondents and the interviewer is not allowed to change the wording or order of any question. Because little is left to the discretion of the interviewer, the likelihood of interviewer bias is reduced (Waltz, 1991). The benefits of this approach are that it ensures the consistency of the questions, it facilitates the assessment of reliability, and allows comparability across the respondents (Breakwell, 2006).

Within the context of the randomised controlled trial, structured but open-ended interviews were preferred in order to allow comparability between the interventions and serve the primary aims of the RCT.

### **3.3. Methods**

A detailed description of the methods followed in the RCT was provided in a PhD thesis (Nair, 2007) and therefore it will be summarised here.

#### **3.3.1. Ethical considerations**

The study was approved by the Nottingham and Derbyshire Research Ethics Committees. Informed consent was sought and all participants agreed to have an audio-taped interview. All data were anonymised and stored in accordance with the Data Protection Act (1998).

#### **3.3.2. Study Design**

A single-blind randomised controlled trial design was used in the ReMind study. Participants with memory problems following traumatic brain injury, stroke and multiple sclerosis were randomly allocated (in blocks of four) to one of three programmes: a compensation-based memory rehabilitation programme, a restitution-based programme or a self-help control programme. It was suggested that the use of RCT methodology would allow the minimisation of bias that might occur in rehabilitation research such as variation in the severity, size, extent of lesions, demographic characteristics and spontaneous recovery of TBI and stroke participants (Nair, 2007).

Follow-up assessments were carried out five and seven months after randomisation by an assessor blind to the group allocation. After the second follow-up, a different assessor conducted the post-intervention feedback interviews (Ms Kristina Vella).

Figure 3 summarises the design employed in this study.

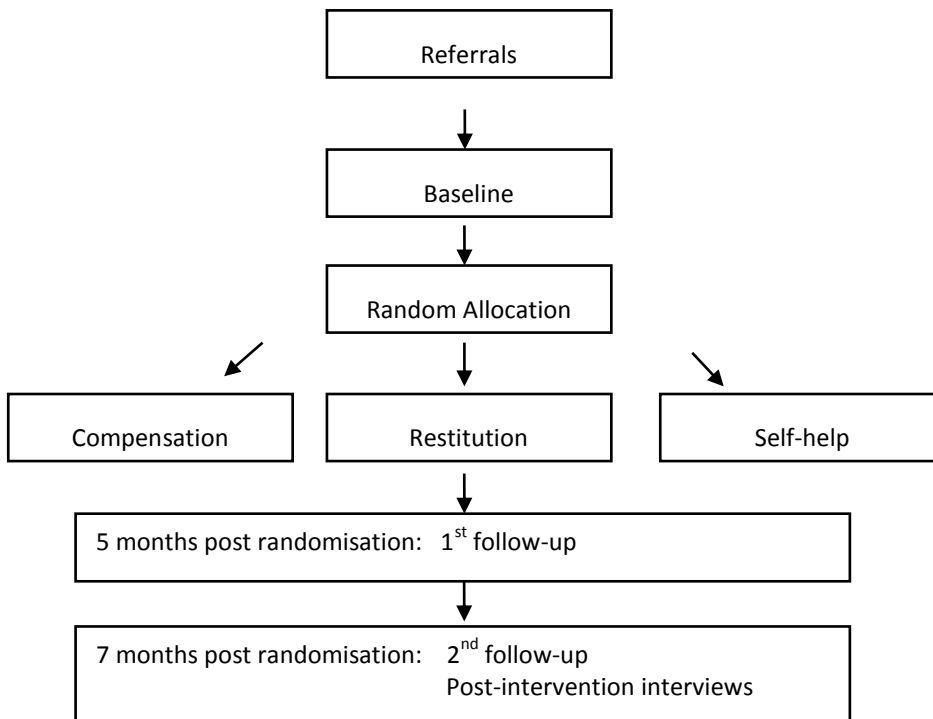


Figure 3. Diagram of the RCT design.

### 3.3.3. Recruitment

Patients with memory deficits following stroke, traumatic brain injury and multiple sclerosis were identified and invited to take part in the study. The use of a mixed aetiology sample was preferred in order to reflect the reality of clinical services where the provision of memory rehabilitation is not done on the basis of the diagnosis. Information about the study was sent to potential referrers working in hospitals and/or rehabilitation centres, general practice (GP) services, and Stroke, MS and TBI services. The researchers also met with staff working in hospitals and rehabilitations centres in order to present the study and answer questions. Self-referrals were encouraged by putting up posters advertising the study in various locations, such as nursing homes and stroke clubs.

Only out-patients and community-based patients were considered for recruitment. The reasons for that decision were that people in the acute phase of recovery and living in a hospital environment may not fully acknowledge the extent of their cognitive deficits and many practical difficulties are associated with organising group sessions in such settings.

The initial patient contact was made by treating clinician/ healthcare professional who informed patients of the study. Referrers were provided with details of the study and a copy of all the information that was to be sent to interested participants that included the Patient Information sheet, Consent Form, and a poster advertising the study for the surgery notice board. They were also given a referral form listing the inclusion and exclusion criteria Referrers were asked to inform suitable patients and take their consent to pass on their relevant medical and contact details to the researchers.

Following referral researchers contacted potential participants by telephone in order to provide more information about the study and ask them whether they would be interested in taking part. If they expressed an interest then they were sent the information pack which included the Patient Information Sheet, the Consent Form, a map and directions to the assessment venue. Participants were contacted again a couple of weeks after being sent the information pack and were asked if they had come to a decision. If they showed interest, an initial interview was arranged which was conducted at the Institute of Work, Health and Organisations at the University of Nottingham. During that interview participants were given details about the randomisation procedure and the interventions. The researcher went through the Patient Information and the consent form in order to clarify any points of confusion and answer patients' questions. Once informed consent was obtained, the baseline assessments were conducted.

### **3.3.4. Baseline Assessments**

Participants were assessed with a battery of neuropsychological tests including assessments of premorbid intelligence, language ability, executive and memory functions. The order the assessments were presented was the same for all participants. The assessments lasted for about two hours, however, participants could take a break or split the assessments into two or more sessions if they had issues with fatigue or poor concentration.

Participants were assessed with the following tests:

- Memory function was assessed with:
  - Rivermead Behavioural Memory Test- Extended version (RBMT-E) (Wilson et al., 1999). The overall profile score was used; a score of 0 indicates impaired memory functioning, 1 indicates poor memory, 2 indicates average memory, 3 shows good memory and an overall profile score of 4 indicates exceptionally good memory. This test was chosen over other

similar tests because it is simple and easy to administer and score, it is ecologically valid, with good age norms and parallel forms. It is also commonly used in clinical practice and research, facilitating comparisons between studies (for a more detailed review see p. 42).

- Doors and People test (Baddeley et al., 1994). This test was included in the battery of baseline assessments because it has good face validity, it provides a broad-based measure of clinical components of memory and it is more sensitive than RBMT-E in picking up discrete problems such as visual or verbal deficits. It has been used in research with neurological populations and has good British norms (for more information see p. 40). The test was not used as an outcome measure as it is lengthier than RBMT-E and less evidence exists regarding its ecologic validity.
- The Spatial and Digit Span subtests of the Wechsler Memory Scale- third edition (WMS III) (Wechsler et al., 1997) were used in order to obtain a discrete score of working memory. The tests are short, easy to administer and have good norms (Lezak, 2002).
- Perceived memory function was assessed with Everyday Memory Questionnaire (Sunderland, Harris & Baddeley, 1983). The Royle & Lincoln revision was employed in this study as it was shorter than the original version. Responses were rated on a 5-point scale (0-4); the minimum score possible is 0 (least forgetting) and the maximum score 112 (most forgetting). The questionnaire was employed over others for its merits which were described in page 49.
- Disability was assessed with the Nottingham Extended Activities of Daily Living Scale (Nouri & Lincoln, 1987). The EADL was chosen over other measures for its sound psychometric properties and its widespread use which facilitates comparison with other studies (see also p.54).
- Mood was assessed with the General Health Questionnaire (GHQ-12) (Goldberg & Williams, 1998). Although there are different ways of scoring the GHQ, this trial used the GHQ scoring method (0-0-1-1 on a 4 point scale). The minimum score possible is 0 (emotionally well adjusted) and the maximum score 12 (low mood). In the ReMind trial, the GHQ-12 was chosen over other mood/quality of life measures due to its strengths which were outlined in page 53.

- The National Adult Reading Test – Revised version (NART-R) (Crawford, 1992) was used to assess premorbid intellectual function. Premorbid IQ is usually estimated using tests of present ability which are relatively resistant to physical and/or psychiatric conditions (Crawford, 1992). NART is a reading test that consists of 50 short, irregular words, which do not follow normal grapheme-phoneme correspondence rules. According to Nelson and O’Connell (1978) previous knowledge of these words is required for correct pronunciation. NART is considered to be the most frequently used instrument to predict premorbid IQ in clinical and research settings (Crawford, 1992). The revised version has been standardised against the WAIS-R in the UK. Crawford (1992) reported high split-half, inter-rater and test-retest reliabilities. In the ReMind trial it was used to interpret the scores of the RBMT-E memory assessment.
- The Sheffield Screening Test for Acquired Language Disorders (Syder et al., 1993) was used to assess language ability. As the rehabilitation programmes in the trial required the participants to have adequate language skills, it was important to screen for these at baseline. It consists of statements that are read out, which requires a verbal or a motor response from patients. The maximum score is 20, indicating the absence of high-level language disorders; age-related cut-off scores are provided by the authors. It is short and easy to administer and has been used with TBI and stroke populations (e.g. Blake et al, 2002). In contrast to other similar tests (e.g. FAST) it is not affected by visual field problems, visual neglect or inattention, which are sometimes associated with acquired brain injury.
- Executive functioning was also assessed for the purposes of the RCT. These tests are not relevant to the current study and, therefore, they will only be presented briefly:
  - The Trail Making Test (Reitan, 1958). This test was employed because it is brief and easy to administer and score and is frequently used in research.
  - The Stroop Neuropsychological Screening Test (Victoria version; Regard, 1981). This test is quick and easy to administer and is both highly reliable and sensitive to brain dysfunction (Lezak, 1995).



Following the assessments, participants' eligibility for recruitment was established:

### **3.3.5. Eligibility criteria**

Patients with neurological disabilities are a highly heterogeneous group regarding the type and severity of impairments as well as the presence of comorbid diagnoses. As it was not possible to equate groups on all characteristics, broad but precise inclusion criteria were used to obtain a sample representative of participants with memory deficits seen in clinical practice:

#### **Inclusion criteria**

Patients who met the following criteria were eligible for recruitment into the study:

- They had memory problems as a result of brain damage related to medical condition/head injury such as traumatic brain injury, stroke, multiple sclerosis, tumours. If relevant information was not provided in the referral form, the referrer was contacted by the research team.
- Participants had an overall profile score of 2 (average memory), 1 (poor memory), or 0 (impaired memory) on the RBMT-E or a score below the 25<sup>th</sup> percentile on the Doors and People test, indicating memory impairment.
- They were more than three months post-injury and/or diagnosis. The decision on this time point was based on previous studies in TBI and stroke literature. It was suggested that it would allow some time for adjustment to the diagnosis and community reintegration.
- They were over 18 years at the time of recruitment. The study was designed for an adult population and most of the assessment tools had been validated on such populations.
- They lived in or around Nottingham or Derby. The geographical area had to be specified as only limited funding was available for reimbursing participants' travel expenses.
- They did not have a previous diagnosis of brain damage, dementia or other severe disability. It was considered unlikely that patients with dementia would benefit from the intervention.

### **Exclusion criteria**

- They were blind or deaf. This was because most of the assessments could not be administered to these patients.
- They were not able to understand and speak English, as the assessments and interventions for this study were in English.
- Had severe activity limitations such that they could not travel to the venue of the group meetings.
- They were diagnosed with psychiatric/mental health problems, as this could potentially affect their ability to engage in the group. The exclusion was decided on the basis of referrer information for those who were referred by a clinician, and on clinical judgement made by a clinical psychologist for those who self-referred.
- Had impaired language skills defined by a score of less than 15 on the Sheffield screening battery, as they would not be able to engage in the intervention.

Participants who satisfied the above criteria were recruited in the study. A report was sent to the referrers informing them on participants' performance in the assessments and whether or not they were included in the programme. A second meeting was arranged with all participants that were assessed in order to give them feedback on the results of the assessments and tell them whether they were offered a place in the groups. Participants who did not meet the eligibility criteria were told that they would not benefit from the specific rehabilitation programme and alternative strategies or sources of support were suggested. Participants were informed that their allocation to the type of programme was to be determined by chance. However, if they were allocated to the self-help programme, they had the option of attending an intervention group after they completed the second follow-up.

### **3.3.6. Allocation and concealment**

Every time four participants who met the criteria and were able to attend a group on the same day and location were identified, they were allocated as a group to one of the three interventions. Cluster randomisation was used in order to facilitate the formation of groups with participants able to attend the same sessions. The decision on the size of the groups was based on feedback from rehabilitation professionals. Randomisation was performed by an independent randomisation centre using a computer generated randomisation list. After a cluster was recruited, the randomisation centre was contacted

by telephone and the treatment allocation was revealed to the principal researcher, who was also the clinician running the groups. Due to the nature of the intervention, blinding the leader of the groups was impossible.

### **3.3.7. Content and structure of the programmes**

Once the group allocation was known, the researcher met the participants for one individual session. The aim of this session was to collect information regarding the specific memory problems they faced and how they affected their everyday life. Specific goals they hoped to achieve by enrolling the programme were explored and a brief outline of the programmes they were randomised to was provided. The content of the individual session was the same across all the three programmes. The session closed with the researcher answering participants' questions.

The group sessions were conducted between March 2004 and July 2006 at the University of Nottingham and at the Derby City General Hospital. The format and content of the group sessions were mainly informed by the Rivermead Memory Group described by Wilson & Moffat (1984). The rehabilitation programme comprised of 10 weekly sessions lasting about 90 minutes with a 10 minute break. The group members were four participants and the group leader. In case participants missed group sessions the group leader arranged individual sessions with the participant. The group session was rescheduled if less than two participants were present. Each session was conducted according to the appropriate manual in an attempt to ensure consistency in the administration of the interventions. The structure of the sessions was similar for all the programmes. At the beginning of each session participants provided feedback regarding the application of the coping strategies between the sessions and the completion of the homework tasks they were set to do. The previous session was briefly reviewed before moving on to the activities planned for the new session. Sessions finished with setting homework assignments that promoted transfer of the training to every-day life, and a preview of the following session. The content of the first session was the same for all the three programmes and included information on brain damage and its effects on cognition as well as an introduction to memory and rehabilitation concepts. For all the other sessions the content varied according to each programme. In the compensation programme training focused on external memory aids and ways of adapting and adjusting to memory problems. Participants were also informed about the importance of attention and how to improve it. In the "restitution" programme the main focus was memory retraining using

internal memory aids and attention training techniques. The aims of both treatment programmes were: a) to increase participants' knowledge about brain damage and memory functioning, b) to encourage the use of memory aids, c) to develop and enhance participants' ability to cope with memory problems, and d) provide group members an opportunity to meet people with similar problems. A "self-help" programme served as a control group. This was an emotion-focused programme that did not offer memory training but instead encouraged participants to discuss emotional issues related to their impairments and to practice relaxation exercises, such as Jacobson's Progressive Muscular Relaxation technique.

### **3.3.8. Outcome assessments**

Participants were assessed at five months post-randomisation to examine the immediate effects of the intervention. A follow-up assessment was conducted seven months after the randomisation to examine whether the treatment effects, if any, were maintained. The outcome assessor was blind to treatment allocation. In order to avoid the occurrence of accidental unblinding, the assessor explained to participants that they must not discuss any aspects of the group sessions during the assessment. Participants were informed that they would have the opportunity to talk about their experiences in the programme to another researcher who would conduct the feedback interviews.

The outcome measures used were:

- Rivermead Behavioural Memory Test-Extended version, (Wilson et al., 1999) to assess actual memory function,
- Everyday Memory Questionnaire (EMQ; Sunderland et al., 1983) to examine perceived memory ability,
- Internal Memory Aids Questionnaire and External Memory Aids Questionnaire (adapted from Wilson & Moffat, 1984 and Brown, Pinnington & Ward, 2004) to assess the use of memory aids,
- The Extended Activities of Daily Living Scale (Nouri & Lincoln, 1987) to assess disability,
- Mood was assessed with the Abbreviated Wimbledon Self-Report Scale (Coughlan & Storey, 1988) and General Health Questionnaire-12 (Goldberg & Williams, 1988).

These measures were chosen because of their sound psychometric properties and use in previous memory rehabilitation studies.

### 3.3.9. Feedback Interviews

People who had consented to participate in the study were invited for an interview following the completion of the programmes. A research psychologist (Dr Kristina Vella), who was not involved in any other aspects of the trial, conducted the feedback interviews. The interviews were carried out in the period between October 2005 and July 2006 at the Institute of Work, Health and Organisations, University of Nottingham. A structured interview schedule was developed (Table 3). It included some general questions exploring the effects of the intervention in participants' personal, professional and social lives and other more specific related to the aims of the programmes (e.g. use of memory aids). In order to avoid imposing any assumptions on the expected effects of each programme, the same schedule was used to interview participants from all the three programs. Interviews lasted approximately 10 to 20 minutes. The interviews were recorded using a digital voice recorder and were transcribed by the interviewer verbatim. The present author checked each interview against the original recording and conducted the analysis of the interviews.

Table 3  
*Structured Interview schedule*

- What effects have you noticed on your personal life as a result of the group sessions?
- What effects have you noticed on your professional life as a result of the group sessions?
- What effects have you noticed on your social life as a result of the group sessions?
- Have you, or anyone else, noticed any difference in your mood as a result of the sessions? What are these changes (if any)?
- To what extent have the sessions affected your confidence? For example, are you less anxious about disclosing your problems?
- Are you able to give an example of how the sessions have helped you deal with what would have been a previously frustrating situation?
- How useful was the first introductory session on memory itself? e.g. information on short-term to long-term stores, brain anatomy etc.
- Have you obtained more insight into your own memory difficulties as a result of the sessions?
- What have you valued most about being in a group-based session?
- Have the sessions affected your planning and organisational abilities? If yes could you explain how and use examples if relevant.
- Have the sessions affected your problem solving abilities? If yes could you explain how and use examples if relevant.
- Could you comment on any changes on your assertiveness and ability to take the initiative as a result of the sessions?
- Are you more motivated to explore different strategies to help your problems?
- Have you developed your own memory aid techniques based on those you were informed about during the sessions? If so, could you describe them and how you came about devising them?
- Have you found the concept of errorless learning useful? Have you been able to apply it in everyday life?

### 3.3.10. Thematic analysis of interview data

The most appropriate approach to the analysis was considered to be thematic analysis, a method for encoding qualitative information in a systematic manner (Burman, 1994). Thematic analysis involves identifying, analyzing and reporting themes within data in order to organize and describe the data set in rich detail (Braun & Clarke, 2006). A theme is often described as a pattern found in the data set capturing something important about the data in relation to the research question. Luborsky (1994) however, suggested that the term “pattern” may be best used to describe findings from the researchers’ point of view. He proposed that themes should be defined as “the manifest, generalized statements by informants about beliefs, attitudes, values or sentiments” (p.195.). According to Luborsky this definition highlights two important properties of the method: a) the aim of thematic analysis is to understand and reflect the respondents’ own views, b) the analysis is based on manifest and explicit statements of the respondent rather than inference and background information on the person or the situation. Other theorists suggested that thematic analysis can go beyond the manifest content of data in order to interpret the underlying aspects of a phenomenon (Boyatzis, 1998). Although Boyatzis (1998) proposed that both manifest and latent thematic analysis can be used at the same time Braun & Clarke (2006) argued that a thematic analysis typically focuses on one level.

According to Luborsky (1994) there are two basic approaches to identifying themes. One is to seek those statements that occur most frequently or are repeated. When this approach is followed, themes are counted in order to pick the most frequent ones (Luborsky, 1994). This can be done by either counting the occurrence of each theme across the entire data set or the number of different speakers who articulated the theme (Braun & Clarke, 2006). However, an analysis relying exclusively on frequency indexes to describe content is considered to violate the basic assumptions and aims of qualitative research. An alternative approach in identifying themes is to look for those statements that are important for the respondents or that capture something important in relation to the research question. Instead of identifying repetitive themes, the researcher can look for statements where the respondents express directly their own view of what is important (Luborsky, 1994). While frequency can be a secondary concern when identifying salient themes, many authors suggest that providing some indication of whether themes occur commonly or rarely can be very helpful for the reader (Joffe & Yardley, 2004; Braun & Clarke, 2006). Part of the flexibility of thematic analysis is that it allows for both

approaches to be used in combination (Luborsky, 1994). This can be a great advantage of the methodology, provided that researchers remain consistent in the process they follow throughout the dataset (Braun & Clarke, 2006). Another decision for the researcher to make is whether the themes will be identified in an inductive or “bottom-up” way or in a theoretical or “top down” way (Braun & Clarke, 2006). In the inductive approach the themes are informed by the data rather than being driven by the researchers’ theoretical assumptions. In the “theoretical” thematic analysis, on the other hand, coding is informed by a theoretical framework or previous research in the field. Instead of describing the entire data set this form of analysis might focus on some specific research questions. The downside of this approach is that researchers may end up using the questions that were asked to participants as themes.

Thematic analysis draws on core features that are common to many approaches in qualitative research (Attride-Stirling, 2001). According to Holloway and Todres (2003) the identification of “thematising” meanings is one of a few shared generic characteristics across qualitative analysis (p.347). This is probably the reason that thematic analysis has been described as an analytic tool to use across different methodologies and analytic traditions, such as grounded theory, rather than a specific method (Boyatzis, 1998). Braun and Clarke (2006), on the other hand, argued that thematic analysis should be considered as a method in its own right. In order to clarify the sources of confusion it is important to differentiate thematic analysis from other methods.

Thorne (2000) noted that thematic analysis relies on an analytic strategy called “constant comparative analysis”. This strategy involves taking one piece of data (e.g. an interview, a statement or a theme), and comparing it with all others in a data set in order to understand the relations between them. The process is inclusive, meaning that rather than reducing the data in a few numerical codes new categories or themes are added in order to provide a rich description of the data set (Pope et al., 2006). This approach was originally developed for use in the grounded theory methodology (Glaser & Strauss, 1968). The process of analysis in grounded theory methodology is very similar to that of thematic analysis and this is probably the reason for which some researchers use them as if they were actually the same method (Tuckett, 2005). This assumption is erroneous as important differences exist between the two methodologies. Whereas thematic analysis seeks to describe the data without necessarily building a theory, the main aim of grounded theory is the development of a theory that explains the findings within the data (Burman, 1994). Moreover, a central feature of grounded theory is the cyclical nature of the procedure as

the analysis feeds into subsequent sampling and data collection in order to further test the initial findings and slowly build a new theory (Pope & Mays, 2006). Consequently, theoretical sampling is necessary for grounded theory as the researchers have to select new respondents or settings that will allow them to assess their emerging theories. This method provides rich and detailed interpretations, however, the need for continual sampling and analysis can be very time consuming and potentially overrun the resources of the study (Pope & Mays, 2006).

Braun and Clarke (2006) suggested that qualitative methods can be divided according to whether they are related to a particular theoretical or epistemological orientation. Based on that division the authors identified two broad groups of approaches, the ones that are tied to a theory such as phenomenological research, grounded theory and narrative analysis, and the methods that can function independent of epistemological approaches such as thematic analysis. Interpretative phenomenological analysis also seeks patterns in the data, however it has a strong philosophical component to it. It is interested in peoples' experiences of a concept or a phenomenon and aims to develop a description of the essence of a phenomenon for all individuals (Creswell, 2007). Narrative research on the other hand, is best for capturing the detailed stories or life experiences of one or a small number of individuals (Creswell, 2007). Whereas thematic analysis identifies experiences that are valid across many individuals, narrative analysis undertakes an in depth and exhaustive analysis of individual cases. Both narrative and discourse analysis rely heavily on speech and linguistic representation in order understand human experience. Discourse analysis, in particular, uses theories developed in fields such as sociolinguistics and cognitive psychology in order to unveil the representations behind the various ways in which people communicate ideas (Thorne, 2000).

Content analysis is another method that can be used to identify patterns across qualitative data and is sometimes treated as similar to thematic analysis. This is not surprising considering that thematic analysis shares many of the principles and procedures of content analysis. It is notable that Boyatzis (1998) described thematic analysis using the terms code and theme interchangeably. Thematic analysis, similarly to content analysis, can be used to transform qualitative data into a quantitative form (Boyatzis, 1998). However this is not a very common use of the method and thematic analysis usually pays greater attention to the qualitative aspects of the material analysed (Brown & Clarke, 2006; Joffe & Yardley, 2004). In contrast, content analysis has been criticized for relying too much on frequency measures and for de-contextualizing the outcomes. According to



Joffe & Yardley (2004) the problem with this approach is that there are many different reasons for which a word or coding category may occur more frequently in a narrative. The frequency with which a theme appears does not necessarily indicate the extent to which it is relevant to the interviewees (Luborsky, 1994). Frequent occurrence could simply reflect greater willingness or ability to talk at length about the topic or might even occur in repeated assertions the topic was not of relevance to the respondents (Joffe & Yardley, 2004). As Luborsky underlined, numbers cannot always tell the whole story. Thematic analysis, on the other hand attempts to understand human experience within the context in which it occurs (Thorne, 2000). While content analysis uses words or short phrases as units of analysis in thematic analysis the unit of analysis tends to be longer incorporating, in this way, more contextual information (Braun & Clarke, 2006). According to Braun and Clarke (2006) thematic analysis combines the systematic element of content analysis with the richness of descriptions that only a truly qualitative analysis permits.

The widespread use of thematic analysis in social sciences and health research is well founded according to Luborsky (1994). As already shown, among its benefits is that it provides information on the frequency of themes while keeping their meaning in context. This qualitative perspective in the study of narratives facilitates the emergence of respondents' beliefs, perceptions and experiences. This is of great importance particularly in health research as it allows for the voice of individual consumers or patients to be heard alongside the views of the researchers or medical staff (Luborsky, 1994). In this way, valuable information can be obtained on the experience of living with a disease as well as feedback on the quality of the medical services and interventions. Another contribution of thematic analysis is that it can communicate a wealth of information in a simple and standardized way. The rich descriptions of individuals' thoughts and concerns become accessible to the general public and policy makers. A large body of data can be summarised in key themes that reflect the salient concepts and meanings. The themes are then readily comparable with other parts of the narrative of the same or different speakers. Consequently, the similarities and differences across the data set are highlighted allowing for the range of opinions to be represented in the results (Braun & Clarke, 2006). As well as facilitating systematic comparisons it is also the ease of the coding that makes thematic analysis a popular option across disciplines (Luborsky, 1994). Thematic analysis is a relatively straightforward and quick form of qualitative research which does not require from the researcher the same detailed theoretical and technical knowledge as other

approaches (Braun & Clarke, 2006). This makes the method accessible to researchers without great experience in the field of qualitative research.

Despite its simplicity there are a number of methodological issues for the researcher to consider. First of all, the researchers need to be clear about the analytic process and provide an explicit description of the steps they followed. According to Braun & Clarke (2006) a potential pitfall is to oversimplify the analysis to the point of not analysing the data at all. Thematic analysis does not stop in the identification of themes or the selection of extracts but should go beyond that point. Researchers should attempt to make sense of the data and communicate their understanding to the reader through illustrative analytic narratives (Braun & Clarke, 2006). Another issue to consider is that the entire dataset should be included in the analysis instead of simply selecting parts of the narratives that confirm the researchers' assumptions (Joffe & Yardley, 2004). In that sense a successful thematic analysis should include negative examples or statements that contradict the identified themes or interpretations. The negative examples might strengthen the conclusions of the researchers or provide the material for alternative readings of the data.

Despite its popularity, there are surprisingly few publications that provide adequate guidance on how to carry out thematic analysis. The procedure that was followed in this study was based on the one suggested by Braun & Clarke (2006).

### Process of thematic analysis

The process that Braun and Clarke suggested involves six phases of analysis. They authors noted, however, that thematic analysis is not a linear but a recursive process where the researchers can move through the phases as required.

*Phase one. Familiarisation with the data.* According to Braun & Clarke this phase includes the process of transcription. In this study, checking the transcripts against the original recordings allowed the author to become acquainted with the data. The author then obtained a more thorough understanding of the data by repeatedly reading the entire dataset. Some initial ideas and first impressions were noted down although no formal coding was performed in that stage.

*Phase two. Generating initial codes.* In this stage some preliminary codes were used in order to organise and make sense of the dataset. As analysis followed an inductive approach, the codes were "data driven", meaning that they were produced from the data. The dataset was read through and a code was assigned to each text segment that conveyed some interesting information and could potentially form the basis for a theme.

The text segments that were coded were highlighted and short description was written next to the text. That procedure was applied to the entire dataset in order to avoid excluding information that might be meaningful in later stages of the analysis. These text segments that were assigned the same code were then grouped together in a separate document. During that procedure attention was paid to include some of the data surrounding the coded extracts in order to avoid stripping the codes from their context.

*Phase three. Searching for themes.* That phase involved abstracting potential themes from the coded text segments. Themes were identified at a semantic or explicit level. The author went through the text segments that formed each code in order to identify common meanings, differences and contradictions between codes. A constant comparison process was applied where the views of respondents within the same programme and across the three programmes were continuously compared in order to identify commonalities and differences, build themes and identify exceptions to these themes. The same extracts of text were coded more than once in as many different themes as they fitted to. Relevant codes were grouped into sub-themes that were then summarised to form main themes. Key themes mainly included issues that emerged across several of interviews as well as isolated factors since these were potentially very important. Following Luborsky's (1994) suggestions, salient themes were identified by examining the pervasiveness of a theme across different discussion topics. Another strategy was to look for markers such as connectives and intensifiers (e.g. because, very etc.), potentially used to highlight important events and thoughts (Luborsky, 1994). As a result of this procedure, a number of core themes and subthemes were identified.

*Phase four. Reviewing themes.* In this phase the candidate themes were refined. Individual themes were reviewed to ensure that: a) each theme encapsulated the ideas contained in the included codes, b) the meanings of included codes were coherent. The thematic map (the group of identified themes and subthemes) was also revisited in order to assess whether: a) each theme made sense in relation to the rest of the themes, b) there were clear distinctions between the themes, and c) the thematic map accurately represented the set of ideas contained in the data. This process allowed the author to spot the repetitive and overlapping themes, code any data that were missed in previous phases, and discard the themes that were not supported by the data.

*Phases five and six:* The two final phases involved naming the themes and producing the report. Representative quotations were selected to illustrate particular themes from the range of participants. The number of patients that reported benefits in relation to the

content areas represented by each theme was also reported. This should not be viewed as an attempt to quantify the qualitative findings as this would negate the very purpose and assumptions of qualitative research. Braun & Clarke (2006) cautioned against judging the "keyness" of a theme based solely on quantifiable measures. Qualitative research acknowledges that researcher judgement is necessary to determine which themes are important. However, it was considered useful to provide a clear overview of the most frequently reported benefits of the interventions and highlight the identified differences between the three programmes. Individual cases that contradicted the themes or conveyed an interesting idea were also incorporated in the report. In line with the aims of qualitative research, the report needed to reflect the range of different views in the dataset and allow the voice of each participant to be heard.

In qualitative research, issues of sampling, representativeness and generalisability need to be reframed in a new perspective (Gobo, 2008). Qualitative research does not aspire statistical generalisability or representativeness (e.g. Barbour, 2001). The aim of the sampling strategy is to maximise the opportunity of producing data that represent a range of views on the topic (e.g. Green & Thorogood, 2010). In this study, it was important to demonstrate that the sample was not biased, due to exclusion of certain individuals, and that the identified themes reflected a range of views from all the three groups. In order to avoid excluding people with potentially negative experience of the programme, participants who had dropped out of the group sessions were also invited for an interview. Furthermore, the sample of people who were interviewed was compared to those who did not take part in the interviews on basic demographic characteristics. Comparisons were also conducted between the three programmes on demographic characteristics that could have affected individuals' ability to benefit from the interventions (i.e. memory ability, language skills, premorbid intelligence and mood).

The analyses were conducted using the SPSS statistical package version 16.0.

### 3.4. Results

#### 3.4.1. Participant characteristics

Interviews were conducted with 19 participants of the 24 who were allocated to the two compensation, two restitution and two self-help groups. Four participants of the 24 dropped out of the group sessions but were invited for an interview. One participant had dropped out of the compensation groups (she did not get along with one of the group members) but she agreed to be interviewed. Another participant allocated to the compensation groups did not attend any sessions (she did not feel she was ready to meet others with memory problems) and she did not agree to undergo the follow-up assessments. One participant dropped out of the restitution group (he got a job and moved to another town) and could not be traced. One participant dropped out of the self-help groups because she had a relapse and could not continue participation. Two participants who had fully attended the restitution and compensation programmes respectively did not feel they could undergo the follow up assessments due to poor health (MS relapse).

In total, 70% of participants allocated to the compensation groups, 80% of participants in the restitution groups and 86% of participants in the self-help groups were interviewed. Table 4 presents the demographic characteristics of the interviewees as compared to those patients who dropped out of the study. Fisher's exact test was used to examine the differences between the two samples on gender and diagnosis. This test is recommended for use on two independent samples when one or more cells have an expected frequency of five or less cases (Field, 2005).

It was found that the two samples did not significantly differ in terms of age, gender or diagnosis.

Table 4  
 Comparisons between interviewees and withdrawn participants on demographic characteristics.

			Interviewed sample (N=19)	Withdrawns (N=5)	P value
Gender	Female	N	13	3	.55*
		%	68.0	60.0	
	Male	N	6	2	
		%	31.0	40.0	
Diagnosis	TBI	N	3	1	.34*
		%	15.0	20.0	
	MS	N	12	4	
		%	63.0	80.0	
	Stroke	N	4	0	
		%	21.0	0	
Age	Median		46.5	45.7	.89†
	IQR		37.6-52.0	42.0-45.7	

\* Fisher's exact test; †Wilcoxon Signed Rank Test

The demographic and neuropsychological characteristics of the interviewees based on their group allocation are shown in tables 5 and 6 respectively. There were no missing items on the baseline assessments. It was not possible to examine the differences between the three programmes on categorical variables as more than 25% of cells had an expected frequency of less than five cases. However, some variation could be observed between the programmes in relation to gender and diagnosis. This was particularly obvious in the compensation group which consisted exclusively of female participants diagnosed with multiple sclerosis. Regarding the continuous demographic characteristics, no significant differences were found between the three programmes.

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Table 5  
Demographic characteristics of the interviewees based on their group allocation

Demographic Characteristics		Group			
		Compensation (n=5)	Restitution (n=8)	Self-help (n=6)	P value †
Age	Median	42.0	45.5	52.0	.23
	IQR*	39.5-52.5	39.2-49.5	37.7-63	
Gender	Female	n	5	6	2
		%	100	75.0	33.3
	Male	n	0	2	4
		%	0	25.0	66.7
Diagnosis	TBI	n	0	3	0
		%	0	37.5	0
	Stroke	n	0	12.5	3
		%	0	12.5	50.0
	MS	n	5	4	3
		%	100	50.0	50.0

†Wilcoxon Signed Rank Test

Table 6  
Psychometric characteristics of the interviewees based on their group allocation

Psychometric Data		Group			P value†
		Compensation	Restitution	Self-help	
NART estimated IQ	Median	107.6	99.0	107.5	.14
	IQR*	98.5-115	94.2-106	104.5-108.7	
SSTALD total score	Median	20.0	19.0	19.0	.52
	IQR	20.0-20.0	18.2-20.0	18.0-20.0	
RBMT-E Overall profile score	Median	2.0	1.0	1.0	.32
	IQR	1.0-2.0	1.0-1.75	0-2.0	
EMQ total score	Median	40.0	53.5	58.5	.55
	IQR	30.0-80.0	22.5-81.2	48.0-81.7	
GHQ-12 Total score	Median	4.0	3.0	4.5	.54
	IQR	2.5-8.5	1.0-6.5	0.7-8.5	

\*IQR (Interquartile range) = Q25-Q75; † Kruskal-Wallis comparison; NART, National Adult Reading Test; SSTALD, Sheffield Screening Test for Acquired Language Disorders; RBMT-E, Rivermead Behavioural Memory Test-Extended Version; EMQ, Everyday Memory Questionnaire; GHQ-12, General Health Questionnaire-12.

### 3.4.2. Identified themes

Nine main themes emerged from the data analysis. Table 7 provides a summary of these themes including the subthemes that they consist of. The number and percentage of participants in each programme who benefited from the interventions in relation to the area defined by each theme is also provided. Participants who are not represented by these numbers were people who: a) reported that they did not experience any relevant benefits (although not included in the frequency table these cases were presented and discussed in results); b) did not think the question was relevant/applicable to them (e.g. participants may have not observed any benefits in relation to areas such as professional life, mood or confidence levels simply because they were unemployed, or did not experience any mood or self-confidence issues prior to the groups); c) they were never actually asked that question (i.e. interviewer's omission). Not every respondent provided feedback on every topic and, therefore, presenting the number of people who did not report benefits in relation to a theme would not be informative. It would also be out of the scope and methodological approach of this study as counting negative instances is only relevant to some types of quantitative content analysis (e.g. Boyantzis, 1999). The addition of further categories to represent these cases (e.g. negative, non-applicable) would have led to a structured "questionnaire type" response format, compromising the richness of qualitative descriptions and negating the very purpose of qualitative interviewing.



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Table 7

Summary of identified themes and subthemes and number of interviews in which each theme was identified

	Compensation (n=5)		Restitution (n=8)		Self-help (n=6)		Total (N=19)	
	n	%	n	%	n	%	n	%
<b>Generic memory knowledge</b>	<b>4</b>	<b>80</b>	<b>6</b>	<b>75.0</b>	<b>2</b>	<b>33.3</b>	<b>12</b>	<b>63.2</b>
<b>Self-awareness</b>	<b>5</b>	<b>100</b>	<b>6</b>	<b>75.0</b>	<b>2</b>	<b>33.3</b>	<b>13</b>	<b>68.4</b>
-severity of memory problems	3	60.0	3	37.5	0	0	6	31.6
-strengths and weaknesses	4	80.0	4	50.0	1	16.7	9	47.4
-false representations	2	40.0	2	25.0	0	0	4	21.1
-accepting the problem	4	80.0	5	62.5	1	16.7	10	52.6
<b>Confidence</b>	<b>5</b>	<b>100</b>	<b>6</b>	<b>75.0</b>	<b>1</b>	<b>16.7</b>	<b>12</b>	<b>63.2</b>
-coping with memory problems	4	80.0	5	62.5	0	0	9	47.4
-disclosing the problem/use of memory aids	3	60.0	3	37.5	1	16.7	7	36.8
-specific memory skills	1	20.0	3	37.5	0	0	4	21.1
<b>Memory aids</b>	<b>5</b>	<b>100</b>	<b>7</b>	<b>87.5</b>	<b>1</b>	<b>16.7</b>	<b>13</b>	<b>68.4</b>
-learning new strategies	4	80.0	7	87.5	1	16.7	12	63.2
-use strategies effectively	5	100	5	62.5	0	0	10	52.6
<b>Independence</b>	<b>3</b>	<b>60.0</b>	<b>4</b>	<b>50.0</b>	<b>0</b>	<b>0</b>	<b>7</b>	<b>36.8</b>
<b>Motivation</b>	<b>5</b>	<b>100</b>	<b>5</b>	<b>62.5</b>	<b>4</b>	<b>66.7</b>	<b>14</b>	<b>73.9</b>
- exploring new strategies	5	100	3	37.5	0	0	8	42.1
-engaging in activities beneficial for cognitive functions	2	40.0	4	50.0	4	66.7	10	52.6
<b>Cognitive skills affecting memory performance</b>	<b>4</b>	<b>80.0</b>	<b>6</b>	<b>75.0</b>	<b>3</b>	<b>50.0</b>	<b>13</b>	<b>68.4</b>
-attention	2	40.0	6	75.0	0	0	8	42.1
-organisational skills	3	60.0	3	37.5	3	50.0	9	47.4
<b>Mood</b>	<b>4</b>	<b>80.0</b>	<b>4</b>	<b>50.0</b>	<b>5</b>	<b>83.3</b>	<b>13</b>	<b>68.4</b>
-control anxiety/stress	0	0	0	0	5	83.3	5	26.3
-stress about memory problems	4	80.0	4	50.0	1	16.7	9	47.4
-general mood	1	20.0	1	16.7	3	50.0	5	26.3
<b>Benefits of group setting</b>	<b>5</b>	<b>100</b>	<b>7</b>	<b>87.5</b>	<b>5</b>	<b>83.3</b>	<b>17</b>	<b>89.5</b>
-meeting people with similar problems	3	60.0	7	87.5	4	66.7	14	73.9
-enhancing social interaction	0	0	1	16.7	2	33.3	3	15.8
-exchanging tips and strategies	4	80.0	4	50.0	1	16.7	6	31.6
-emotional sharing	2	40.0	3	37.5	2	33.3	5	26.3

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### Generic memory knowledge

Participants in all the three intervention programmes received some basic information on memory functioning. An introductory session was devoted to the description of memory processes, the consequences that a disruption of these processes can have and the natural mechanisms of recovery. For twelve participants the rehabilitation programme responded to their needs for information on brain damage and its effects on memory. Respondents valued the use of simple language which allowed them to better understand complex ideas.

*ID 41: It was fascinating to actually think of your brain as a basically, email filing system. And it really, it does make sense because sometimes now I tend to visualise what's happening in my brain. If information is actually going somewhere and is stored or whether it's going straight out. (line 39, self-help group)*

*ID 36: It's quite scary to realise how many different sorts of memory you've got (line 31, compensation)*

Despite the positive feedback, not everyone agreed on the benefits of these sessions. Before admitting that she found information to be “stimulating”, a lady with multiple sclerosis talked about her choice not to know much about her condition.

*ID 16: I don't really want to know much about MS. I think I just want to carry on. Sometimes if you read or you really go into these things everything that happens you think “oh dear, it's MS” but it's not necessarily that (line 27, compensation)*

Another participant identified the theoretical information on brain function as one of the main reasons she dropped out of the programme as it was against her religious beliefs.

*ID 12: I am a witness and I believe that God created the earth I don't believe in the evolution (...) because he said “that part of the brain was the last to evolve” and I was thinking “Hang on a minute I am not enjoying this! (line 15, restitution)*

### Self-Awareness

The provision of information and feedback and the interaction with other group members led to improvements in participants' awareness of their memory deficits. This was one of the most salient themes as gains were reported by 13 respondents, mainly from the two intervention groups. The improvement in awareness was manifested in

different ways. In some cases, the mere decision to enrol in the programme triggered a process of reflection. One lady with multiple sclerosis said:

*ID 12: When this letter came and it said brain damage on the top (...) I thought what? I've never been told before that its brain damage, so it took me a good while to sit down and start thinking about it and comprehend it. (line 83, restitution)*

For five participants it meant the realisation of the true extent of their difficulties which, prior to rehabilitation, had been underestimated or exaggerated. Often, that realisation was far from being easy and pleasant and instead it was described as an initial shock.

*ID 39: Very shocking that my memory is as bad as it is! (line 13, compensation)*

*ID 23: At one point I thought it was worse than I thought. And then coming again, I thought no (...) it's not really, it's better than you thought. (line 39, restitution)*

*ID 24: I think it has made me realise I have got problems more than what I had thought. (line 10, restitution)*

Four participants described a period before rehabilitation when, although they noticed their difficulties, incomplete knowledge and false interpretations caused confusion and distress about the source of the problem. Rehabilitation helped them to clarify their misunderstandings and dispel maladaptive beliefs and illness representations.

*ID 44: Because I felt like I was either going insane or I was maybe being a bit of a hypochondriac (...) (line 83, compensation)*

*ID 23: I was thinking at my age I shouldn't be this and that (...) thinking it was dementia rather than MS. (line 45, restitution)*

Eight members of the two intervention programmes underlined the importance of learning to distinguish between memory processes as this allowed them to identify their personal strengths and weaknesses. However, for one lady with multiple sclerosis this process raised questions rather than providing definite answers.

*ID 21: It certainly raised questions for me. I am not sure of where the breakdown is in the process of taking information and processing it, filing it and putting it away and retrieving it. I used to think it was a difficulty in the filing process not the taking in. It was a difficulty between those two steps but I still don't know and I don't even try to make out that I do.*

*But it is just interesting having got that information to be questioning the process for yourself. It's interesting to know the theoretical journey that your memory takes in taking that information, processing it and storing it. (line 52, restitution)*

Rehabilitation was also mentioned as a context that supported the process of acknowledging the problems. By offering respect and providing explanations it helped members to normalize their experiences and accept the changes. This was highlighted in the narratives of ten participants.

*ID 44: I just wanted someone to acknowledge me. The groups have given me permission to sort of let it out. Let all that out (...) and by doing that I've actually been able to see with brighter light now as to what the issues were rather than in the dark just fretting around and not knowing what was going on and why I was like that. (line 41, compensation)*

*ID 28: It has made me think, well perhaps some things you cannot change and you have to live with it and some things you can change and you have to work at it. You sort of have to draw lines. (line 39, self-help)*

*ID 39: I've accepted how bad my memory is. And I think that's some of the problem, in accepting it. And that helps you. (line 116, compensation)*

### Confidence

Participants did not report major changes in their memory function itself. What they did notice, however, were changes in their coping skills. Nine members of the intervention programmes talked about how rehabilitation strengthened their confidence in their ability to effectively deal with memory problems. Drawing upon the knowledge they obtained during the rehabilitation programme, participants approached memory tasks more confident that they would manage.

*ID 21: It is facing the difficulty and saying "yes, I can do it!". It is recognising the fact that there are ways to conquer this difficulty and yes and you have got to keep looking for different alternatives. (line 89, restitution)*

*ID 39: I don't feel like I benefited in the way that I retain more information. But it's definitely made me feel more able because of having the different techniques that I can now use. I still forget, which is probably part of the course, but I feel like I'm not going to forget so much. (line 17, compensation)*

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Specific memory tasks that respondents appeared most confident about were related to prospective memory ability. Four participants revealed important benefits that were attributed to the rehabilitation programme. Despite these improvements two respondents commented that, due to their memory problems, they still did not feel confident enough to engage in conversations.

*ID 16: You know, I was sort of standing there making a conversation and then I sort of froze and could not think of the word (line 53, compensation)*

For six participants confidence was reflected in becoming more assertive in social situations. They also reported being more open about disclosing their disability and the use of memory aids.

*ID 36: I have told more people actually since I have gone to the group. (line 22, compensation)*

*ID 28: I feel I have got the confidence to say 'hang on, you cannot just fire this at me and expect me to remember this. You need to write it down or something, you know, which at the moment is not happening. And don't feel that I will be judged by that, you thinking I am stupid because I cannot do it, but hopefully they will think it is because of the stroke. (line 137, self-help group)*

One lady, however, appeared hesitant to expose her problems outside the safe environment of the rehabilitation groups.

*ID 20: In the circumstances obviously we were able to talk about problems (...) But I wouldn't say that it has made me any better at telling other people anything that is wrong or the problems that I have. I have learnt umpteen times to keep them to myself. 9 times out of 10 there is no point of telling anyone anything anyway. That's the way I feel. (line 23, restitution)*

### Memory aids

Adopting internal and external memory aids in their everyday lives was a dominant theme that came up repeatedly in the narratives of the intervention groups' members. On the whole, participants referred very positively to the use of external and internal strategies as leading to improvements in their memory performance. Twelve participants reported that the rehabilitation programme introduced them to new ideas and techniques that would probably not occur to them otherwise.

*ID 36: It has taught us how to use different objects (...) I never thought of using my mobile phone as a reminder. Whereas now I do and I've always carried a diary with me but now I have a notebook as well whereas before I used to write on the back of my hand. (line 46, compensation)*

*ID 33: I write down my appointments which I never used to do, and if I do forget I have a small diary with me in which I put everything (...) it's really helpful (...). I'm better about appointment. (line 59, compensation)*

Seven participants said that they had already been using some of the strategies prior to rehabilitation. Their efforts, however, had not been very successful and they were generally disappointed by the outcome. For these respondents the main reason for improvement was not because of starting to use memory aids but because of learning how to use them effectively. The training they received in the groups helped them to identify and find solutions to specific problems they encountered when using memory aids. It also guided them in being better organized and more systematic in the application of these strategies.

*ID 21: Now I am disciplined and I make a list and I don't deviate from that list. I feel so good as I know that I have achieved it might be a very small bit but I have achieved something. (line 36, restitution)*

*ID 39: The things I've took (...) like I say, I'd already got the memory board but the group leader giving me the different colour pen idea was great cause that's made a big difference. (line 195, compensation)*

Four participants realised that not all strategies are suitable for everyone. The group offered them a context where they could experiment with a wide range of options. They explored different possibilities, put them into practice in their everyday lives and returned to the group in order to give and receive feedback. In this way they were able to spot the strategies that were the most appropriate for them or modify memory aids in order to adapt them to their individual needs.

*ID 21: During the discussions I said yes that sounds great but there were other things that we either rejected or we said yes that might work for me but not for you. (line 103, restitution)*

*ID 39: Before I started doing the groups I was trying different methods, but it's finding which one works best for me (...) because there are so many things I can do which is too much, I need to find which is best for me. (line 176, compensation)*

Six participants also learned to take into consideration the nature and the demands of each memory task when employing different memory aids. They reported that rehabilitation enhanced their ability to choose the most appropriate strategy for a particular task. The range of different strategies was described by one participant as a 'toolbox' from which 'the best tool is pulled in for a specific task' (ID 44, line 12).

*ID 44: That for me was the most powerful thing because you've given me a box of tools to take away with me now. In my head that's what I've got, a memory toolbox. And rather than just possibly using the same old strategy I know now I can apply this one for that or etc. (line 106, compensation)*

The respondent further demonstrated how she used the alternative strategies in the following extract where she described the way she processed a memory task during the follow-up assessment:

*ID 32: I was doing the test and I had to look at those pictures (...) 15 seconds to look at them. And I was glancing away at them so my initial reaction is first letter Q (...) no I will sing a little song about the elephant ate the cake went on the aeroplane and the aeroplane crashed into the bike and you know, I kind of did that. And then looking at pictures of people's faces I thought I'll use a different strategy there. (line 147, restitution)*

### Independence

Some respondents also noticed that they relied less on other people to remind them of things to do. Four participants reported feeling more independent and in control of their lives following rehabilitation.

*ID 21: My husband seems to know where everything in the house is no matter what it is. It makes me slightly nervous; I can feel myself almost thinking at one point "Anthony will know where it is. Anthony can you find this?" Now I think I don't want him to be doing it, I should know where it is. I also do ask the children now not to finish my sentences, which is what they used to do before but I do try to finish my own sentences. (line78, restitution)*

From their point of view, expecting others to remind them put participants in an uncomfortable position where they depended on other peoples' benevolence. The use of

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memory aids allowed them to be as independent as possible and affected the family functioning by “preventing arguments and unnecessary stress in the house” (ID 44, line 6, compensation).

*ID 23: My grandson tells me that I’ m a lot easier to live with! (line 14, restitution)*

### Motivation

In their interviews respondents appeared more proactive towards their problems as a result of rehabilitation. Six participants from the intervention groups talked about the ways rehabilitation motivated them to explore new strategies or develop their own memory aids. However, gains were not restricted to the intervention groups as participants from the self-help groups also commented on their motivation to take action and engage in activities beneficial to their cognitive functioning.

*ID 41: I’ve been sort of trying to do puzzles and things like that more than I did before. Cause obviously that stimulates my brain when I’m not at work. So I have tried. (line 98, self-help group)*

*ID 16: We got a little shop and I thought right, I am going to try and just go and sit, just sit and you know, meet people more and try to motivate myself. (line 11, compensation)*

*ID 21: It’s just pushing yourself and making sure you do these things and making sure that you keep your brain working. (line 93, restitution)*

### Cognitive skills affecting memory performance

As part of the training participants were informed about the important role that other functions, such as attention, have in supporting memory performance and an attempt was made to practice them through exercises and tasks. Eight participants reported being more attentive to the information they needed to remember. They also experienced improvements in their planning and organizational skills.

*ID 32: I am more aware of what is going on around me as well, where I have parked and concentrate more as well (...). We are moving house at the moment so it has taken a lot of planning and organisation. So I felt a lot better to cope with that and it hasn’t stressed me out as much. (line 25, restitution)*

*ID 39: I do plan things better, I am better organised. Before I would just think we’re going away on holiday right I’ll just leave it to the last night and chuck it (...) oh yeah, I need this I*



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*need that. But I know now I need to plan, I need to make lists and go through it. So it's taught me that I need to pay more attention really to what I'm doing. (line 143, compensation).*

*ID26: I definitely plan things better now. I went into finding work, part time work. I would never have done it any other way. (line 44, self-help)*

### Mood

For participants in all the three programmes improvements in mood were mainly manifested as an ability to control anxiety and stress. Thirteen respondents highlighted the reduction in stress levels as a benefit of attending the rehabilitation programme.

*ID 41: I've got an easier way of relieving stress that I didn't have before which in certain situations can actually help me to think whereas before it's been totally blank. (line 3, self-help)*

*ID 26: I know how to calm down a bit more. Cause after brain injury I was irritable and quite short-tempered. But now I know how to calm down and settle down and so I can get on with it. I approach things differently now. (line 20, self-help)*

Five respondents appeared to be less stressed about memory problems, an improvement that was mainly observed in the intervention groups.

*ID 36: I don't get as worried when I forget things as I used to. Before if I forgot something it really upset me but now I think no, I know why I forgot it so I take a moment to myself and then I'm able to remember. Whereas before I used to panic but now I don't because I've got different ways now of remembering things. (line 3, compensation)*

*ID 32: We are moving house at the moment and I have felt a lot better to cope with that and it hasn't stressed me out as much. Because I have obviously used the techniques I have learnt and it has been fine. (line 52, restitution)*

Five interviewees, however, commented that rehabilitation did not have a great impact on their mood or that they could not arrive at safe conclusions as other important changes were taking place in their lives.

*ID 44: It's difficult to say because I'm going through a lot of stress at work because of another issue. So if that wasn't happening I think it probably would be more noticeable cause I can feel it within myself. But now, I wouldn't say it's been picked up because it's*

*been masked. The benefit of doing this has been masked by other issues that are going on. (line 27, compensation)*

### Benefits of group setting

This was a major theme repeated in virtually every interview. The benefits of having group sessions were acknowledged by participants in all the three programmes. Respondents described how meeting people with the same problems helped them realize that they were not alone. Members valued greatly the shared experience of ‘being in the same boat’ and of being with people who “know what it’s like”. Sharing experiences with others made them feel “less alone” and had a normalizing effect.

*ID 23: I think the biggest thing for me was listening to other people and realising that I’m not alone and I could laugh at a lot of things rather than becoming very anxious about it. (line 27, restitution).*

*ID 26: Knowing that there are other people who have the same problems out there. You’re not on your own sort of thing. If I was on my own, no I would never get through it at all. Now I feel that there are a number of people out there that are the same. (line 34, self-help).*

The group offered the possibility of developing relations between equals and a context where one’s difficulties could be expressed, shared and supported. At the same time it gave participants a listening and sharing environment for their feelings, distresses and fears. It was a separate place where they could deal with their issues without feeling that they put a burden on family and friends. One respondent described how by overcoming his hesitation and opening up in the group, he discovered the benefits of offloading and releasing his emotions.

*ID 29: Basically you could get out of your system what you’re feeling. And I felt that the sessions did me good in the fact that I’m not the greatest person for telling people things, getting stuff off my chest. It was quite good because I felt relaxed I could talk to the group leader but I felt comfortable with the other people. Like I say, I tend to keep things close to my chest, found out that’s not really a good thing anymore you know, I’ve learned that I could talk to people a bit more about it now. I don’t know if it’s a man thing or what but it was like, you know, I thought I can cope with this I can deal with it and I couldn’t. It’s like everything builds up and up and up and eventually the cork will come out and that’s it! (line 72, self-help)*

The group setting also appeared as an opportunity to enhance the range of social interactions and encouragement available to the participants.

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*ID 20: It was nice to have the social talking about things because that is something that I think its lacking in anybody's life after some sort of crisis. It is very difficult to have a social engagement where you can talk about things and can say what you can or cannot do. (line 53, restitution)*

Another benefit identified by participants was the exchange of information and ideas. This allowed group members to look at different ways of coping with memory problems or other health related issues.

*ID 36: We've all shared our own experiences and we've all had problems in different areas of our memories so we've all been able to say "Well I do this, or I do that". So as a group we've all managed to come up with lots of new ideas. (line 40, compensation)*

The group was also viewed as a relaxing environment that afforded its members the opportunity to decide on the degree of their contribution. Some participants valued the fact that they could withdraw for a bit and take some time to process information at their own pace:

*ID 21: It has been very comfortable working in a group; to an extent it kind of takes the pressure off a bit if there is two or three people because you can take any piece of information and process it whilst someone else is talking. So you don't feel that you've got to constantly be responding, you can take some quiet time for yourself and tick things over in your brain. (line 52, restitution)*

The only drawback of the group format identified by two participants was the unpredictability of attendance of other group members.

*ID20: "I think in our group the attendance was not as expected. But that is something you cannot predict but it would have been nice to see more people." (line 47, restitution)*

*ID44: "The only thing that could have been improved really is that all four the members of the group are there every week ...I think one of them had family problems ...obviously you can't predict ... nothing could be done about that unfortunately" (line 102, compensation)*

### 3.5. Discussion

#### 3.5.1. Participant characteristics

Although statistical comparisons could not be performed due to the small sample size, some differences were noticed between the programmes in relation to gender and diagnosis ratios. This was particularly obvious in the compensation group which consisted exclusively of female participants diagnosed with multiple sclerosis. Despite the observed variation in gender and diagnosis, the same key areas of improvement were identified in both the compensation and restitution programmes. To my knowledge, there is a lack of evidence on whether gender and diagnosis affect participants' self-efficacy and control perceptions or the use of memory aids. What previous studies have found is an association between self-efficacy beliefs and age (e.g. Rebok, 1989). It has also been argued that the use of memory aids may be affected by the severity of memory and mood problems (e.g. Wilson, 1996). In this study, it was shown that the groups were comparable in terms of premorbid intelligence, memory ability, language skills and mood.

#### 3.5.2. Identified themes

The analysis of the narratives indicated that participants benefited from the rehabilitation programme in a number of ways. Consistent with the aims of the rehabilitation programme participants reported improvements in areas such as awareness of memory problems, use of memory aids, confidence in ability to cope etc. In contrast, the assessment tools used in the RCT showed little statistically significant evidence of the effectiveness of memory rehabilitation in improving memory or mood. Participants' feedback provided a different more positive picture than was apparent from looking at the quantitative results. Participants reported considerable gains which are important aspects of memory rehabilitation.

One of the themes with the highest number of responses referred to a perceived increase in participants' *generic memory knowledge*. Cavanaugh et al., (1998) used this term to describe the knowledge that a person holds about how memory works. Although not all participants in the present study wanted detailed information, there was a general agreement on the usefulness of the knowledge they acquired in the groups. Respondents talked about how new knowledge about the consequences of their neuropsychological deficits helped them to understand the mechanisms of rehabilitation and influenced their self-awareness. This is in line with recommendations that educating a person with brain

injury about the nature of their injury, the resulting impairments and the functional implications should be an essential component of cognitive rehabilitation (Lucas & Fleming 2005). Evidence on the importance of didactic information provision has also come from studies in stroke rehabilitation. Mclean et al (2000) suggested that a lack of information can demotivate stroke patients for rehabilitation. A later study by these authors confirmed the positive effects of information on motivation to perform exercises and make the most out of a rehabilitation programme (Maclean et al., 2002). In a qualitative study by Dixon et al., (2007) neurologically disabled individuals reported that the quality of the information they received affected significantly their experience of rehabilitation and their ability to stay motivated. Acknowledging the importance of increasing participants' understanding of memory functioning, Evans & Wilson (1992) underlined the usefulness of measuring improvements in this area following rehabilitation.

The majority of participants in the intervention programmes also felt that the groups enabled them to obtain a more realistic appreciation of the severity of their memory difficulties. This is consistent with the aims of holistic rehabilitation which stresses the importance of addressing self-awareness issues. Research has shown that patients tend to have a greater difficulty in accurately appraising cognitive deficits than physical impairments (Sherer et al., 2003), a dichotomy that was illustrated in the narratives of two participants. Many participants also mentioned that understanding and accepting their problems helped them take on responsibility for their situation. This is in agreement with the notion that people can only engage in the learning and application of coping strategies if they are aware of the need and the usefulness of doing that (Prigatano, 2008). In their study on a memory group for TBI patients, Port et al., (2002) noticed that participants with good self-awareness were more likely to effectively employ memory strategies and compensate for their problems.

As seen in the results, participants differed in the ways they experienced the improvement in self-awareness. This is in line with the hypothesis that self-awareness should not be treated as a unitary concept but involves different components. Crosson et al., (1989) suggested a three level model of self-awareness. The first level, intellectual awareness, refers to patients' ability to understand that a mental or physical function is impaired. Emergent awareness, the second level, involves an ability to recognise and describe the consequences of the impairment in their everyday life (or disabilities). Finally anticipatory awareness involves the patient predicting when the impairment will affect his/her performance. The importance of anticipatory awareness has been stressed in the

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literature as it has been shown to increase the likelihood of achieving rehabilitation goals (Prigatano & Wong, 1999). Prigatano and Schacter (1991) proposed a similar model which distinguishes between the ability to identify deficits objectively and the subjective understanding of the significance of deficits on daily functioning.

The volunteer nature of the present study suggests that participants already had some level of intellectual awareness which was further improved as a result of the information that they received in the groups. According to Lucas & Fleming (2005) it is the intellectual component of awareness that education mainly targets. For some participants the intellectual understanding evolved to an emotional acceptance of their problems. This is particularly important as overcoming avoidance and wishful thinking has been found to facilitate adjustment to chronic illness (Jopson & Moss-Morris, 2003). However, what seemed to differentiate the intervention groups to the self-help programme were improvements on emergent and anticipatory awareness. To use Prigatano and Schacter's (1991) phrasing, although participants already had "knowledge of" their memory impairment rehabilitation appeared to have given them "knowledge with" the true extent of the impairment and the personal and interpersonal impact (p.13). Participants in the intervention programmes had also the opportunity to identify the occasions where they usually noticed their problems. According to the model of Crosson et al (1989), this training may have helped participants to recognise in advance the situations where the problems were likely to occur and employ the right coping mechanisms. The ability to plan and choose the most appropriate strategies between alternatives, was a prevalent theme in the interviews and could be related to improvements in anticipatory awareness.

Four respondents from the intervention groups talked about how, in an effort to better understand and explain their memory problems, they had developed their own perceptions about the nature and seriousness of these problems. The lack of sound information on their problems led to further confusion, disappointment or unrealistic expectations. They, therefore, welcomed the information that they received in the groups and recognised it as a factor that helped allay unreasonable worries (e.g. losing their sanity). Research on the beliefs that patients' develop about their conditions has demonstrated their role as important determinants of functioning. The illness representation model proposes that people attempt to make sense of a threat to their health, such as symptoms or an illness, by constructing their own cognitive representation of this threat. These perceptions consequently affect how people will respond to the health problem, their interpretations of information from healthcare professionals as well

as their patterns of coping and adjustment (Jopson & Moss-Morris, 2003; Petrie et al., 2002). For example, Kit et al (2007) argued that maladaptive memory beliefs regarding one's memory capacity and memory strategies can lead to negative affective functioning.

Participants also referred to a sense of overcoming feelings of discouragement and taking control over their problems. The majority of respondents from the two intervention groups commented that rehabilitation increased their confidence in their ability to manage with memory problems. The degree of confidence in one's abilities to perform behaviours or management strategies in specific areas of functioning is also referred to as *self-efficacy* (Bandura, 1977). *Memory self-efficacy* in specific refers to peoples' judgments of their capability to use memory effectively (Bandura, 1989). Holding positive or even optimistic self-efficacy beliefs is not to be confused with making inaccurate appraisals of one's own capabilities. As already seen earlier, rehabilitation helped participants acquire a more realistic appreciation of their memory ability. It is important to note here that health beliefs are not necessarily associated with objective indicators of illness severity (Petrie et al., 2002). Perceived self-efficacy is a belief about what one can do in various situations with the skills they possess rather than a measure of the skills one actually has. In this study, the self-efficacy beliefs expressed by participants referred to their ability to cope with memory failures rather than their actual capability to remember things.

Although control beliefs are relatively independent of ability, they may interact with ability differences to affect performance (West et al., 2003). Some evidence even suggests that self-efficacy beliefs may contribute to performance prediction above and beyond actual ability (Phillips & Gully, 1997). Cicerone et al (2004) showed that functional disability is better predicted by perceived self-efficacy than by the degree of actual physical impairment or duration of illness. In relation to memory performance, Lachman et al., (1995) showed that people who judge themselves as inefficacious on memory tasks and who believe they lack control over their memory ability perform more poorly on these tasks. The way control beliefs affect performance is not yet clear in the literature, although a number of mechanisms may be implicated. First of all, control beliefs represent an important determinant of choice behaviour, which refers to the initial decision to perform an action. People tend to avoid activities that are thought to exceed their coping capabilities but they undertake those they think themselves capable of managing (Bandura, 1982). This applies to the decision to initiate the use of memory aids. Despite having an understanding of how memory works and knowing that certain coping strategies typically improve memory the actual practice of memory aids would seem pointless to

someone who does not believe in his ability to cope with memory problems (Berry, 1999; Cavanaugh & Hertzog, 1998; Terry, 2009). In the current study many participants reported that although they were already aware of some memory aids, it was only after the group sessions that they felt confident in their ability to use these aids in order to manage with memory problems.

Self-efficacy beliefs may also affect individuals' general motivation levels and coping style (Maibach & Murphy, 1995). According to the model proposed by Folkman & Lazarus (1980) individuals may engage in either "problem focused" (i.e. taking action over the problem) or "emotion focused" coping (i.e. cognitive reappraisal of the problem). The process of taking active steps to try to remove or circumvent the stressor or ameliorate its effects has been described as "active coping" (Carver et al., 1987). The construct has been shown to incorporate planning and organizing action strategies and engaging in activities that could improve adjustment (Ibid). In the present study participants from all the three programmes reported becoming more proactive towards their problems as a result of the groups. It could be said that participants' decision to attend the rehabilitation programme indicates motivation to do something about their problems. According to participants, however, this sense of motivation was further reinforced by the rehabilitation programme. More specifically, some respondents from the intervention groups expressed their willingness to explore more memory aids or attempt to develop their own in order to cope with memory issues. Participants in the self-help groups also noticed an increase in their motivation levels; however, this improvement was not focused on memory problems but related to their general health and well-being. These respondents described a change in their attitude towards health issues, adopting a more proactive stance and engaging in a series of activities that could improve their adjustment.

Furthermore, some respondents from all the three programmes answered that participating in the groups positively affected their planning and organisation skills. Some differences were noticed between participants in the intervention and self-help groups in how these improvements were described. The responses of people in the intervention groups focused on benefits in planning and monitoring actions in order to facilitate memory recall. It was not clear from their responses whether this improvement generalised to other aspects of their lives. The opposite pattern was observed in the answers of self-help groups' participants. They reported more generalised benefits which they attributed to coping skills developed in the groups. For example, some participants



mentioned learning to simplify tasks and allowing longer time frames to complete activities.

Some gains were noticed in terms of participants' attention ability. Although the interview schedule did not include a relevant question, some participants from the intervention groups spontaneously talked about the effects of the groups on their attention levels. They reported making a conscious effort to reduce distractions in their environment and pay attention to the information they wanted to memorise. They also appeared more knowledgeable and active in managing situations in order to enhance their capacity to attend. All participants were informed about the importance of attention as a prerequisite to remembering information. However, the fact that benefits were reported only in the two intervention groups indicates the potential contribution of attention training provided in these groups. Participants in compensation and restitution programmes were taught strategies for dealing with internal and external distractions and practiced naturalistic tasks. Improvements could also be related to enhancement of motivation and control beliefs. As already discussed, control beliefs affect the amount of effort and commitment towards a task and mobilise individuals' resources (Tam & Man, 2004). Attributing memory failures to a modifiable factor such as attention may have motivated participants to allocate more attentional resources to information (Lachman et al., 1995). It has been shown that people with increased self-efficacy perform better in memory tasks through enlistment of attention and other cognitive resources (Berry, 1987). On the contrary, people who doubt their capabilities might impede the cognitive processing of information and undermine their analytic thinking (Bandura, 1989). It has to be noted, however, that only a small number of participants reported improvements in their attention and these improvements were specifically referring to the intentional activation of attentional resources in order to facilitate memorising. No feedback was given in terms of other attentional domains such as sustained or divided attention.

The advantages of the group format of the sessions comprised one of the most salient themes in this study. Almost all respondents recognised the presence of other group members as one of the most positive and rewarding aspects of the programme. This is in line with the findings of Evans & Wilson (1992) who also highlighted the beneficial aspects of the group context. The contribution of the group setting in facilitating change during psychological therapies has been widely accepted. Even in self-help groups, where no specific intervention is taking place, important benefits have been reported leading to the assumption that people facing a similar challenge can help each other simply by coming

together (Davison et al., 2000). Feelings of loneliness are common in patients with acquired brain injury (Martin et al., 2001). Some participants reported entering the programme with the sense that they were alone and no one else could understand how they felt. They became members of groups of people who shared the experience of brain injury and could empathise with their problems in a way that non-sufferers would probably be unable to do. In this context, many participants reported overcoming their feelings of loneliness and experiencing what Yalom (2005) described as “universality” which refers to the realisation that there are other people who share similar challenges and concerns. The commonality of experience helps group members to normalise and accept their problems and reinforces their commitment towards the common aim (Ephraim, 1988).

Many participants also benefited from exchanging ideas and tips with other group members and from observing one another tackling similar problems. They witnessed their peers admitting their deficits, setting goals and managing with their difficulties. Sherer et al., (1998) argued that group meetings can help members learn from each other’s successes or mistakes and appreciate the value of receiving feedback. Constructive comparisons with other members can promote self-reflection and observation. The groups also appeared to contribute to participants’ emotional management, providing a place where they could get things off their chests and share their distresses and fears. The group setting allowed for some fundamental therapeutic processes to take place such as opportunities for disclosure and emotional expression, empathetic connections between members and development of shared goals. A supporting group context may help participants discover their resources and use them to better adjust to illness, as was suggested in a study of people with multiple sclerosis (Landoni et al, 2000).

There appeared to be a general perception that the rehabilitation programme contributed to the emotional coping of participants. Interestingly, benefits were not restricted to the self-help group but also reported in the intervention programmes. Although not directly addressing emotional issues, some participants of these groups noticed considerable improvements. As already seen, with the help of rehabilitation, some participants reported challenging maladaptive beliefs about memory function, coming to terms with memory difficulties and regaining a sense of control over their management. Respondents also reported being less embarrassed about their memory difficulties and more eager to share them with other people. Overall, a sense of optimism was present in the interviews with many interviewees expressing the belief that memory problems can be manageable. Another important benefit documented by participants in all the three

programmes concerned their ability to cope with anxiety. In their narratives, respondents from the intervention groups, focused on anxiety induced by memory problems. Gains were reported in that respect, which were mainly attributed to improvements in the use of memory aids. For self-help group participants it was the application of relaxation techniques and other anxiety management skills that accounted for the reduction of stress levels. What participants from all the three programmes seemed to recognise was the interplay between stress and cognitive functions. This knowledge may have given them the incentive to consciously try to do something about their anxiety in order to avoid further hampering their performance. Their efforts to control stress levels were also supported by the improvements in planning and goal setting. For some respondents learning to set small and achievable goals contributed to improvements in stress management. A few respondents also reported becoming more confident in negotiating and setting limits to other peoples' expectations on them.

Despite the reported benefits in stress management, the majority of participants did not perceive any changes in depressive symptomatology as a result of the rehabilitation programme. There are a few possible explanations for this finding. The intensity of the intervention may have not been sufficient to alleviate depressive feelings. In terms of the content, the strategies and exercises practiced in the self-help groups (e.g. progressive muscular relaxation) were mainly tackling anxiety. Moreover there was not enough evidence in the interviews of compensation and restitution groups to suggest that their optimistic attitude towards memory problems generalised to other domains of their life. As some of the respondents commented, the benefits of rehabilitation could have been "masked" by other challenges they were facing at the time. The unpredictability that often characterises the symptomatology of multiple sclerosis may force people to continually redefine their emotional adjustment (Baretz & Stephenson, 1981). Other participants reported that even before enrolling in the programme mood problems were not an issue for them. Furthermore, respondents might have found it easier to talk about anxiety and stress rather than to touch the loaded concept of depression. Feeling stressed or anxious is increasingly used by healthy individuals to describe the effects of a hectic lifestyle without necessarily implying the existence of a diagnosed disorder. Depression however carries a social stigma that may make sufferers ashamed and secretive about it (Wolpert, 2001). The formalised style of structured interviewing might have further discouraged participants from discussing these sensitive issues. On the other hand, participants did report changes in their motivation levels, considered to be one aspect of depression (Wade, 1992). This

hints at the existence of some signs of improvement expressed indirectly in the narratives. Lack of motivation to use memory strategies has been proposed as a possible mechanism explaining memory difficulties in depressed individuals (Burt et al., 1995; Ellis, 1990).

For some respondents, rehabilitation appeared to have indirectly affected aspects of interpersonal relationships. Participants in the intervention groups described how the practice of memory aids, in addition to their decisiveness to take control, contributed to them relying less on other people from prompting. At the same time, respondents from all the programmes reported becoming more eager to share their difficulties and accept others' support when needed. From the narratives, it appears that rehabilitation helped some participants from the intervention groups to overcome the embarrassment and the secretiveness related to their memory problems, and feel more comfortable to use memory aids in front of others. This has important implications as it has been shown that one of the main impediments in the use of memory aids is people being embarrassed by them (Wilson & Watson, 1996). Participants in the intervention groups associated this improvement with a deeper understanding and acceptance of memory problems that rehabilitation promoted. Respondents from the self-help groups focused on the contribution of the group setting in reducing their sense of loneliness and uniqueness. They reported regaining a sense of trust that other people will be understanding of their problems and won't be judgmental about them.

### **3.5.3. Issues related to outcome assessment**

Caution is needed when interpreting the findings of this study as they are based on participants' reports and therefore they are open to biases related to self-evaluation. Respondents' poor self-awareness as well as their willingness to provide feedback that would satisfy the researchers may have led to exaggerated and inaccurate descriptions. Although a possible interference of these factors cannot be ruled out, they cannot fully account for the benefits reported in the interviews. In their narratives, respondents appeared capable and eager to provide a realistic appreciation of the programme and identify both gains as well as domains that rehabilitation fell short of improving. Similar to the study of Quemada et al. (2003), participants in the current study acknowledged that rehabilitation did not manage to restore their memory impairment but enhanced their coping mechanisms. The amount of information participants could retain was still limited, however, they experienced fewer repercussions in their everyday life because of their ability to compensate.

Interestingly, where a reduction of memory failures was reported, it was in tasks that allowed the application of memory aids. The domain of improvement most frequently mentioned by participants in the intervention groups was prospective memory. Respondents appeared to be more confident about their ability to cope with prospective memory tasks. This is in line with the results of quantitative studies reviewed in Chapter 1 showing prospective memory tasks as the main area of improvement following memory rehabilitation. Taken together, these findings seem to indicate that an improvement in prospective memory function may be feasible following rehabilitation and experienced by participants in their everyday lives. Despite the encouraging evidence in the field, only a limited number of studies incorporate ecologically valid measures specifically tapping prospective memory. As noted by Fleming (2005) the assessment and rehabilitation of memory impairment in brain injury has mainly focused on retrospective memory. This seems to be an important omission, as the advantages of using prospective memory measures have been stressed by many researchers. For example, it has been argued that prospective tests may be more sensitive measures of memory impairment than other standardized retrospective tasks such as learning lists of words (Mantyla, 2003). The importance of including prospective memory measures in the neuropsychological assessment is, consequently, stressed. Despite the benefits reported in relation to prospective memory, some respondents commented that participating in a conversation was an activity they still did not feel confident about. One possible explanation is that the speed of the task in combination with the high cognitive demands that it places, as it involves other cognitive processes in addition to memory, leave little room for the use of memory aids. The same is true for many subtests of the RBMT who are unlikely to be affected by the application of compensatory techniques (Quemada et al., 2003). This finding highlights the need to use outcome measures that allow participants to put into practice their compensatory strategies.

Respondents perceived improvements in the use of memory aids as one of the most beneficial aspects of the groups. These improvements, however, were not reflected in the memory aids questionnaires used in the trial. One possibility is that these frequency measuring questionnaires failed to detect qualitative differences in the use of memory aids. As seen in the interviews, participants had a number of strategies in place before enrolling the programme. What changed with rehabilitation was learning how to make the most of these strategies. Through a process of exploration and experimentation group members discovered the strategies that were most suitable for them and rejected others

that did not work. This is in line with the study of Evans & Wilson (1992) where positive reports from participants were followed by reductions in the use of memory aids as seen in a memory aid questionnaire. The researchers explained this discrepancy by referring to participants' efforts to try out the strategies taught in the group and find the ones that worked for them. Consequently, it could be argued that improvements in coping behaviour might also be translated to a decrease in the actual number of memory aids used. Taken together, these findings suggest that relying exclusively on frequency indexes might not be an adequate method of assessing the use of memory aids.

In relation to emotional changes, the positive effects that participants reported in stress management were not reflected in the scores of GHQ-12 (see Chapter 1, p.32). There are a few possible explanations for that discrepancy. Firstly, the perceived effects may not have been strong enough to lead to statistically significant changes following rehabilitation. Furthermore, the benefits reported by participants receiving the intervention were specific to the management of memory related stress. There was no evidence in their narratives suggesting a generalised improvement that affected other problematic areas. As already seen in the previous section, participants did not report any benefits in relation to depressive feelings. Therefore, the lack of significant effect may be related to the fact that GHQ-12 does not allow the computation of separate depression and anxiety scores and therefore changes in anxiety may be masked by a lack of change or deterioration in depressive symptoms. Research has shown that the rate of depression in brain injured patients tends to rise as they develop more realistic self-perceptions (Bowen et al, 1998; Lucas & Fleming, 2005). Studying anxiety and depression separately is not always easy as there is a considerable symptom overlap (Thomas, 2006). However, the use of questionnaires such as GHQ-28 or 30 or HADs that provide a split between depression and anxiety might have allowed the detection of the improvements participants talked about.

As mentioned in Chapter 2, an important issue that needs to be considered when choosing measures of outcome is distinguishing between global and domain specific scales. The majority of the outcome measures available tap generalised improvements whereas the benefits reported by participants in this study were very specific and limited to memory related functions. For example, participants reported becoming more independent at performing memory tasks which would not necessarily be picked up by an ADL index including mobility and basic self-care items. The enhancement of control beliefs appeared as a very strong theme in the interviews. Questionnaires developed to measure constructs such as self-efficacy, locus of control and motivation could, therefore, be a

useful addition to the battery of tests used in memory rehabilitation. A number of widely used and well validated global scales of control beliefs are available (e.g. Rotter's LOC scale). It has been recognised, however, that domain specific measures of perceived control are better predictors of behavioural outcomes with respect to cognitive performance (Smith, 1989; Valentijn et al., 2006). That means that measures should be preferably targeted to specific populations and areas of behaviour (Anastasi & Urbina, 1997).

In response to this need, a few scales specifically tapping memory control beliefs have been developed. Some of the identified areas of improvement in this study correspond to components of the Metamemory in Adulthood questionnaire (MIA; Dixon and Hultsch, 1983). These authors suggested that metamemory should be viewed as a multidimensional construct including aspects such as the use of memory strategies, knowledge of memory processes, memory anxiety and locus of control in memory abilities. In its most frequently used version, MIA consists of 108 items (Dixon & Hultch, 1984), scored on a 5 point Likert scale measuring either agreement (agree strongly-disagree strongly) or frequency (never-always). The three scales, Capacity, Change, and Anxiety together form the factor 'Memory Self-Efficacy' (MSE) and higher scores indicate a higher MSE level. Interestingly, Hultch et al., (1988) found that the constructs identified in the MIA were not accounted for by generalised locus of control and mood scales. However, the use of this questionnaire as an outcome measure in memory rehabilitation is limited by certain drawbacks. As it has been developed for use with healthy elderly individuals, the content and wording of some questions is irrelevant or inappropriate for young neurological patients (e.g. "the older I get the harder it is to remember"). It also includes a number of statements assessing factual knowledge about memory that appear too lengthy or ambiguous (e.g. "most people find it easier to remember visual things than verbal things") or have little relevance to memory rehabilitation aims and priorities (e.g. "I remember my dreams much less now than 10 years ago").

Another available measure is the Memory Self-Efficacy Questionnaire (MSEQ; Berry et al., 1989) which asks participants to indicate their confidence in performing a memory task using 10 unit increments (10% to 100% confidence). The scale has not been used with neurologically impaired individuals and it is therefore questionable whether people from this population would be able to differentiate between 10 response categories. The Memory Controllability Inventory is another questionnaire developed to specifically address memory control beliefs (MCI; Lachman et al., 1995). It measures beliefs about

current level of memory ability (e.g. I can remember things I need), beliefs about potential improvement (e.g. I can think of strategies to help me keep up my memory), the degree to which people believe memory functioning is controllable through effort (e.g. If use my memory a lot it will stay in shape just like my muscles do if I exercise) as well as the degree to which memory deteriorates uncontrollably with age (e.g. when it comes to memory there is no way I can make up for the losses that come with age). However, it has only been validated in elderly healthy individuals and there is inconclusive evidence on its responsiveness to improvements following memory rehabilitation (e.g. Mohs et al, 1998; Rasmussen et al, 1999).

What seems to be a common problem with the questionnaires described above is that none of them has involved memory impaired individuals or cognitive rehabilitation users in its development and consequently the degree to which they reflect these patients' needs and priorities is questioned. One first step for future studies would be attempting to adapt the items related to age concerns in order to tap concerns related to progressive neurological conditions. Another problem is that the format of the questions used by self-efficacy questionnaires may undermine the ability of these measures to tap improvements associated with memory rehabilitation. Patients are asked to evaluate how confident they are in their memory ability and not in their ability to cope with memory problems. For example, people may continue reporting low levels of confidence in their actual ability to remember names because it is their ability to cope with forgetting names that has improved. Furthermore, in order to tap the range of areas where improvements were reported in this study, the use of multiple outcome measures would be required. Although the inclusion of several different outcome measures might be informative, it is not without problems. The duration of administration extends, leading to a lengthy and tiring assessment procedure, inappropriate for clinical populations. There is also a statistical drawback; increasing the number of measures increases the probability that statistically significant results will be found by chance and, therefore, a big sample size would be required (Roland & Torgerson, 1998).

#### **3.5.4. Methodological issues and limitations**

The possibility of spontaneous recovery needs to be taken into consideration when evaluating the effects of rehabilitation on people with traumatic brain injury and stroke. Differentiating the effects of spontaneous recovery to those of the actual intervention is



not an easy task, particularly when patients are at a relatively early stage post-injury (less than 2 years). One way to control for spontaneous recovery would be to incorporate time since injury in the inclusion criteria. This is problematic, however, because the rate of recovery is multi-faceted and a consensus has not been reached regarding when such recovery slows down considerably or stops (Kennedy & Turkstra, 2006). The use of multi-aetiology groups further complicates things. According to Nair (2007), the randomisation process in the ReMind trial could possibly control for this effect, creating groups comparable regarding the levels of spontaneous recovery.

Describing participants' basic demographic and psychometric characteristics is considered to allow future readers to evaluate the relevance of this group of patients to their sample of interest. However, it has to be noted that what is more important to qualitative researchers is not the comparability of the demographic characteristics but the comparability of the topic or the problem that is of concern (e.g. Morse, 1999). People with neurological disabilities represent a heterogeneous population. Therefore, controlling for all the variables that may affect the outcome of neurological rehabilitation is a difficult task which becomes more challenging when attempting to trace the factors that affected the subjective perceptions of this outcome. Qualitative methodologies do not permit the detection of cause and effect relationships and therefore evaluating whether a relationship existed between participant characteristics and the identified themes was out of the scope of this study. Future studies following quantitative designs could shed light to the complex interaction between personal characteristics and effects on participants' perceived memory function, control beliefs and use of memory aids.

The constant comparison analytic process allowed the identification of similarities and differences between the three programmes and highlighted benefits specific to the two intervention programmes. It has to be noted, however that these qualitative comparisons cannot provide information on the significance of the observed differences. Rather than evaluating which programme was more effective, this study was interested in the patient-perceived effects of all the three programmes. This is important as the three programmes correspond to integral components of the memory rehabilitation interventions that are usually offered in clinical practice. As this study did not set to do quantitative comparisons between the groups, it is suggested that the observed variation of patients' characteristics between the three programmes does not undermine the value of the findings. Instead, it may reflect the heterogeneity of the groups in clinical practice and allow capturing a range of different viewpoints.

Although not a common practice in qualitative research, in this study it was considered meaningful to present a detailed account of the number of people across the three programmes who experienced benefits in relation to each theme. Counting themes via frequencies and percentages helped in identifying patterns across the datasets and highlighted the differences between the three programmes. Although this can provide an idea of the prevalence of each theme, caution is needed when interpreting these frequencies. Given the small sample sizes, numerical findings can give a false impression of precision where none exists. As noted by Padget (2012), reporting the frequency of a theme can imply that a denominator exists when it does not. For example, to state that a percentage of participants mentioned getting more or less confident following the programme would only be accurate if every respondent commented on that topic. Even when using a structured interview schedule, a rate calculated from such a small number of individuals needs to be interpreted cautiously, without taking out of context (Padget, 2012). It is important not to read the volume of responses in each theme as a hierarchy but rather as an insight into the range of different ways in which rehabilitation affected participants. As the aim of qualitative methodology is to look at the whole picture, a point that is mentioned only once can still have great relevance and conceptual importance (Joffe & Yardley, 2004). For this reason, the present study attempted to consider variation and contradiction in the results by incorporating key isolated statements.

Methodological issues related to the design of the interviews need also to be considered. One of the limitations of the interview schedule was that it did not incorporate instructions for the interviewers to follow in case contingencies occurred during interviewing (e.g. steps to be taken if respondents provide incomplete responses or misinterpret questions). At the same time, like most structured schedules, there was little room for the interviewer to improvise or make own judgments in order to respond to the difficulties. The phrasing of the questions was such that it sometimes elicited one word or ambiguous answers. There was inadequate encouragement from the interviewer for further clarification of vague statements or elaboration of brief comments. Unfortunately there was no way to confirm the meaning and the genuineness of these statements other than looking at them within the context of the entire interview and comparing them with other occasions when the interviewee talked about the topic. If the meaning could not be verified the statement was excluded from the analysis. This may have led to the exclusion of potentially informative data, undermining the completeness of the findings.

Another limitation was that some of the questions were leading. For example, asking participants what were the effects of the groups on his/hers personal life, was in a way implying that the groups did actually have an effect on the respondent's life. As a result, researchers may have imposed their own assumptions about the programme whereas respondents may have replied in a way that would please the interviewer. One of the items in the schedule included two questions at once, which may have caused more confusion to participants. Participants were asked about the effects of rehabilitation on their confidence and their anxiety about disclosing their problems in one question. An association was inferred between the two concepts whereas, as shown from the responses, each of them had a different meaning to participants. Moreover, the use of technical vocabulary might have led to ambiguity and misinterpretation of the questions. Some participants found it difficult to understand terms like "problem-solving ability", "insight" and "assertiveness". Some participants directly expressed their confusion and asked for clarification. Others, however, provided "yes" or "no" answers which were not followed up by the interviewer. Finally, the transition from one question to another could have been smoother by having general questions preceding more specific ones. Sensitive questions about mood were placed very early in the interview probably not allowing participants the time to relax and feel comfortable with the interviewer.

Although this was an exploratory study the structured approach did not allow the interviewer the flexibility to follow up interesting points and explore unanticipated themes that emerged from the responses. Therefore, there was little room for discoveries that were beyond the assumptions of the developer of the schedule. These methodological limitations may have significantly compromised the validity of the results. In order to confirm the findings there is a need to repeat the study using an approach that would elicit more descriptive responses and communicate the participants' experience in all its rich detail. The characteristics and difficulties of the brain injured people also need to be taken into consideration. A more relaxed style of interviewing that would fit the respondents' comprehension and would allow them to tell their stories at their own pace would probably be more appropriate for this specific population. The study needs to be replicated employing semi structured interviews, in order to promote conversational communication and deeper exploration of patients' experiences.

Overall, important gains from memory rehabilitation were reported in the interviews, which were not reflected in the assessment tools used in the trial and other outcome

measures currently available. The findings of this exploratory study highlighted the need for an outcome measure sensitive to the effects of memory rehabilitation for neurologically

### **3.6. Aims and Design of the following studies**

The aim of the following studies was to develop and assess the psychometric properties of an outcome measure responsive to the effects of memory rehabilitation for people with acquired brain injury.

The development of the questionnaire was conducted in two stages:

**Stage 1):** At this stage data were collected in the context of the main phase of a randomised controlled trial (“ReMind”) comparing the effectiveness of a “compensation-based” and a “restitution-based” memory rehabilitation programme with a self-help control programme in affecting change in everyday memory performance. The content areas included in the questionnaire were identified based on patients’ input over the course of the programme and in post-intervention interviews. A mixed methods design was followed and information was drawn from two sources: a) observations of the actual running of the programmes (Chapter 4), and b) semi-structured post-intervention interviews (Chapter 5). It was considered that this process would offer a more rounded view of participants’ experience in the programme, allowing the development of a questionnaire grounded in patients’ valued outcomes.

**Stage 2):** At this stage a pool of items was generated to cover the areas identified in the previous stage. The psychometric properties of the questionnaire were then examined by posting the questionnaire to a group of people with acquired brain injury (Chapter 6).

### Methodological approach

Qualitative and quantitative methods were interwoven throughout the process of this research project. It has been suggested that mixed methods designs are advantageous over mono-method approaches by:

- a) providing a more comprehensive picture than either method alone (Creswell et al., 2003)
- b) enabling the strengths of one method to be used in order to overcome the weaknesses of the other method (Forthofer, 2003).

The theoretical underpinnings of mixed methods methodology are described in the following section.

### Mixed methods methodology

For a long time research methodologies had been defined by a clear-cut dichotomy between qualitative and quantitative research paradigms. Quantitative purists argued that psychological phenomena should be approached in much the same way as physical phenomena. The aim is to achieve objectivity and allow generalisability of findings by testing specific a priori developed hypotheses, by minimizing or eliminating bias and by judging the value of findings against strict criteria of validity and reliability. Qualitative purists, on the other hand, reject positivism and maintain that subjectivity is inherent in the research process as decisions are made by researchers on what to study, how to measure and interpret a phenomenon and what findings should be emphasized and published. According to that approach, it is impossible to make time and context free generalizations and this should be acknowledged by researchers in the way they collect, interpret and report data. Explanations are generated inductively from the data in an attempt to explore and provide rich descriptions of a phenomenon.

Mixed method methodology can be considered as a third research paradigm which attempts to overcome the dichotomy and bridge the differences between the purely quantitative and qualitative approaches (Johnson & Onwegbuzie, 2004). Mixed methods studies involve collecting and analyzing qualitative and quantitative data within a single study or multiple studies within a research project (Creswell & Clark, 2007). In the latter case, they are relatively complete and follow their own methodological assumptions but they are used together to form essential components of a bigger research project.

Pragmatism has been suggested as the epistemological foundation of mixed methods research (e.g. Johnson & Onwegbuzie, 2004). Rather than being tied to a specific research paradigm, researchers are encouraged to employ the methodological tools that would best answer a specific research question. No single mixed method design exists but qualitative and quantitative components can be combined in many different ways in order to serve the aims of a particular study.

The actual process of combining qualitative and quantitative research within a given stage of the research process is called integration or triangulation (Creswell & Clark, 2007). The term triangulation carries some ambivalence as different meanings have been assigned by different authors. The term integration will, therefore, be used in this thesis. Key issues to be considered prior to employing a mixed methods design are the purpose and the stage of the study that integration takes place. Two main uses of integration have been described in the literature: verification and complementarity. In the former case, it is suggested that if two or more research methods produce similar findings then it is more likely that these findings are valid. This is based on the assumption that the strengths of a method may compensate for the weaknesses of the other method. Combining these methods allows the mutual verification and corroboration of the results. What this approach fails to consider, however, is that different methods may have similar weaknesses resulting to the problem being masked and ignored (Moran-Ellis et al., 2006). Alternatively, researchers may engage in a purposeful search of divergences between findings in order to explore new dimensions of the phenomena under study (Erzberger & Kelle, 2007). When complementarity is the purpose of integration, it is expected that different methods will not provide identical findings but will highlight different perspectives of the phenomena (Creswell & Clark, 2007). Different methods are combined in order to generate deeper insights than either method alone and create a more comprehensive picture of the research topic.

Another important issue to consider is the stage of the research process at which integration occurs. Integration might take place within the research questions, by developing both qualitative and quantitative questions, within the data collection, such as including open ended questions in a questionnaire, within the data analysis stage (e.g. transforming qualitative themes into quantitative items of a questionnaire) or when interpreting the findings (assess convergence or complementarity) (Creswell et al., 2003). Regarding the relative importance of each method within the study or research project Creswell et al., (2003) suggested that, ideally, all methods should be equally emphasized.

This contrasts the view of Morse (2003) who argued that within the same study, one method should be dominant with the other one used to provide additional insight.

In the first stage of this thesis, findings from observations and interviews were integrated in order to offset the weaknesses of each method and provide complementary insights. Both studies served the same overall research aim however each of them was complete and independent addressing specific research questions and exhibiting methodological integrity (Morse, 2003). Information on the research questions and the rationale for the selection of each method is presented in the background of each chapter. In the observational study qualitative data were collected and the data analysis combined a qualitative and a quantitative phase, however, the theoretical drive of the study was deductive, seeking to address quantitative research questions. The interview study was exploratory and purely qualitative, seeking to elicit rich descriptions of participants' experience in the groups. Datasets from both observations and interviews were analysed separately and were not compared until analyses were complete. The findings of both studies were then combined in order to define the content of the outcome measure. In this way, the qualitative themes obtained from the interviews were further transformed into quantitative items of a questionnaire. The structure of the studies within the current thesis is shown in Figure 3.

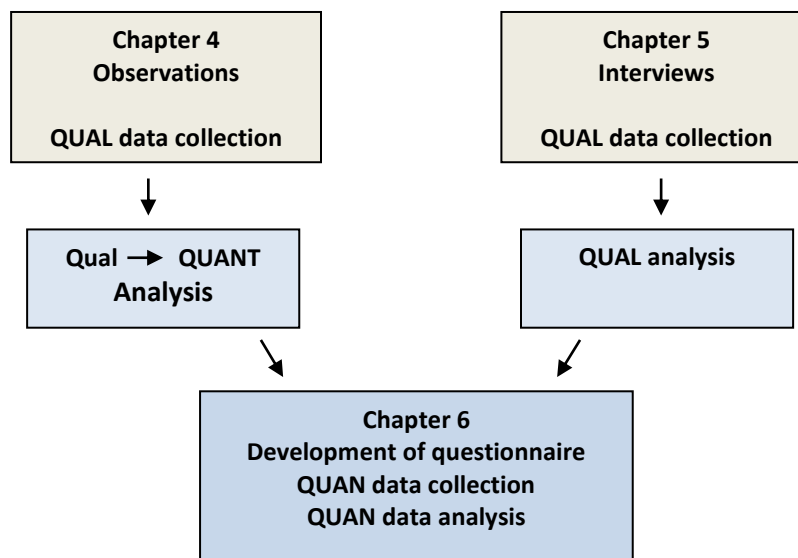


Figure 4. Diagram of the structure of the studies.

**Part B.**

**Chapter 4: Observational recording of a memory rehabilitation programme**

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**4.1. Introduction to observational methods**

Observational methods used in social sciences involve the systematic, detailed observation of behaviour and talk, under precisely defined conditions (Mays, 1995). Scientific observation is a research method in its own right but it can also be incorporated into other research methods, such as interview studies, focus groups and clinical case studies (Dallos, 2006). It has been suggested that observational methods should, ideally, be part of mixed methods research designs, so that the observed events can be verified by independent sources (Bowling, 2002; Robson, 2002). Within that context, observations can be used to validate or set in perspective data obtained by other means such as interviews and questionnaires. Although all data gathering methods involve some form of observation, observational designs rely on obtaining direct records of behaviour as it occurs rather than requesting information from participants, as in the case of interviews and questionnaires (Cooligan, 2004). According to Langdrigde (2009), the main advantage of observational techniques is that they tap directly into participants' behaviour, rather than perceptions or self-reports of behaviour. The directness of observation methods overcomes the discrepancy between what people say and what they actually do (Robson, 2002). Observation of behaviours, actions, activities and interactions can also help to understand complex situations more fully (Bowling, 2002). Therefore, observational methods have proved particularly useful in the assessment of innovative interventions (Beins, 2009). They can provide detailed rich insights into the effects of the intervention and help identify confounding factors influencing their success or failure.

Observational methods can be classified according to the degree to which the observer intervenes in the observational setting and the manner in which behaviour is recorded (Shaughnessy & Zechmeister, 1997).



### 4.2. Levels of participation

Dallos (2006) proposed that the roles adopted by the observer in the situation observed can be described along a continuum with the “*complete observer*” and the “*full participant*” at either extreme and the “*participant as observer*” and “*observer as participant*” in intermediate positions.

The “*pure observer*” observes an event without becoming part of it and, depending on the level of intrusion, participants may not even be aware the researcher is conducting research (Dane, 1990). A researcher using this method of observation acts as a passive recorder of what occurs naturally without any manipulation or control on the part of the observer (Shaughnessy & Zechmeister, 1997). Because this type of observation occurs in natural settings, without any attempt by the observer to intervene, it is frequently called naturalistic observation. The risks of observational reactivity – the effect that the observer has on the behaviour of those studied- are in this way minimised. However, opportunities for the observer to access the thoughts, feelings and intentions of the participants are also limited (Dallos, 2006).

The “*observer as participant*” joins the group with the expressed intention to observe (Dallos, 2006). The observer is known to the participants as a researcher but does not take an active part in the events (Dane, 1990). The observer avoids initiating activity and conversation with participants but is responding to the initiatives of the group members (Dallos, 2006). Because the observation is not entirely unobtrusive, the researchers need to manage their role carefully in this situation by maintaining their neutrality, not interfering in the actions of the setting being observed and by developing trust between them and the participants. The latter is very important as it is this development of trust that is thought to minimise reactivity effects and facilitate the expression and sharing of intimate information between participants (Langridge, 1990). The role of the observer here is less active than that of the “*participant as observer*”. As result, the researcher is less constrained by the demands of participation and can concentrate fully on observations (Dallos, 2006).

Being a “*participant as observer*” involves being known as a researcher but fully participating in the ongoing activities (Langridge, 1990). The researcher’s role is not secret but simply kept quiet. The explanation given for the researchers’ presence is not their role as observers but some meaningful social role within the group. This allows a relative

freedom in observation although the demands of the particular role adopted in the group may obstruct observational activity (Dallos, 2006).

In “*full participant observation*” observer’s identity may not be disclosed. The researcher seeks, instead, to establish some role within the group being observed (Robson, 2002). The participant observer is often in a position to have the same experiences as the people under study allowing a deeper understanding of individuals and groups (Shaughnessy & Zechmeister, 1997). Using a qualitative approach the events observed are recorded together with the interpretation and explanation of them by the participants (Coolican, 2004). This may provide detailed and insightful data not only on the experiences of people but also on the meanings they attach to them. However, as observation and interpretation may be taking place at the same time it may be difficult to separate the data collection and analysis phases (Robson, 2002). Moreover, by identifying with the individuals under study, the observer faces the risk of losing the required scientific objectivity (Bowling, 2002). Reactivity effects may also be a major issue especially when the group under observation is small or the activities of the observer prominent. This is why the generalisation of the results in other settings may be particularly problematic in studies using that technique (Shaughnessy & Zechmeister, 1997).

### **4.3. Methods of recording observations**

Decisions regarding the method of recording behaviour will depend on the purpose of the observational study, on the nature of the data that the observer aims to collect, either qualitative or quantitative, and on how the results of the study will eventually be summarised and analysed. A general classification can be done according to whether the observer seeks to obtain a comprehensive description of the behaviour or only selected aspects that are related to the specific goals of a study. In the former case the behaviour exhibited in a given setting is described in considerable detail whereas in the latter only particular units of the behaviour are recorded (Shaughnessy & Zechmeister, 1997).

#### Narrative records

Narrative records form a continuous description of the phenomenon being observed. The observer aims to provide a more or less accurate description of what takes place in a particular setting. For that reason, narrative records need to include descriptions and accounts of people, tasks, behaviours and conversations (Dane, 1990). Descriptions may be

either written or in the form of spoken and visual records obtained with video tape and movie cameras.

A major difference between narrative records and other forms of behaviour measurement is that particular hypotheses and expectations about the behaviours under observation can be tested after obtaining the data (Shaughnessy & Zechmeister, 1997). Instead of classifying or coding the behaviour at the time of observation, everything that takes place is targeted for recording, minimising the amount of inference required from observers (Bentzen, 2000). Once narrative records are obtained the researcher can review the data and organise, classify and analyse the particular information that is critical for evaluating the study's hypotheses (Bowling, 2002). By excluding any inferences or impressions on the part of the observer, it is hoped that the content of the narrative record can be classified and coded in a more objective manner (Shaughnessy & Zechmeister, 1997).

An important drawback of narrative records is that the observer is expected to record a large amount of information in a very short time. As this information is unstructured, its organisation and analysis may also be a very demanding task (Bowling, 2002). Moreover, narrative records have to be made during or as soon as possible after behaviour is observed (Shaughnessy & Zechmeister, 1997). This is particularly difficult when observational activity is concealed and participants are not aware of being observed. If the recording occurs too long after the observation, it may be harder to reproduce the original sequence of actions and important features may become underestimated or forgotten. According to Robson (2002) a way to deal with this problem may be the inclusion of several participant observers in the setting or the use video or audio tapes. This allows independent analyses to be conducted and then compared in order to assess agreement (Robson, 2002).

### Coding Schemes

Researchers may want to focus on certain behaviours and specific aspects of individuals and settings. In that case the observation variables will take the form of pre-specified categories of behaviour or interaction which will form the basic units of a coding scheme (Humphreys, 1992). Decisions about coding definitions and the included categories must be made in relation to the theoretical purposes of the study, in advance of data gathering (Cozby, 2009). When defining the categories, a researcher should be aware of the "level of

analysis” problem. Observed phenomena may consist of different levels, hierarchically arranged, with larger and more inclusive concepts occupying higher levels of abstraction and smaller and more detailed occupying lower levels (Bakeman & Gottman, 1997). Categories should not continually multiply and, therefore, researchers need to decide what conceptual level seems appropriate for the purposes of the study. As proposed by Bakeman & Gottman (1997) choosing categories on slightly more detailed level than required can increase the chances of capturing an accurate and comprehensive description of selected activities and interactions and facilitate reliability checks. In order to permit a quantitative analysis of the observations, categories must be exhaustive, meaning that the coding scheme covers all the possible events, and mutually exclusive, which means that only one code can be associated with a particular activity or behaviour (e.g. Irwin & Bushnell, 1980).

The use of coding schemes has methodological and practical advantages. A simple and straightforward coding scheme allows the observer to record very quickly the target behaviours and consequently the collection of a large amount of data, on many individuals. By setting out a predetermined set of categories and an explicit set of criteria for assigning occurrences to them an amount of structure is imposed on what is observed (Smith & Davis, 2007). It is only explicit behaviour and not the observer’s interpretation of the meaning of the behaviour that is recorded, minimising one aspect of the subjectivity which normally occurs in an individual’s descriptions of events (Croll, 1986). This method of recording produces data which can be presented in quantitative form and which can be summarised and related to other data using statistical techniques (Croll, 1986).

However, the use of a limited number of pre-defined categories has given rise to a certain number of criticisms. According to Irwin and Busnell (1980) “observers may end up looking for things to fit the categories rather than describe what is occurring” (p.159). As a result, behaviours that may be important in understanding the phenomenon under study could be totally overlooked. Coding categories that are too vague provide little specification of what to record allowing space for observer bias (Kerlinger & Lee, 1999). Conversely, when the categories are too specific, although they may reduce ambiguity and uncertainty, they may also be too rigid and inflexible. In that case researchers may end up collecting irrelevant or trivial information. It has also been suggested that coding schemes can only give a partial view of the situation as they fail to capture contextual factors or relations between behaviours (Bowling, 2002; Croll, 1986). Consequently, the phenomena being observed may appear as de-contextualised isolated bits of behaviour stripped of the

richness and spontaneity of the specific situation. Irwin & Bushnell (1980) suggested piloting the coding scheme in the observational setting in order to allow the researchers to spot any limitations and make any necessary additions or modifications prior to the main study.

### **4.4. Sampling strategies**

Before conducting an observational study a researcher must decide on the amount of information that will be targeted for recording (Robson, 2002). In some studies, it may be possible to observe and record all the behaviour of interest. For example, the researchers may continuously record the behaviour on a schedule that allows the categories to be precisely timed (Croll, 1986). In the vast majority of observational studies, however, only certain behaviours occurring at particular times can be observed. In that case, behaviours captured by the sampling techniques must be representative of the behaviours that observers were not able to observe and record (Shaughnessy, 1997).

Before selecting a particular recording strategy the investigator needs to decide what “units” are to be targeted for recording. The recording unit identifies what prompts the observer to record and this is usually either a time interval or an event (Robson, 2002). Based on that distinction two main types of sampling strategies can be identified, event sampling and time sampling.

#### Event Sampling

In event sampling the unit of measure is behaviour itself and the observer records each event that meets a predetermined definition (Irwin & Bushnell, 1980). Events can be recorded by simply making a tally whenever one of these codable events occurs (Croll, 1986). A sequence record can also be obtained to provide information on the order in which different events occur (Bakeman & Gottman 1997).

Event sampling may be a more efficient method of sampling than other “time-triggered” strategies when the event of interest is infrequent and rare (Humphreys, 1992). Another strength of event sampling is that it preserves the context in which an event occurs (Humphreys, 1992). However, bias may be introduced when, for instance, an observer samples at the times that are most convenient or only when an event is certain to occur.

### Time sampling

Time sampling allows the researcher to structure observations over time. The observer samples a relatively small amount out of the total amount of time in the observational settings (Dane, 1990). The observation period is divided into equal n-second intervals and records of behaviours are related to these (Russell & Roberts, 2001). Time intervals during which recording takes place are interspersed with intervals during which, even if the behaviour of interest occurs, there is no recording (Robson, 2002). Three types of time sampling can be identified: 1) *partial interval time sampling*, also known as interval coding, in which the observer may record the target behaviour if it occurs at any time during the interval, 2) *whole interval time sampling*, for which the target behaviour has to occur throughout the observation interval, and 3) *momentary time sampling* where the observer records only if the behaviour is occurring at the last instant of the interval no matter what occurs during the rest of the interval (Ary & Suen, 1982).

The intervals at which observations are made are chosen either systematically or randomly with the goal of obtaining a representative sample of behaviour (Shaughnessy, 1997). Variables such as the length, spacing, and number of intervals have been manipulated experimentally in order to evaluate the accuracy of different time sampling procedures. Comparisons between momentary and interval sampling procedures showed that momentary sampling was superior in estimating the duration of the behaviour (Powell, 1975, 1977). Partial-interval sampling systematically overestimated behaviour duration and whole-interval sampling systematically underestimated it while momentary time sampling yielded the most accurate estimate of duration. The results were replicated in a later study by Rhine and Linville (1980). Rhine and Linville (1980), however, found that partial-interval sampling was superior to momentary time sampling in estimating the frequency of behaviours. When the behaviour was infrequent, momentary time sampling techniques were found to underestimate its occurrence. It has been suggested that this problem may be minimised if the recording interval length is shorter than the shortest behaviour instance and non-recording interval (Ary & Suen, 1982). Croll (1986) showed that when momentary time samples were conducted at intervals shorter than 2 minutes, little distortion occurred.

Time sampling has certain advantages over continuous measurement. As it regulates precisely the amount of time and the content of the observation it demands lower energy and concentration from the observer (Sackett, 1978). Because of the ease of recording, larger numbers of observations can be gathered in shorter time. According to Irwin &

Bushnell this technique is particularly useful in group observation. This is because time sampling allows the observer to collect information about many individuals at the same time. Furthermore, if the coding categories have been well defined and a large number of observations are gathered, time sampling can provide representative and highly reliable data (Langdrige, 2009). One of its advantages is that it allows the combination of different recording techniques such as a coding scheme and a narrative description (Goodwin and Discroll, 1980). After recording the target behaviour on the coding scheme, the observer can write a brief narrative description of the behaviour and its context. This allows the observer to obtain highly reliable and quantifiable data as well as a more rounded view of the behaviour under study.

### **4.5. Qualitative and quantitative approaches in observation**

A distinction is often made in the literature between qualitative and quantitative observational methods. Considerable variation is noticed, however, in the definitions and the terms used to describe these two approaches. Some authors refer to qualitative observational methods as either “participant”, “unstructured” or “open” observations whereas the terms “structured”, “systematic” and “closed” observations are used interchangeably to describe the quantitative observational approach. Definitions also vary, underlining different aspects of the two methodologies.

The quantitative approach to observation comes from a positivist tradition that seeks to observe human behaviour in an accurate and precise way by deriving data that can only be measured quantitatively (Dane, 1990). Emphasis is placed on the prior definition of phenomena to observe, the specification of a systematic set of rules for recording events, and the measurement of variables in a consistent manner. Qualitative observational techniques originate from a tradition that attempts to understand behaviour through a detailed examination of the context in which it occurs. In contrast to quantitative methods here the observer will begin with the observations and postpone definitions and structures until a conceptual categories have been identified in the data (Bowling, 2002).

The degree to which the methods of recording observations define the nature of the data obtained is an issue of controversy. According to Croll (1986), the preparation of structured observational schedules and the use of techniques such as time sampling, results in quantitative data that can be subjected to statistical analysis. Benzten (2000) suggests that when a coding scheme is applied, raw data are lost and it is that loss that defines quantitative methods whereas, to the extent that a method preserves raw data it

is considered to be qualitative. It has been argued, however, that the rigid division between qualitative and quantitative observation is only theoretical as, in practice, observational data can be collected and analysed using a combination of methods e.g. coded events and illustrative narratives (Bowling, 2002; Croll, 1986). Video recording, for example is extensively used as a continuous measurement of behaviour, however as noted by Bowling (2002), the obtained data could be later sampled and quantified using an event or time sampling strategy. Sometimes researchers, although they have a clear idea on the events in which they are interested, they may not be in a position to specify the categories of a variable. In that case Croll (1986), suggested following a “quasi-systematic procedure” where researchers except for coding pre-determined categories they also make a brief note under categories to describe aspects of the behaviour or the interaction observed. Similarly, narrative accounts do not need to be dependent on qualitative approaches but can be developed from structured coding schemes (Robson, 2002). According to Bowling (2002), studies using narrative records and generating a lot of raw data in qualitative form are not necessarily conducted under a qualitative research banner. This is because a rigid structure may be imposed on the data during analysis, by independent raters trained in a specific coding scheme, which reduces qualitative data to frequencies of occurrence. An example of this method is the observational study of the quality of life in nursing homes and hospital wards conducted by Clark & Bowling (1990). The researchers developed an observational schedule that recorded codable events and made qualitative recordings of observations. It was shown that the structured observational data were clearly supported by the narratives and that observational methodology was sensitive to the effects and the differences between settings.

### **4.6. Analysis of observational data**

Following data collection, decisions need to be made on how to analyse the results. If observations were classified into mutually exclusive categories, statistical techniques can be used to analyse and present the data in quantitative form (Shaugnessy, 1997). Researchers will have to choose the appropriate measures and statistical tests for evaluating research hypotheses. Data from continuous sampling of behaviours can yield measures of frequency, duration and sequence for each category (Sackett, 1978). For non-sequential data obtained from time and event sampling techniques, four basic measures are available: 1) each category can be scored for its frequency of occurrence, 2) probability or relative frequency, which is the most commonly used descriptive measure and refers to



the proportion or percentage of times that various behaviours occur in terms of the total frequency of the events observed, 3) the total duration (seconds), and finally 4) the relative duration of each category (per cent of total duration) can be measured by dividing each individual duration by the total session time (Sackett, 1978).

Observational qualitative data collected from narrative records can be analysed using techniques that apply to data collected by other means, e.g. interviews (Simpson, 1995). Various ways of dealing with observational data have been described including “analytic induction” and “constant comparison analysis”. According to May (1995) these approaches, stripped of their theoretical framework, are all variants of content analysis.

### **4.7. Content analysis**

The basic idea of content analysis is the classification of words or a piece of text into content categories of interest (Weber, 1990). This requires the development of a coding scheme which is a system for classifying text that operationalizes concepts and establishes categories. The object of content analysis can be any kind of recorded communication, such as interviews, protocols of observations, video tapes and written documents in general (Kohlbacher, 2006). Multiple definitions of content analysis have been suggested over the years, reflecting the different conceptualisations of the method through its historical development. Originally content analysis referred only to those methods that concentrate on quantifiable aspects of text content (Titscher et al., 2000). Berelson (1952) defined content analysis as “a research technique for the objective, systematic and quantitative description of the manifest content of communication” (p.18). The manifest content refers to “recurring easily identifiable aspects of text content” (White & Marsh 2006, p.23.). From that perspective, content analysis is essentially a quantitative method. The simplest type of evaluation consists of assessing the number of times content categories occur, assuming there is a relationship between frequency of content and meaning (Kohlbacher, 2006).

Quantitative content analysis is deductive in its approach and its objective is to test hypotheses flowing from related research and theory (George, 2009). In quantitative content analysis the coding scheme is determined before the coding begins (White & Marsh, 2003). Categories can be drawn from previous studies in the area with similar aims or from theories that can be operationalised into categories for coding texts (Krippendorff, 2004). Another strategy is to start each content analysis from scratch by developing categories that are uniquely tailored to the available text. In that case, Waltz (1991) recommended that the categories be semantically as close as possible to the wording in

the original text so that the meaning is distorted as little as possible. This strategy can ease the coding task and increase reliability. The weakness of this method is that it produces results that are not comparable with other studies (Krippendorff, 2004). Categories need to be mutually exclusive (a single segment of text can only be coded in one category) and exhaustive (all data are represented in the coding scheme). It is suggested that the process of quantitative content analysis minimises the danger of coding irrelevant content, and offers precise and reliable observations about the frequency with which content characteristics occur (George, 2009).

Kracauer (1952) criticised the one sided reliance on quantitative content analysis claiming that it may reduce the accuracy of the analysis. According to Kracauer, communications involve latent meanings and it is not possible to isolate and describe only the manifest content. These critiques finally led to the development of qualitative approaches to content analysis (Kholbacher, 2006). Whereas quantitative analysis assesses the number of times one or more content characteristics occur in order to make inferences, the qualitative approach goes beyond mere counting of occurrences and analyses more subtle aspects of the text in order to reach an understanding of its meaning (Hsieh & Shannon, 2005). According to Thompson (1999), qualitative content analysis may also begin with predetermined categories. However, contrary to quantitative analysis, “qualitative analysis constantly tests and revises those categories during and after the data collection process” (p.156). There is an emphasis on allowing categories to emerge out of data and on recognising the significance of the context in which an item is analysed (Bryman & Bell, 2007). It should be noted, however, that quantification is not specific to quantitative content analysis. The findings of qualitative content analysis may also be presented quantitatively through descriptive statistics (e.g. skew, percentages). However, they cannot be analysed using inferential statistics (e.g. chi-square, ANOVA) which investigate differences between groups and make generalisations about the population from which the sample was drawn (White & Marsh, 2006).

There has been an on-going debate on the characteristics and applications of quantitative and qualitative approaches in content analysis (Kohlbacher, 2006). The validity and usefulness, however, of this distinction has also been widely questioned (Krippendorff, 2004). Quantitative content analysis includes qualitative aspects as it originates in qualitative considerations (Kracauer, 1952). Reading a text involves a qualitative process even if parts of this text are later converted into numbers (Krippendorff, 2004). On the other hand, qualitative analysis often requires quantification in order to allow a statistical

evaluation of the data collected (Kracauer, 1952). The development of mixed methods research has eventually led to a reconciliation of both approaches (Kohlbacher, 2006).

### 4.8. Observation studies in neurological rehabilitation

Observational methods, particularly time sampling, have been used to explore the components of interventions and assess and compare rehabilitation practice on neurological rehabilitation wards. Lincoln et al. (1989) and De Wit et al. (2005) conducted observational studies of stroke units providing intensive rehabilitation. Behavioural mapping, a time sampling technique, was used to observe and record location, behaviour and patterns of interaction of patients in the stroke unit. This method describes the distribution of predetermined behaviours in a setting by allowing for observation of more than one person at a time (Keith, 1988). Newall et al., (1997) investigated therapeutic activity and social interaction among inpatients in a neurological rehabilitation ward. The multidisciplinary team providing the care in the ward aimed to promote patients' activity, independence, confidence, social contacts and participation in leisure pursuits as well as to encourage the involvement of relatives in rehabilitation. A time sampling schedule was developed for the study, including three groups of codes to categorise activity (e.g. resting, eating, walking, reading), location (e.g. bed area, bathroom, kitchen) and interactions (interactive or non-interactive). The observational data were analysed as frequency counts and the proportions of time spent by the patient group in various types of activities were calculated as a percentage of the total number of observations. In the study of Balinger et al. (1999) a time sampling strategy was employed to describe components used in occupational therapy and physiotherapy interventions for people with stroke. The frequencies of use of the therapies together with other details about the delivery of the interventions were recorded using a coding system designed by the therapists. The coding system, which was based on a pilot study exploring the content of stroke rehabilitation, was designed to provide a simple and practical way of recording components of therapy interventions in stroke rehabilitation. The interactions between a brain injured woman with behavioural disturbances and her care providers were observed in a study by Graneheim et al. (2001). The aim was to illuminate various aspects of the ongoing interaction related to identity, autonomy and security issues. The observational notes were tape recorded and then transcribed and analysed using content analysis methodology. Interestingly, relevant studies on the interaction of care providers with acquired brain injury patients revealed a discrepancy between care providers' understanding of their actions, as that was expressed in interviews, and their actual behaviour as shown in observations (Hallberg & Norberg., 1990; Hallberg et al., 1993).

O' Brien (2006) used time sampling methodology in order to record and compare the activity and the content in the compensation, restitution and control groups enrolled in the pilot phase of the "ReMind" trial (Nair, 2007). The study aimed to compare the differences in rehabilitation practice between each type of group and ensure that the group leader followed the predefined protocol for each session. Two information categories, activity and content, were recorded for the group leader and each participant every minute on the minute. Observations were recorded qualitatively and were then assigned to two activity and ten content categories. These categories were identified by the observer a priori based on the treatment protocols and included external and internal memory aids, memory theory, memory processes, social activity/lifestyle, emotion/feelings, forgetting issues, relaxation, group related issues and a miscellaneous category. These subcategories were grouped into two main categories: "memory rehabilitation content" and "non-memory" rehabilitation content. The three types of programmes were then compared on the basis of these general categories. No significant difference between the compensation and restitution programmes in the amount of time spent in memory rehabilitation discussion. Programmes did, however, differ in the amount of time spent discussing internal and external memory aids, which was consistent with the therapeutic aims of these groups. Moreover, the treatment groups were significantly different from the self-help groups in the amount of time spent discussing memory related and non-memory topics. It was suggested that the treatment groups received a similar memory rehabilitation training whereas the self-help group spent more time engaged in the discussion of non-memory related issues.

In the current study, observations were employed in order to obtain insight into the content of a memory rehabilitation programme and use this information in the development of the outcome measure. Observations were the preferred method for this study for a number of reasons. Systematic on site observations, although they place heavy demands on an observer's time, are considered to provide more accurate information than that obtained from interviews and retrospective questioning (Keith, 1980). Although self-report measures permit the collection of a large amount of information from the respondents quickly and easily, they can be inaccurate if respondents are unaware of or unwilling to express their true beliefs (Stangor, 2007). Participants' accounts may also be biased by their wish to present themselves in a good light or to please the researchers with their responses. As already seen in Chapter 2, recall bias can be a major threat to the

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validity of studies using self-reported data (Hassan, 2006). On the contrary, observation provides the opportunity to document activities and behaviour without having to depend upon people's willingness and ability to respond to questions. Because they do not rely on the interviewees' memory or knowledge, they may uncover behaviours or routines of which the participants themselves may be unaware (Bowling, 2002). Participants' perceptions of the effects of an intervention may also be affected by experiences that followed their participation. Observations, on the other hand would allow the collection of information during the implementation of the memory rehabilitation programme and the "real time" recording of participants' input in the groups. By identifying the most frequently discussed topics it was suggested that observations would provide valuable insight into participants' issues of concern, rehabilitation priorities and domains of improvement. Direct comparisons between the intervention and the self-help groups would allow a quantitative evaluation of differences in the content of these programmes. This was important as the new questionnaire was intended to be specific to the effects of memory rehabilitation. Comparisons between the interventions and the self-help groups would also provide evidence on whether the programmes were run in accordance with the predefined therapeutic goals. Another benefit of the approach would be acquiring a detailed account of the therapeutic programme that the outcome measure was based on.

As already seen, the current study was conducted as part of the main phase of the "ReMind" RCT assessing the effectiveness of memory rehabilitation for people with acquired brain injury. The rehabilitation programme was run following the same treatment protocol as the pilot study observed by O'Brien (2006). Although a similar categorical scheme was developed in O'Brien's study the aims of the present study required a more specific, data led categorical system, close to the wording of the recorded observations, which would allow questionnaire items to be derived.

More specifically, the objectives of the current study were:

- a) to provide a systematic description of the content of the three programmes and to identify the most frequently discussed topics in each group,
- b) to examine whether there were significant differences between the three types of groups in terms of the amount of time spent on these topics,
- c) to identify the most frequently discussed topics in the two memory rehabilitation groups compared to the self-help control groups.

### **4.9. Method**

#### **4.9.1. Design**

The current study took place within the context of the main phase of a randomised controlled trial (“ReMind”). The main phase of the trial followed the same protocol as the pilot phase which was described in more detail in Chapter 3. For the present study, the observational method of momentary time sampling was employed to document activity and content in the memory rehabilitation groups. The total sampling period was defined as the duration of each group session. Each sampling period was divided into 1 minute intervals. Every minute on the minute the researcher observed and recorded information for ten seconds. The observation interval was followed by a 50 second interval during which no data was collected no matter what occurred during that period. A “quasi systematic” design was followed as information was recorded using both predetermined categories to code activity and narratives to record content.

#### **4.9.2. Ethical considerations**

The study was approved by the Nottingham and Derbyshire Research Ethics Committees. Informed consent was obtained from all participants. All data were anonymised and stored in accordance with the Data Protection Act (1998).

#### **4.9.3. Participants and setting**

The observed groups ran in the period between May 2007 and June 2008. The rehabilitation groups were mainly carried out in the University of Nottingham, although groups were also run at Derby City General Hospital. In both cases the four participants and the group leader were sitting around a table in the middle of the room whereas the observer was sitting in the corner of the room, allowing some distance between her and the group, in order to make her presence less intrusive.

#### **4.9.4. The observational instrument and procedure**

The author carried out real-time observations of the group sessions. Her role was overt, meaning that participants knew the purpose of her presence. At the beginning of the first session the group leader introduced the observer as a research psychologist. It was explained that the observer would record information discussed during the sessions as she was interested in the content of the rehabilitation groups. However, the aim of the study,

to develop a questionnaire on the effects of memory rehabilitation, was not discussed with the participants in order to ensure they would not change their behaviour in response to this. Before data collection commenced the group leader ensured that all participants consented to the presence of the observer during the sessions. The observer did not take an active part in the discussions of the group and interacted only casually with participants.

Three group leaders were involved in the running of the groups. One of the leaders was Dr Roshan Das Nair, clinical psychologist, who developed the rehabilitation programmes and ran the groups in the pilot phase of the RCT (Nair, 2007). The groups were also run by two research assistants familiar with the content of the programmes and cognitive behavioural principles. The research assistants ran three groups each: one compensation, one restitution and one self-help group. The clinical psychologist also attended a few of the sessions of these groups, as a second group leader, in order to ensure consistency in the running of the groups. An effort was made by the observer to attend as many of the group sessions as possible. This was done in order to ensure that a similar amount of time was allocated to all the three types of groups and extensive data were acquired. When participants missed a group session the group leader arranged individual sessions with them; these were not observed as part of this study.

Group activity and content were recorded using a simple paper and pencil recording procedure. The data collection tool was designed specifically for this study. The observation schedule devised consisted of a structured section for recording general activity of participants and group leaders in predetermined categories (see table 8). It was complemented by a qualitative observational log for recording the group content. Each recording sheet was divided in rows representing 1 minute sampling intervals. The number of rows corresponded to the duration of a group session. Rows were divided by seven columns. The first left hand column was used to indicate time in minutes e.g. 14:01, 14:02 etc. The initials of each group member were noted in the top row of each column. Enough space was allowed for the "Comments" column where the group content was recorded qualitatively. The schedule also included a "Topics" column which was not completed during observation but only after the analysis of qualitative data with the code corresponding to the category discussed on that minute.



Table 8.

An example of a completed section of the recording sheet.

Time						Topics	Comments
	PI	BM	MH	HJ	PS		
<u>14.00</u>	T				X		Page 5..we were talking about memory aids
<u>.01</u>			T				I really practiced remembering the homework
<u>.02</u>		T					I forgot about the homework but I'll do it
<u>.03</u>			T				It's a name that I couldn't remember it before...Natasha Kablensky
<u>.04</u>	T						Last two sessions we talked about attention, why do you think it's important about memory?
<u>.05</u>		T					It's the first thing of a process...if you don't attend to sth you are not gone learn it
<u>.06</u>	T						Things like pain, mood, tiredness affect your attention
<u>.07</u>	T						Is there anything that you r doing in your everyday life in order to improve attention?
<u>.08</u>			T				I put the timer in the cooker so that when it rings it gets my attention to do it

At the beginning of every minute the observer noted on the schedule what the group members were doing on that moment. Three mutually exclusive codes describing activity were used: "T" for talking, "DE" for doing a group exercise and "B" for having a break. The absence of a group member was noted an "X" under his/hers initials. In case a member joined the group after the start or left before the end of the session, observations were taken for as long that person attended the group. If a group member was talking, the observer recorded verbatim and for 10 seconds what the person was saying e.g. "*encoding is how you put information to your memory*". If participants were silent or were having a break, no qualitative data were recorded. If the group leader or the participants were talking as part of an exercise that was recorded on the schedule as "doing a group exercise" and qualitative information on what was said was obtained. At the end of every minute the observer moved to the next row. The format of the questionnaire and the length of the observation interval were piloted over the first 2 sessions of the first compensation group (which were not included in the analysis).

### 4.9.5. Analysis of qualitative data

The method of content analysis was employed to code and analyse the qualitative data from observations. The analysis was done in two phases. An inductive process was followed in the pilot phase in order to identify the main concepts and categories. The category scheme was not defined a priori but developed to be semantically as near as possible to the material. This was done in order to gain direct information from study participants without imposing preconceived categories or theoretical perspectives (Krippendorff, 2004). As suggested by Mayring (2000), the main advantage of qualitative content analysis is that it gives answers to the question from where the categories come and how the system of categories is developed. However, what qualitative analysis is eventually aiming for is to examine language intensely and uncover the underlying intentions of communication; this was beyond the more limited descriptive purpose of this study. Furthermore, the ambiguity of the coding process makes the inductive approach more vulnerable to coder bias and the reliability of interpretations more difficult to establish. For these reasons it was decided to use a quantitative approach to analyse the whole data set in the main phase of the study. It was suggested that this approach would make it possible to subject the findings of the study to independent tests in order to judge their reliability.

1) Pilot phase. The definition of the content categories and the development of a categorical scheme to apply to the qualitative data were achieved via a pilot content analysis process. Developing the categorical scheme was done inductively by deriving categories from the data themselves and constantly reviewing them during the coding. The aim was to describe the manifest content of observational data. The procedure that was followed was based on a multistep process described by Waltz (1991).

**Stage 1.** The first step was to define the universe of content which refers to the totality of recorded information to be analysed. That was identified as the qualitative data recorded on the time sampling schedule over the total number of the sessions observed.

**Stage 2.** In this stage the characteristics or concepts to be measured should be identified. For this study, instead of imposing predefined concepts, all observations were coded, no matter whether they were relevant or not to memory issues. In order to code memory-related observations, theories and models of memory were employed. For

example, statements referring to participants' ability to remember to perform an intended action (e.g. forgetting appointments) would be coded as "Prospective memory".

**Stage 3.** The units of analysis were selected. Units of analysis are mutually exclusive units of text which are separately described or categorised and provide the basis for statistical account (George, 2009). The unit of analysis was the narrative recorded over the 10 second interval. The unit of meaning, defined as the amount of text related to the same concept, set the limits on the amount of text to be coded and categorised. Due to the short recording interval, it was assumed that each narrative would represent only one discussion topic. If the recorded text was a compound sentence and each part of the sentence had a different meaning, only the first part of the sentence was recorded. Punctuation and the word "and" were used as markers to segment compound sentences.

**Stage 4.** A sampling plan was developed. A representative random sample of observational data was identified to be included in the pilot phase. Thirty per cent of the group sessions in each type of group (compensation, restitution, and self-help) were randomly selected from the total number of sessions observed in each group. A random number generator within the Excel computer programme was used to generate the sample.

**Stage 5.** A scheme for categorising the content was developed (Appendix 1, p.329). The development of the scheme proceeded inductively, deriving codes from the data themselves by identifying clusters of similar data. The analysis started with reading through all the observational notes to obtain a sense of a whole. Each unit of analysis (narrative) was abstracted and assigned a code, defined as a neutral label that described directly the content of the narrative. Observations that were unclear and ambiguous were coded as miscellaneous. Once all observations were coded, the whole data set was reviewed and the various codes were compared based on differences and similarities in order to group them into categories sharing a similar meaning. Categorisation was undertaken at two levels: a) codes were organised on a basis of a common characteristic to form sub-categories, and b) sub-categories were then sorted and abstracted into categories. The following figure presents an example of the coding process:

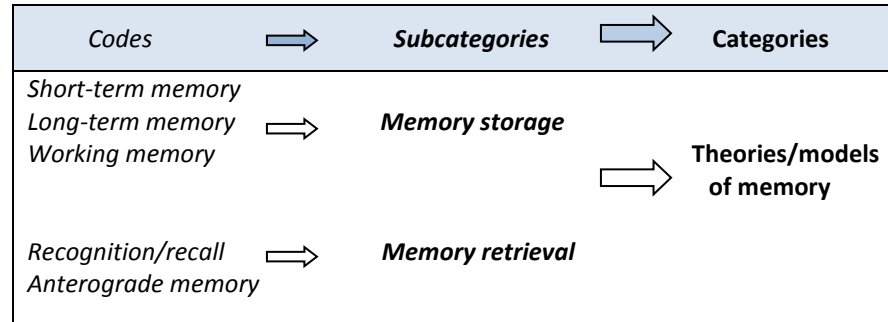


Figure 5. Example of the coding process of observations.

As stressed by Rourke & Anderson (2004) it is important to ensure that the coding scheme neither leaves out categories that should be included nor includes categories that should be left out. The developed categories were, therefore, exclusive and exhaustive and semantically as close as possible to the wording in the original text. It has to be noted here that the coding scheme was developed keeping in mind that the results would be used to inform a questionnaire. For this reason the coding scheme was based on codes as close as possible to the wording of the raw data allowing, in this way, to trace back the categories in the original text. That would enable the derivation of questionnaire items directly from the codes or the raw data examples that were included in the coding scheme. Each code or participant quote could potentially be transposed into a questionnaire item.

**Stage 6.** Explicit coding instructions were developed for processing the content and assigning the units of analysis to categories. A diagram showing the hierarchy of codes and categories was produced (Appendix 1, p.329). Lists of key phrases associated with each of the codes were drawn from the original text to serve as examples of the concepts of interest. When these concepts were encountered they were scored as instances of the codes.

**Stage 7.** The coding instructions were refined by applying them to the random sample of observations selected for the pilot phase. The categorical scheme was revised as needed and new codes were added when encountering data that did not fit into an existing one until the number of codes stopped expanding.

2) Main phase of analysis. The coding scheme developed in the pilot phase was applied on the whole data set of observations. Each unit of analysis was coded using the predefined categorical scheme. No new categories were added in that phase.

### **4.9.6. Statistical analyses**

The demographic and psychometric baseline data were evaluated and the differences between the three groups on these variables were examined to determine whether the groups were comparable. The psychometric data were treated as ordinal and nonparametric statistics were used. Kruskal-Wallis one-way between-groups analyses of variance and Chi square tests were used for continuous and categorical data respectively.

A numerical code was assigned to both the activity categories and the content categories that emerged through the content analysis and were used as nominal data. These numerical codes were used in order to classify the observations as nominal scale variables and perform statistical analyses. To determine the use of time by the groups, the number of sampled instances of codes was counted and the proportions of time spent by participants in various categories were calculated as percentages of all observations. Chi-square analyses were employed in order to investigate whether there were any significant differences in the use of time by participants between the three types of programmes. Comparisons between the three programmes were initially performed, followed by comparisons between the two intervention programmes, compensation and restitution, and finally between the two intervention programmes and the self-help group.

All statistical analyses were performed using the SPSS statistical package version 16.0.

### **4.9.7. Inter-coder agreement**

Inter-coder reliability, or inter-coder agreement, measures the extent to which independent judges make the same coding decision in evaluating the meaning of texts (Lombard et al., 2002). It is considered to be the primary test of objectivity in quantitative content analysis (e.g. Rourke, 2000). It is expressed in a numeric value indicating the level of agreement between two independent coders. Coders must be capable of understanding the coding rules and applying them consistently throughout an analysis. George (2009) suggested that coders should have similar backgrounds in order to interpret the written instructions alike.

For this study, consistency in coding was assessed by an independent coder, blind to the original coding, who categorised a sample of data using the coding instructions. The second coder (Dr Alana Tooze) was a research psychologist familiar with the concepts of cognitive rehabilitation. The coder received a half an hour of training with the coding scheme, during which the instructions were explained. The coder was then asked to apply the coding instructions to a small subsample of observations that were not part of the

sample to be assessed. This was done in order to enable the coder to adapt to the use of the instructions and also provide her with immediate feedback on her performance. No difficulties were encountered in that phase. Following that informal assessment of agreement, a random sample of 30% of the group sessions was coded by the second coder. Two indices were chosen to assess inter-coder agreement for each unit of coded text: per cent agreement and Cohen's kappa. Per cent agreement was calculated by dividing the number of times the two coders agreed by the total number of coded units of text (Rourke et al., 2001). The main advantage of per cent agreement is that is simple, easy to calculate and can give us a first impression of what the results would be (Lombard et al., 2002). Cohen's kappa gives a numerical rating of the degree to which agreement is due to chance (Viera & Garrett, 2005). It has received extensive use across the behavioural science literature because it is generally considered a more robust measure than simple per cent agreement which fails to account for agreement occurring simply by chance (Lombard et al., 2002; Perreault & Leigh, 1989). The calculation is based on the difference between how much agreement is actually present ("observed" agreement) compared to how much agreement would be expected to be present by chance alone ("expected agreement") (ibid.). Kappa coefficients were interpreted according to the cut-offs suggested by Landis & Koch (1977), i.e. .01-.20 as slight, .21-.40 as fair, .41-.60 as moderate, .61-.80 as substantial, and .81-1.00 as almost perfect agreement. The threshold for the acceptability of the kappa score was set at  $>.61$  (Landis & Koch, 1977).

### 4.10. Results

#### 4.10.1. Participants

Twenty-four people were randomised to two compensation, two restitution and two self-help groups with four people allocated in each group. Two participants dropped out of the first restitution group, after attending two and three sessions respectively. One of them had a relapse of MS and the other one did not want to continue coming to the groups. One participant dropped out the second restitution group after attending one session due to deterioration in his physical health (relapse of MS). One participant dropped out the second self-help group after attending one session due to poor health (relapse of MS). There were no dropouts in the compensation groups.

The demographic and psychometric characteristics of participants at recruitment are shown in Tables 9 and 10 respectively (pp.139-140). It was not possible to examine the differences between the three programmes on categorical demographic variables as it was found that more than 25% of cells had an expected frequency of less than five cases. Regarding continuous demographic characteristics, the Kruskal-Wallis analyses of variance showed no significant differences between the three programmes. Similarly, Kruskal-Wallis analyses on psychometric characteristics indicated that the three programmes did not differ significantly.

Observations were taken in 15 compensation (1022 minutes), 14 restitution (871 minutes) and 14 self-help group sessions (855 minutes). The median duration of group sessions in minutes per intervention was 67.5 for compensation, 63.5 in restitution and 62 in the self-help group. The observer did not attend five sessions in the compensation programmes, six sessions in the restitution programmes and six sessions in the self-help group programme due to health and other personal reasons. As the content of each session varied according to the pre-defined protocol, it was important to examine whether every session was represented in the sample. It was found that for each programme all sessions were represented in the sample except for the last session of the self-help programmes for which no observations were recorded in either of the two groups. However, as this session consisted mostly of revision of the content covered in the previous sessions its omission was not expected to significantly affect the results.

Table 9  
Demographic characteristics of participants at baseline

Demographic Characteristics		Group			<i>p</i> Value †	
		Compensation ( <i>n</i> =8)	Restitution ( <i>n</i> =8)	Self-help ( <i>n</i> =8)		
Age		<i>Median</i>	40.0	44.5	56.0	.13
		<i>IQR</i> *	35.0-54.0	37.0-52.50	42.0-64.0	
Gender	Female	<i>n</i>	5	3	2	-
		%	62.5	37.5	25.0	
	Male	<i>n</i>	3	5	6	
		%	37.5	62.5	75.0	
Diagnosis	TBI	<i>n</i>	3	1	2	-
		%	37.5	12.5	25.0	
	Stroke	<i>n</i>	1	1	4	
		%	12.5	12.5	50.0	
	MS	<i>n</i>	4	6	2	
		%	50.0	75.0	25.0	
Living Arrangements	With partner /family	<i>n</i>	6	4	5	-
		%	75.0	50.0	50.0	
	Alone	<i>n</i>	2	1	2	
		%	25.0	12.5	25.0	
	Partner is carer	<i>n</i>	0	2	0	
		%	0	25.0	0	
Employment status	Full time	<i>n</i>	2	2	2	-
		%	25.0	25.0	25.0	
	Part time	<i>n</i>	2	0	2	
		%	25.0	0	25.0	
	Unemployed	<i>n</i>	4	5	3	
		%	50.0	62.0	37.5	
Time since injury/ Diagnosis (no. of months)		<i>Median</i>	73.0	96.0	75.5	.20
		<i>IQR</i>	20.3-120	37.7-150	37.3-110	
Education (no. of years)		<i>Median</i>	16.0	13.00	11.0	.07
		<i>IQR</i>	12.3-16.0	11.0-16.0	10.3-11.5	

\* *IQR* (Interquartile range) = Q25-Q75; †Kruskal-Wallis comparison



Table 10  
Psychometric characteristics of participants at baseline

Psychometric Data		Group			<i>p</i> value <sup>†</sup>
		Compensation	Restitution	Self-help	
NART estimated IQ	<i>Median</i>	107.4	102	110	.28
	<i>IQR</i> *	98.3-115.3	96.7-113.5	100-122	
SSTALD Total score	<i>Median</i>	20.0	19.0	19.0	.51
	<i>IQR</i>	19.0-20.0	17.0-20.0	19.0-20.0	
RBMT-E Overall profile score	<i>Median</i>	1.0	1.0	1.0	.48
	<i>IQR</i>	1.0-2.0	0-1.0	0.25-1.75	
EMQ-total	<i>Median</i>	31.0	46.0	41.5	.54
	<i>IQR</i>	25.0-53.0	29.0-57.0	34.2-57.0	
GHQ-30 Total Score	<i>Median</i>	36.0	20.0	35.0	.12
	<i>IQR</i>	22.0-56.0	10.0-30.5	20.5-39.0	

\* *IQR* (Interquartile range) = Q25-Q75; <sup>†</sup>Kruskal-Wallis comparison; NART, National Adult Reading Test; SSTALD, Sheffield Screening Test for Acquired Language Disorders; RBMT-E, Rivermead Behavioural Memory Test-Extended Version; EMQ, Everyday Memory Questionnaire; GHQ-30, General Health Questionnaire-30.

#### 4.10.2. Group activity

Table 11  
Time spent in each activity by the group leader and participants

	Type of Group					
	Compensation (1022)		Restitution (874)		Self-help (855)	
Group Leader	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%
Talking	338	33.0	312	35.7	207	24.2
Listening	421	41.1	298	34.0	406	47.4
Doing exercises	264	25.8	264	30.2	242	28.3

Participants						
Talking	421	41.1	298	34.0	406	47.4
Listening	338	33.0	312	35.7	208	24.2
Doing exercises	264	25.8	264	30.2	242	28.3

Chi-square analysis indicated that there was a significant difference between the total amounts of time the group leader spent talking across all three groups ( $\chi^2 (2) = 32.1, p < .001$ ). As can be seen in Table 11, the group leader spent approximately one third of the time talking in both the compensation (33.1%) and the restitution groups (35.7%) groups whereas in the self-help groups participants spent more time talking (47.4%) compared to the time occupied by the group leader (24.2%). No significant differences were observed in the proportion of time occupied by group exercises across all three types of groups ( $\chi^2 (2) = 4.53, p = .104$ ). The amount of time spent doing exercises was highest for the restitution groups (30.2%) while 25.8% per cent of the compensation and 28.3% of the self-help groups were taken up by group exercises.

The distribution of activity categories in the restitution and compensation groups showed that the overall proportion of time spent in these categories was similar in the two treatment groups. Chi-square showed that the two treatment groups were not significantly different in the amount of time spent by the group leader talking ( $\chi^2 (1) = 1.32, p = .25$ ). However, a significant difference was found in the proportion of time the group leaders spent talking between the treatment groups and the self-help groups ( $\chi^2 (1) = 17.35, p < .001$ ). The distribution of time in each activity category for each programme can be seen more clearly in the following graphs:

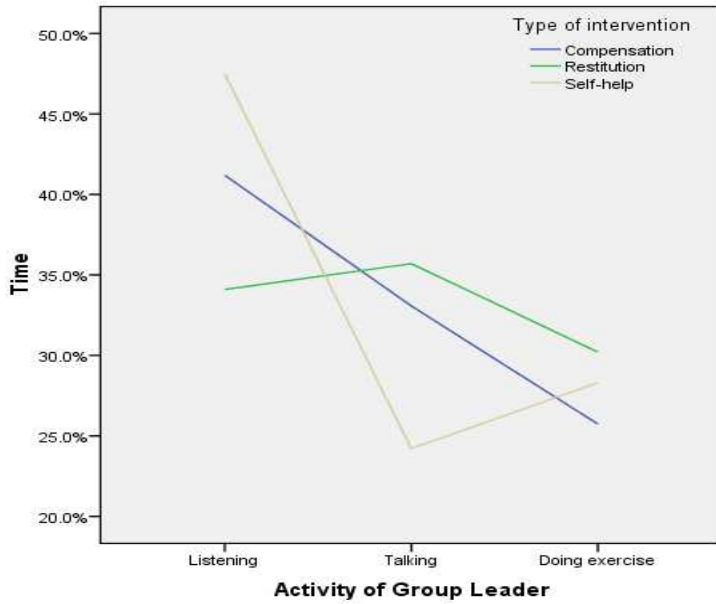


Figure 6. Proportion of time spent by the group leader in each activity category for each programme.

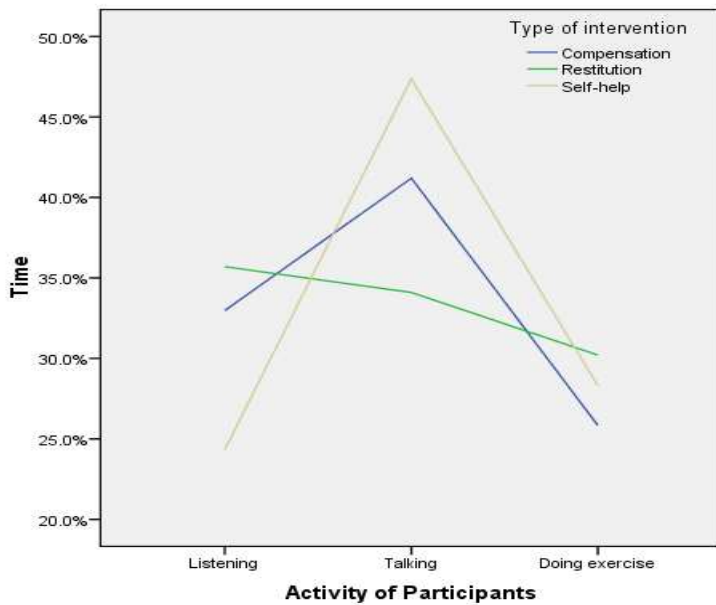


Figure 7. Proportion of time spent by participants in each activity category for each programme.

### 4.10.3. Group content

#### Pilot phase

Following the pilot content analysis of the qualitative observations 134 codes were identified. The grouping of codes into sub-categories and categories generated 35 subcategories and 12 categories (see Appendix 1 p.329 for a full list of the 134 codes and p.334 for examples of the coding process).

#### Main phase of analysis

##### Inter-coder agreement

The second rater coded 792 observations. The results for the inter-coder agreement are presented in Table 12. All of the results demonstrate a high percentage of agreement. In total the coders disagreed on 58 observations, yielding a 92.7% level of agreement between the two coders. The kappa scores, likewise, demonstrated substantial to excellent levels of agreement.

Table 12  
*Inter-coder agreement on the content categories*

Categories	Coder 1	Coder 2	Agreement	Kappa	<i>P</i>
<b>Theoretical Information</b>	59	56	94.9	0.95	<.001
<b>Self-appraisal</b>	18	21	85.7	0.98	<.001
<b>Cognitive skills</b>	1	1	100	0.67	<.001
<b>Memory Aids</b>	144	126	87.5	0.90	<.001
<b>Memory Failures</b>	33	32	96.9	0.92	<.001
<b>Personal Life</b>	42	46	91.3	0.93	<.001
<b>General health issues</b>	37	33	89.1	0.94	<.001
<b>Group setting</b>	6	5	83.3	0.89	<.001
<b>Mood</b>	29	27	93.1	0.93	<.001
<b>Group exercises</b>	346	361	95.8	0.96	<.001
<b>Procedural issues</b>	64	68	94.1	0.85	<.001
<b>Miscellaneous</b>	13	16	81.2	0.98	<.001

## Description of group content

The results are presented in parts corresponding to the categories identified. The frequency of each category and the percentage of time each category takes up in each type of intervention are shown in Table 13.

Table 13  
Distribution and between-groups comparisons of content categories

Categories	Distribution across programmes						Chi-square Comparisons between programmes		
	a Compensation (n=1022)		b Restitution (n=874)		c Self-help (n=855)		a <sup>vs</sup> b <sup>vs</sup> c	a <sup>vs</sup> b	a + b <sup>vs</sup> c
	N	%	N	%	N	%	$\chi^{2†}$	$\chi^{2‡}$	$\chi^{2‡}$
<b>Theoretical Info</b>	<b>108</b>	<b>10.7</b>	<b>106</b>	<b>12.1</b>	<b>12</b>	<b>1.4</b>	<b>65.2*</b>	1.99	<b>61.61*</b>
Models of memory	62	6.0	51	6.0	7	0.8		0.01	<b>36.10*</b>
Attention	46	4.5	55	6.2	5	0.5		1.21	<b>32.22*</b>
<b>Self-appraisal</b>	<b>50</b>	<b>4.8</b>	<b>38</b>	<b>4.3</b>	<b>15</b>	<b>1.7</b>	<b>9.1**</b>	0.30	<b>7.98*</b>
Level of ability	25	2.4	23	2.6	10	1.1		0.01	5.26
Nature of problems	25	2.4	15	2.0	5	0.5		0.88	<b>7.59*</b>
<b>Cognitive skills</b>	<b>10</b>	<b>0.9</b>	<b>6</b>	<b>0.6</b>	<b>5</b>	<b>0.5</b>	1.05	0.19	0.23
Executive functions	5	0.5	2	0.2	4	0.4		-	-
Spatial Orientation	3	0.3	4	0.4	1	0.1		-	-
Other cognitive skills	2	0.2	0	0	0	0		-	-
<b>Memory Aids</b>	<b>301</b>	<b>29.4</b>	<b>207</b>	<b>23.7</b>	<b>16</b>	<b>1.8</b>	<b>25.0*</b>	<b>7.38*</b>	<b>241.7*</b>
General theories	16	1.7	7	1.0	0	0		1.70	<b>12.7*</b>
Problems with MA	22	2.1	11	1.2	3	0.3		1.71	<b>7.76*</b>
Using the right MA	17	1.6	11	1.2	0	0		0.29	<b>11.31*</b>
Developing own MA	25	2.4	20	2.3	1	0.1		-	<b>16.93*</b>
Other strategies	43	4.2	30	3.4	5	0.5		0.57	<b>21.62*</b>
External memory aids	91	9.0	19	2.1	5	0.5		<b>37.83*</b>	<b>38.81*</b>
Internal memory aids	87	8.5	109	12.4	2	0.2		<b>7.54*</b>	<b>88.62*</b>
<b>Memory Failures</b>	<b>51</b>	<b>5.0</b>	<b>46</b>	<b>5.2</b>	<b>28</b>	<b>3.2</b>	<b>5.3**</b>	-	5.86
Prospective memory	12	1.2	21	2.4	6	0.7		1.73	<b>4.84**</b>
Verbal memory	14	1.3	11	1.3	4	0.4		-	3.31
Visuospatial memory	16	1.6	7	1.0	11	1.2		1.70	-
Episodic/Semantic	4	0.4	1	0.1	3	0.3		-	-
Working memory	5	0.5	6	0	4	0.4		0.07	-
<b>Personal Life</b>	<b>61</b>	<b>6.0</b>	<b>25</b>	<b>3.0</b>	<b>101</b>	<b>11.8</b>	<b>40.2*</b>	0.84	<b>38.32*</b>
Family life	21	2.0	12	1.3	30	3.0		0.91	3.44
Professional life	12	1.2	8	1.0	31	3.6		0.10	<b>20.01*</b>
Social life	28	3.0	5	0.6	40	4.6		-	<b>18.56*</b>

<b>General health issues</b>	<b>32</b>	<b>3.1</b>	<b>18</b>	<b>2.0</b>	<b>60</b>	<b>7.0</b>	<b>30.9*</b>	1.71	<b>28.32*</b>
<b>Group setting</b>	<b>10</b>	<b>1.0</b>	<b>13</b>	<b>1.5</b>	<b>12</b>	<b>1.4</b>	5.48	1.93	2.62
<b>Mood</b>	<b>14</b>	<b>1.3</b>	<b>42</b>	<b>4.8</b>	<b>213</b>	<b>25.0</b>	<b>30.4*</b>	-	<b>333.2*</b>
Memory related stress	10	10.	29	3.3	29	3.3		1.30	3.89
Other stressors	0	0	5	0.6	69	8.0		-	<b>120.6*</b>
Other emotions	3	0.3	3	0.3	17	2.0		-	<b>17.91*</b>
Feelings following diagnosis	1	0.1	1	0.1	10	1.1		-	<b>13.0*</b>
Tips to improve mood	0	0	4	0.4	81	9.4		-	<b>169.6*</b>
Personality	0	0	0	0	7	0.8		-	-
<b>Group Exercises</b>	<b>290</b>	<b>28.3</b>	<b>300</b>	<b>34.3</b>	<b>292</b>	<b>34.1</b>	<b>12.1**</b>	<b>10.60*</b>	1.49
Importance of practice	13	1.3	14	1.6	1	0.1		0.19	<b>8.73*</b>
Introducing exercise	26	2.5	33	3.8	35	4.0		0.79	0.81
Attention exercises	86	8.4	114	13.0	0	0		<b>15.36*</b>	<b>100.9*</b>
Memory exercises	165	16.1	139	16.0	3	0.2		-	<b>142.1*</b>
Relaxation exercises	0	0	0	0	252	29.4		-	<b>611.6*</b>
<b>Procedural issues</b>	<b>67</b>	<b>6.5</b>	<b>68</b>	<b>7.8</b>	<b>66</b>	<b>7.7</b>	1.77	0.06	1.46
<b>Miscellaneous</b>	<b>28</b>	<b>2.7</b>	<b>5</b>	<b>0.5</b>	<b>35</b>	<b>4.0</b>	<b>12.7**</b>	0.03	<b>11.8*</b>

†df(2); ‡df(1) ; \*significant at  $p<.001$ ; \*\*significant at  $p<.05$

## Chapter 4

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### Procedural Issues

This category comprised of codes related to group procedures. Prevalent in this category were codes such as “establishing group rules”, “describing the aims and structure of the programme”, “inviting people to talk” or “giving a summary of a session”.

### Theoretical information

Codes related to this category were defined by theories and models of memory and attention. The “models of memory” subcategory included interrelated processes involved in memory (e.g. encoding, consolidation), memory storage systems (e.g. working memory, long-term memory) and memory systems corresponding to different types of information (verbal memory, visuospatial, procedural memory). The other big subcategory, “attention”, comprised codes related to different types of attention (sustained attention, divided attention), the association between memory and attention, as well as ways to improve attention skills (e.g. isolating distracters, practicing attention exercises etc.).

Both compensation and restitution groups spent 6% of their time in discussing memory models while only a small proportion of time in the self-help groups was devoted to that subcategory (0.8%).

### Self-appraisal

This category included statements related to participants’ appraisal of the severity of their memory difficulties based on both their personal beliefs and the feedback gained through assessment or practice of exercises. Participants’ descriptions of their efforts to pace themselves according to their ability (e.g. giving themselves more time to learn something) were also included in this category. Other prevalent codes in this category described discussion on how to distinguish between memory processes and systems (e.g. verbal or visual memory) and understand which areas of one’s memory are affected (recall, short-term memory etc.).

### Other cognitive skills

A small proportion of time was spent by the groups in the discussion of “cognitive skills” as seen in Table 6. This category was mainly comprised of codes referring to cognitive skills, other than memory, that were also affected by participants’ health issues or that may affect memory performance (e.g. executive functions, spatial orientation etc.).

### Memory aids

Participants in compensation and restitution groups spent approximately one third of the time in discussing memory aids (29.4% and 23.7% respectively). Except for external and internal memory aids, other topics of discussion included “theoretical information” on memory aids, learning to use MA effectively, experimenting and developing own techniques and strategies. A considerable proportion of time was taken up by discussing different problems associated with the use of memory aids like forgetting to use them or encountering difficulties due to mobility issues or difficulty in handling technological aids. Compensation and restitution groups spent a large percentage of their time in these subcategories in contrast to the self-help group in which memory aids occupied only a small proportion of time (1.8%).

### Memory Failures

As table 13 summarises, the most frequently mentioned memory difficulties were related to prospective and visuospatial memory. Prospective memory failures were discussed most in the restitution group (2.4%) while both intervention groups spent the same proportion of time on verbal memory problems (1.3%). Only a very small percentage of the groups’ time was spent in discussion of episodic and working memory failures. Working memory problems were not discussed in the restitution group.

### Personal life

This category included codes related to discussions on participants’ family, professional and social life. Dependency on relatives or carers as well as the ways memory and other health issues affect family life were some of the observations that comprised the “family life” subcategory. The “professional life” sub-category referred mainly to participants’ statements about their current or pre-morbid professional status, the effects of their condition on their work life and the support they received from colleagues and employers. The limitations posed on participants’ social life as a result of their health problems were grouped under a separate subcategory. The “social life” sub-category also included discussions of participants’ willingness to disclose information about their condition. There were also comments on the way they were treated not only by friends and acquaintances but also by government health and social policies. “Personal life” issues were discussed most in the self-help control groups (11.8), and least in the restitution groups (3%) while the compensation groups spent (6%) of total time discussing such issues.



### General health issues

In addition memory issues participants also shared their experience on other health issues related to their condition (e.g. mobility problems, sleep disturbances etc.) as well as information on available interventions and conventional or alternative therapies. The codes describing these discussions were grouped under the “general health issues” category. Information was also provided on the nervous system functions, the mechanisms of neuroplasticity, and physiological changes related to the specific conditions.

### Group Setting

Codes related to the effects of the group structure of the programme were grouped under this category. In the included statements, participants described their experience of being in a group of people with similar issues, compared their ability to other group members or expressed openly their understanding and support to them. The proportion of time falling into this category was similar across the three types of groups as can be seen in table 13.

### Mood

The self-help groups spent about one fourth of their time in conversations about mood and emotions. These mainly involved emotions not directly related to memory issues, like worrying about the future, getting angry at people or trying to remain confident and optimistic. Some people also referred to how their condition was a life lesson that affected their personality (0.8%). The self-help groups also spent 8% of their time in identifying different sources of stress and worry in their lives (e.g. work, family, health etc.). There was also some discussion on feelings related to the aftermath of diagnosis ranging from denial and avoidance to acceptance of the problem (1.1%). About 10% of the time in the self-help groups was spent in the exchange of ideas about coping with low mood and promoting emotional adjustment.

On the other hand, emotions related to memory problems like people getting stressed, frustrated or embarrassed when forgetting something, were mainly discussed in the compensation groups (10%) and less in the restitution (3.3%) and self-help groups (3.3%). Effects on personality and ways to increase mood were not discussed in the two memory intervention groups.

### Exercise

Except for the actual practice of group exercises, this category also included discussions on the importance of practice in improving the use of memory aids and promoting brain stimulation. Some codes related to the group leader introducing or explaining group exercises or homework tasks to the group. A large proportion of time was spent in both intervention groups in performing memory related exercises (16%). The importance of keeping the brain active was minimally discussed in the self-help group (0.1%) as was the practice of memory related tasks (0.2%). There was no practice of attention exercises. On the contrary, about one third of the total time in self-help groups was spent in practicing relaxation exercises (e.g. progressive muscular relaxation, guided imagery, etc.).

### Miscellaneous

The term “miscellaneous” was used to classify codes related to off topic conversation (e.g. humorous remarks between group members). The self-help groups spent the most time in these comments (4%) while the least time was spent in the restitution groups (0.5%).

## **Comparisons between the programmes**

### Comparison between the compensation, restitution and self-help programmes

As it can be seen in table 13 (p. 144), Chi-square comparisons indicated that the three programmes differed significantly in the amount of time they spent in the discussion of eight out of the 12 content categories. The topics of discussion in which the three groups did not significantly differ were the “cognitive skills”, “memory failures”, “group setting” and “procedural issues”.

### Comparison between the compensation and restitution programmes

Comparisons could not be computed for five categories as more than 25% of cells had expected frequency of less than 5 cases (table 13). Results indicated that the compensation groups spent significantly more time discussing external memory aids ( $\chi^2(1) = 37.82, p < .001$ ) compared to the restitution groups. On the other hand significantly more time was spent in the restitution groups in discussion of internal memory aids ( $\chi^2(1) = 7.54, p < .001$ ) and attention exercises ( $\chi^2(1) = 15.36, p < .001$ ). No other significant differences between the two programmes were observed on any of the content categories. For this

reason, it was possible to combine observations of the two programmes in one “memory rehabilitation” programme which was then compared with the self-help programme.

### Comparisons between both intervention programmes and the self-help programme

The results of the chi square indicated that the memory rehabilitation groups were significantly different from the self-help groups in the amount of time spent in memory related topics. Memory groups spent significantly more time in discussion of: models and processes of memory ( $\chi^2 (1) = 61.15, p < .001$ ), memory aids ( $\chi^2 (1) = 241.68, p < .001$ ), self-awareness issues ( $\chi^2 (1) = 7.98, p < .001$ ) and the importance of practice ( $\chi^2 (1) = 8.73, p < .001$ ). The two intervention groups also spent significantly more time doing memory and attention related exercises ( $\chi^2 (1) = 142.04, p < .001$ ). Although the general “mood” category occupied significantly more time in the self-help groups ( $\chi^2 (1) = 333.20, p < .001$ ) the percentage of time falling into the “memory related stress” sub-category was significantly higher in the memory rehabilitation groups ( $\chi^2 (1) = 3.89, p = .04$ ). The self-help groups spent significantly more time in the discussion of: professional ( $\chi^2 (1) = 20.01, p < .001$ ) and social life ( $\chi^2 (1) = 18.56, p < .001$ ), general health issues ( $\chi^2 (1) = 28.32, p < .001$ ) and “miscellaneous” topics ( $\chi^2 (1) = 11.82, p < .001$ ).

### 4.11. Discussion

#### 4.11.1. Participant characteristics

Although it was not possible to assess whether the differences were statistically significant, some variation was noticed between the programmes in terms of participants' diagnosis. In the self-help programme, half (n=4) of the participants were stroke survivors while only one patient with stroke participated in the restitution programmes. Stroke patients are likely to differ in various ways from MS and TBI patients and, therefore, the issues they raised during the groups may also differ. This is a risk carried by the use of mixed aetiology groups in the randomised controlled trial. Despite the disadvantages, the use of mixed aetiology groups may better reflect clinical practice as in many clinical services where memory rehabilitation is offered, inclusion is not on the basis of diagnosis (Nair, 2007). Furthermore, the questionnaire that would be developed from this study was not intended to be specific to stroke or multiple sclerosis patients but needed to cover issues common in neurological populations.

Some variation among the groups was also noticed in relation to the number of years of education. Participants in the compensation programmes had an average of 16 years of education whereas participants in the self-help programmes had an average of 11 years. It could be argued that the level of education participants received has affected their input to the programmes. However, it has been suggested that the number of years of formal education may no longer be a good indicator of educational experience (with alternative forms of education and increasing number of adults returning to school later in life) (Kennedy & Turkstra, 2006). Kennedy & Turkstra (2006) felt that estimates such as the verbal intelligence quotient for the National Adult Reading test (NART) might be more useful for equating groups than the years of formal education. As seen in the results, participants in the three programmes did not significantly differ in terms of their estimated premorbid intelligence (NART), memory ability or language skills.

The possibility that clinical or demographic characteristics may have partly accounted for the observed differences between the groups cannot be precluded. Furthermore, the personality characteristics of the group members could also have influenced the communication efficiency and interaction between them (e.g. Bentzen, 2009). Regarding the group leaders, in particular, it has been shown that their qualities are directly related to therapeutic outcomes (e.g. Wheeler, 2000). In this study it is suggested that the effect of the leaders was balanced between the groups as the same leaders run all the three

programmes. As it was shown in the results, the content of the programmes differed in ways that were in accordance with the aims and predefined protocol of each programme. It is, therefore, suggested that the aims and structure of each programme had a greater contribution to the content and activity of the groups than member characteristics.

### **4.11.2. Group content and activity**

Observations allowed a detailed documentation of the content of the memory rehabilitation groups. In the two intervention programmes the most frequently discussed topics concerned: theories and models of memory, with the association between memory and attention being particularly stressed; participants' beliefs about their memory difficulties and exploration of their actual strengths and weaknesses; issues related to learning and applying memory aids as well as developing own strategies; and finally stress and anxiety issues caused by memory problems. Comparisons between the three programmes confirmed the existence of significant differences in their content. When the two intervention groups were compared it was shown that more time was spent in the compensation groups in discussion of external memory aids whereas internal memory aids and attention exercises occupied more time in the restitution groups. More specifically, external memory aids received only a very small amount of coverage in the restitution groups whereas the compensation groups devoted a similar amount of time in discussing internal and external memory aids. These findings replicated the results of O'Brien's (2006) study and suggested that the groups were run in accordance with the restitution and compensatory principles of the programme.

The fact that the compensation and restitution groups did not differ significantly in any other categories allowed the combination of the observations of the two programmes in order to be compared as one memory rehabilitation programme with the self-help control programme. It was found that memory rehabilitation programmes spent significantly more time in the discussion of memory aids, both external and internal, models and processes of memory, stress related to memory problems, self-appraisal and memory beliefs, family related issues, importance of practice and memory and attention related group exercises.

The results were consistent with the predefined protocol and the general aims of the programmes. The topics that came up as most prevalent in the memory rehabilitation groups are important components of a holistic approach in memory rehabilitation which considers the cognitive, social, emotional and social aspects of brain injury. Although the general discussion of mood and feelings was more prevalent in the self-help groups,

participants in the intervention groups were also given the opportunity to talk about the stress and burden that memory difficulties put on them. An unexpected finding was that, in contrast with the other sub-categories of the “personal life” category, “family life” was mostly discussed in the intervention groups. However, after looking at the codes included in the category in more detail, the results seemed less surprising. The most prevalent topics in this category concerned the impact of memory problems and other disabilities on quality of life and wellbeing not only for the participants themselves but also for their families. Issues related to functional independence, autonomy and self-containment were particularly stressed. The implications of family members adopting the role of “reminders” and the possible burden that this imposed on them were also discussed by participants. Grouped under this category were also discussions related to the family’s or carer’s understanding of the severity of memory problems participants experienced. Research suggests that family members have a profound effect on rehabilitation variables such as motivation for rehabilitation (Lee & Yi, 2004) and adherence to treatment recommendations (Tsoume-Hadjis et al., 2000). This effect may be related to the family members encouraging activity or communicating worry and concern about the patients’ efforts (O’Leary, 1985). In this study the prevalence of family issues in participants’ discussions may be indicative of the important role that family or significant others could play in rehabilitation and highlight the value of involving them in the process.

In the self-help groups conversations focused on general health issues, personal life, exploration of strategies for coping with stress and anxiety and practice of relaxation exercises. The “miscellaneous” category was also more prevalent in the self-help programme. According to the intervention protocol the scope of this “emotion-focused” programme was not to provide any active treatment but to serve as an opportunity for participants to discuss their day to day activities, share their emotions, and learn relaxation techniques (Nair, 2007). In this programme, which was characterised by a less strict structure, the role of the group leader was largely that of a facilitator focusing more on guiding than directing, promoting participation and keeping the discussion moving. With the exception of discussions on memory that were generally avoided by the facilitator, following the protocol, participants’ initiative was particularly encouraged in this programme. These conditions allowed participants to share experiences on their professional and social lives, express themselves through stories about their health problems and exchange emotional support. Within this context the large proportion of “miscellaneous” off-topic conversations could be related to the sense of bonding that was

developed between group members and potentially allowed the disclosure of more personal aspects of social and family life. To a great extent the “miscellaneous” category also consisted of humorous comments that group members exchanged between them. The importance of laughter and a general “upbeat tone” in the group meetings has been highlighted in studies assessing the function of self-help groups as providing balance to the shared distresses as well as a mechanism of connecting with others (Gray et al., 1997). As underlined by Damen et al. (2000), however, the main objectives of self-help groups are not only to deal with emotional and psychological stress but also to provide information about the common problem. In this study it was shown that, although participants exchanged information regarding general health issues, provision of information on memory issues was almost non-existent, keeping in line with the predefined protocol.

The discussion of some content categories occupied similar amounts of time in both the self-help and memory rehabilitation programmes. Although the group leader in the self-help groups was not providing information on memory problems and ways of dealing with them, discussions on memory failures did take place in these groups. It could be argued that this was expected considering that memory problems was the main reason that brought these groups together. On the other hand it was expected that discussion of memory difficulties would still be more prevalent within the memory rehabilitation programmes. This was an interesting finding and could be interpreted in relation to the main aims and priorities of the memory rehabilitation groups. Rather than been consumed in discussion of what participants could not remember, time was spent in exploring ways of adapting to these problems. Issues related to the experience of being in a group received similar attention in all the three programmes. Participants’ experience was expressed either by directly commenting on the benefits of the group setting (e.g. “it’s nice to know you are not on your own”) or indirectly (e.g. statements expressing their support to a distressed fellow member) (Appendix 1, p.329). It must be noted here that the sense of mutual bonding and understanding that the groups could offer, although present, may not always be expressed with words. Consequently, the methodology of this study that cannot consider the group dynamics, does not allow an accurate appraisal of the effects of the group setting on participants. Finally, it was observed that “procedural issues” took up a similar amount of time in both programmes. Despite the fact that self-help programmes followed a less strict schedule our findings confirmed group leaders’ attempts to ensure that all programmes and groups were conducted in a consistent manner, keeping in line with the manuals.

Unfortunately these findings cannot be directly compared to those of O'Brien's study (2006) due to the different categorical schemes that the studies adopted. Similar to this study, O'Brien found that compensation and restitution groups received a similar amount of memory rehabilitation training whereas the self-help control group spent more time engaged in non-memory rehabilitation discussion. The proportions of time spent in each subcategory were also reported, however, the subcategories were not used in comparisons between the groups therefore it is not possible to infer which subcategories accounted for the differences. Based on the reported percentages, in O'Brien's study the self-help group spent more time than intervention groups discussing social life, mood and health related issues, which is consistent with the findings of the current study. Whether these differences were significant or not cannot be concluded. Furthermore, by adopting very general categories the contribution of topics within these categories may have been under- or overestimated. For example, although O'Brien noted that "attention" was the most discussed memory process in both the compensation and restitution group the importance of this topic was unclear as results were only reported for the more general "memory processes" category.

In relation to activity patterns in the groups activity observations provided some evidence on the balance of talking and listening in the interaction between the group members and the leader in each programme and across the three programmes. It was shown that the group leader and participants spent similar amounts of time talking in both the compensation and restitution programmes. Significant differences in activity distribution were, however, observed between the intervention and the self-help programmes. In the self-help groups participants spent almost twice as much time talking as the group leader. Participating in group exercises, either memory related or relaxation, occupied similar amounts of time the three groups. These findings contrast with those of O'Brien's who found that in the self-help group the leader spent more time talking than participants. O'Brien attributed this finding to the fact that relaxation exercises, that occupied a large amount of time in the self-help group, were guided by the group leader. Therefore the discrepancy in the results could be due to the group exercises being coded as a separate activity category in this study regardless of who was talking. Coding the time that the leader spent in introducing or explaining an exercise under a separate category may have allowed a more accurate estimate of how the time was shared during the actual group interaction. The greater amount of time that self-help groups spent talking could be related to both the nature of the topics discussed in these groups and the less directive



role of the leader. As already shown these groups encouraged a greater extent of disclosure and participants often engaged in long narratives about their health and emotional difficulties.

Great differences in the distribution of these activities between the groups could have potentially undermined the comparisons of the group content. As group activity was not the main focus of this study only three activity categories were included in the coding scheme. This may have limited the richness of descriptions and information about the group activity that a more detailed scheme may have provided. On the other hand, given the structure and the size of the groups it can be claimed that the range of potential activities was restricted. For instance, while there was generally one person speaking in the group at all times participants may have been also engaging in activities such as taking notes or having a hot drink. However, as this was out of the scope of this study, these activities were not recorded. An assumption that was adopted in both the current and O'Brien' study was that while a group member was speaking the rest of the participants were listening. Although it could not be ensured that group members were actively listening to the speaker it was suggested that, in such small groups, participants' attention would be directed to the other group members (O'Brien, 2006). This seems to be supported by a study on the effects that teaching in a small group has on listening comprehension (Berajano, 1987). In that study Berajano argued that students being taught in small groups spent more time in active, instrumental listening and attention than those in a big group setting.

### **4.11.3. Methodological issues**

#### Sampling

Time sampling has been used in the literature to assess nonverbal behaviours or linguistic aspects of text, such as number of utterances, lexical diversity and vocabulary use (e.g. Friedlander et al., 1972; Marvin et al., 1994). To our knowledge, this was the first study that used time sampling to qualitatively record the content of speech. The design and methods used were developed to address the aims of the particular study. It was therefore important to consider the methodological issues arising from this study. As seen in the introduction of this chapter, previous studies have used qualitative observational methodology to record narratives; however, time sampling methods have mainly been used in recording activity. The fact that the majority of many recent studies in rehabilitation have used the term "behavioural mapping" instead of time sampling may be

indicative of the use of this methodology. A possible explanation may be that time sampling is associated with the use of predefined coding schemes at the point of initial data collection in order to obtain strictly quantitative data. This notion has been challenged by authors like Croll (1986) and Bentzen (2009) who underlined the ability of time sampling methodology to combine several different techniques for recording such as predefined categories and narrative descriptions at the same time. Kerlinger & Lee (1999) recommended that researchers develop a coding scheme to fit the needs of the particular study. Consequently, the adequacy of a coding scheme can only be judged with reference to its purposes (Croll, 1986). For the purposes of this study a coding scheme was needed that would allow a detailed account of the group's content to be obtained while requiring less interpretation from the observers. Despite being developed in order to decrease subjectivity, coding schemes with predetermined categories have been accused of being high inference observation systems (Croll, 1986). The reason is that observers have to make immediate decisions concerning the coding of behaviour (Croll, 1986). Furthermore, the recording schedule developed for this study needed to be quick, efficient and practical to use and ensure that recording would not interfere with observation. As the recording interval was short, the observer would not be able to look up a big amount of categories in the manual while observation was proceeding without undermining the accuracy of the coding. It was suggested that by recording observations qualitatively, a rich understanding of the group content was gained while at the same time the amount of inference and burden put on the observer were minimised. Collecting data at a detailed level allowed their more abstract categorisation at the stage of analysis. According to Bakeman & Gottman (1997), if necessary, behaviour categories can always be lumped together during data analysis, but categories grouped together by the coding scheme cannot be split out later.

### Minimising bias

By making a clear distinction between inferential and descriptive phases of analysis it was suggested that the danger of analytical bias might be reduced (George, 2009). Combining quantitative and qualitative steps in content analysis is not uncommon in the literature. According to Bos & Tarnai (1999) the distinction is far from clear-cut as there is always a qualitative step at the beginning and end of every scientific procedure. At the beginning the researchers have to formulate the object of investigation, identify concepts and categories and establish the analytic tools. This stage can be followed by either a

qualitative or quantitative analysis (Bos & Tarnai, 1999). Following a literature review White & Marsh (2006) concluded that content analysis is a flexible method as many of the reviewed studies were not “purist” but used mixed methods approaches that combined elements of qualitative and quantitative analysis in order to answer the research questions.

It was also suggested that the use of time sampling methodology during data collection may have contributed in minimising some of the bias introduced by content analysis. The potential for selection bias is present in both qualitative and quantitative content analysis. Selectivity leads to consideration of some documents or parts of texts but not others (Waitzkin, 1990). Consequently, certain elements of observations may be emphasised rather than others that disconfirm the assumptions or expectations of the researchers. In this study, it is suggested that selection bias is reduced as a result of the time sampling strategy used at the point of data collection. This is because all the sampled observations were included in the analysis and each of the observations recorded during the pre-specified interval were assigned a code and categorised. The segmentation procedure, during which the units of analysis are identified, may also be a source of bias. Variation in the length of the unit of analysis may result in overlapping units that are assigned different codes by independent coders. If these codes are treated as mutually exclusive, as in the case of quantitative content analysis, this may result in a serious methodological problem which is defined as “unit boundary overlap”(Strijbos et al., 2006). This may have important implications for the reliability of the study as in content analysis unitising reliability (consistency in identifying the units to be categorised) is a precondition for interpretive reliability (consistency in assigning units to categories) (Waltz, 1991). In this study this bias was minimised as the boundaries of the text to be coded were specified before analysis as a result of the time sampling. Furthermore, due to the short duration of the recording interval the recorded text was a sentence or a compound sentence. According to Strijbos et al. (2006) using a small unit such as a sentence may reduce the ambiguity of coding and consequently decrease the unit boundary overlap. This is because the sentences or parts of compound sentences are more likely to contain a single concept (Strijbos et al., 2006). This was also shown in the present study where it was found that the unit of analysis coincided with the unit of meaning.

### Inter-coder agreement

The computation of inter-coder agreement gave acceptable results for all the content categories. It indicated that implementation of the coding process was not significantly different between the coders and, consequently, it could be argued that the coding scheme showed resistance to subjectivity and interpretative bias. It was acknowledged however, that both per cent agreement and Cohen's kappa are susceptible to factors such as the number of observations and the number of categories (Rourke et al., 2000). As the number of categories decreases, the probability of per cent agreement by chance increases (Kolbe & Burnett, 1991). In contrast, Cohen's kappa tends to be stricter in the case of fewer categories (Strijbos, 2006). This discrepancy was evident in the case of the "cognitive skills" category which, being coded only once by both raters, appeared to have the highest per cent agreement and at the same time the lowest kappa coefficient. One of the strengths of the current study was that rather than providing the overall average reliability, reliability levels for each of the content categories were computed. It has been suggested that the overall reliability approach can yield misleading results (Kolbe & Burnett, 1991; Lombard et al., 2002). As Kolbe & Burnett noted (1991) "While agreement may be high in the aggregate, low rating on individual variables may be hidden by polled results" (p. 249). Per cent agreement may also be inflated by adding very low frequency categories. The reason is that when reliabilities are calculated including these categories the agreements on these categories compensate for disagreements on other categories (Kolbe & Burnett, 1991). In terms of determining what constitutes an acceptable level of reliability, the present study adopted the recommendations of Landis & Koch (1977) which, however, are not universally accepted. The exact level of reliability that has to be achieved is not clearly established in the literature (Rourke et al, 2001). Neuendorf (2002), after reviewing different "rules of thumb", suggested that coefficients of .80 or greater would be acceptable in most situations whereas coefficients of .90 or greater would be acceptable to all. In this study the vast majority of the categories exhibited coefficients higher than .90 which suggested substantial agreement irrespective of the criteria adopted. Because of the very good rates of agreement the few cases of disagreement were not further discussed between the coders.

### Validity

In this study categories were exhaustive and exclusive, meaning that all relevant concepts were represented in the coding scheme, which may provide an indication of good

content validity (Neuendorf, 2002). Incorporating a qualitative study where categories were developed inductively from the manifest content of the text of content analysis may have also contributed to achieving content validity (Rourke & Anderson, 2004). An attempt was also made to provide thorough information about inter-rater agreement, training procedures for coders and examples of the coding scheme. As Rourke & Anderson (2004) suggested, this is another important step to be taken towards establishing validity. Empirical evidence for validity can also be gathered mainly through examination of group differences and through the use of alternative methods of data collection to corroborate the results of content analysis (Rourke & Anderson, 2004). This study showed that the developed coding scheme was sensitive to the differences between the different rehabilitation programmes, providing further evidence for its validity.

#### **4.11.4. Limitations and future directions**

##### Reactivity to the observer

The possible effects that the observer's presence may have had on the behaviour of the group members should be taken into consideration. Reactivity effects are associated with observational methodology and, as Robson (2002) noted, there is no complete protection from the observer effect. Participants' reaction to being observed can be subtle. This involves becoming more patient and engaged in the activities, and generally increasing positive behaviour and decreasing socially negative behaviour (Coolican, 2004). In this study steps were taken in order to minimize the influence of the observer. Firstly, the role of the observer was explained to the participants. It is suggested that by taking up an explicit role in the situation and satisfying the curiosity of participants, an observer's presence may appear as more natural and less disturbing to the group (Robson, 2002). Minimising interaction was another strategy to reduce reactivity effects (Robson, 2002). This was achieved by arranging the position of the observer in the setting in order to be out of sight and avoid eye contact. The observer also tried not to reinforce attempts of interaction on the part of the group members. She did respond to participants when they addressed her, however, she was cautious not to encourage conversation. According to Robson (2002) in some cases a totally remote observer may be of more interest and therefore cause more intrusion than an observer that would respond by giving a friendly smile or nod from time to time. When the observer behaves naturally and takes care not to

give the observed the feeling that judgments are being made, reactivity may be reduced (Kerlinger & Lee, 1999).

The observer also attended the majority of the group sessions. This may have facilitated habituation of the group to the observer's presence. It is assumed that when observers spend a great deal of time in the observation setting, participants adapt to their presence and begin to behave as though the observer is not present (Kerlinger & Lee, 1999). Furthermore, due to the fact that the same observer attended all types of programmes it was expected that reactivity effects would not significantly interfere with comparisons between the groups. Robson (2002) argued that although it is not possible to ensure that the presence of the observer did not have any effect, there are some indications that can provide some reassurance. Anecdotally, in this study the pattern of interaction between the members of each group seemed to stabilise over the sessions and participants' interest in initiating interaction with the observer decreased considerably after the first few sessions in all the groups. Robson (2002) suggests that such factors may indicate that the presence of the observer did not significantly interfere with the running of the groups.

### Observer bias

Although measures were taken to minimise reactivity effects, the possibility of observer bias was not formally assessed in this study. Observations may have been biased by the observer's expectations about the nature of the differences between the groups. Factors like fatigue and emotional and physical state may also contribute to observer bias (Smith & Davis, 2007). However, the fact that the observer was recording qualitatively without having to categorise observations may have attenuated bias. Employing a second researcher to observe and record the group sessions would have allowed the evaluation of inter-observer agreement. However, it was thought that having a second observer in a small group could have encouraged reactivity effects.

### Limitations of time sampling

The limitations associated with momentary time sampling methodology should be taken into consideration when interpreting the findings of the study. Questions have been raised about the ability of time sampling methods to provide accurate estimates of frequency or duration of behaviours (Kerlinger & Lee, 1999; Sackett, 1978). It has been argued that momentary time sampling can only obtain representative samples of behaviour that occur fairly frequently (Kerlinger & Lee, 1999). The reason that this

methodology can be insensitive in detecting infrequent behaviours is the low probability of occurrence of the target behaviours over the short time sampling period. According to Kerlinger & Lee (1999) infrequent behaviours have higher probability of escaping the sampling net, unless a very big sample is collected. Regarding the present study, it could be claimed that the occurrence of low frequency topics may have been underestimated and very infrequent topics may have not even been detected. Following the suggestions of Ary & Suen (1982) and Croll (1986) this problem was dealt with in this study by collecting a large number of observations, setting a period shorter than 2 minutes as non-recording interval and by pre-testing the recording interval. Some authors argue that when the sampling interval is shorter than the average duration per occurrence of any codable behaviour, momentary time sampling can yield an accurate count of the frequency of behaviour (Sackett, 1978; Ary & Suen, 1982). In this study the recording interval was short enough to correspond to only one meaning unit and consequently only one code. Caution is still recommended when interpreting the results, as the occurrence of each category should not be looked at individually but in relation to the rest of the categories. The present study did not aim to provide an accurate frequency of each category but an estimate of how discussion time was shared among the content categories. It is worth mentioning here that as this study assessed proportions of behaviours and not absolute frequency or duration, the findings were not affected by the differences in the duration of each session.

Time sampling methodology suffers from a lack of continuity, failing to capture the contextual elements of the group interaction. In the current study, contextual factors, such as group dynamics, may have affected patients' engagement and contribution to the discussions. For instance, the relationship between the group members may have affected the degree to which they felt comfortable to express their own thoughts and opinions and disagree with the group leader or other group members (e.g. Hackman, 1992). Although the influence of contextual factors and members' characteristics should not be disregarded, their evaluation was beyond the scope of this study. Future studies could shed some light on the contextual factors that affect the outcomes of neuropsychological rehabilitation groups.

### Limitations of content analysis

A quantitative content analysis approach was used to categorise observations in the main phase of the study in order to reduce ambiguity in coding. It has to be noted however

that subjective judgment is involved even in quantitative coding and, therefore, the classification of the codes cannot be totally unambiguous. As Rourke (2000) argued, it is impossible to devise coding schemes that do not involve some amount of interpretation on the part of the coders. Therefore, pure quantification offers no guarantee for the validity and reliability of the results. Furthermore, quantitative content analysis is sometimes accused of being atheoretical (Bryman & Bell, 2007). According to Bryman & Bell this may be because an emphasis is placed on what is measurable rather on what is theoretically significant or important. However, Rourke (2000) argues that some amount of subjectivity is unavoidable in coding texts, but this does not entirely undermine the objectivity and reliability of a study.

A limitation of the coding scheme was that it did not convey the contextual elements of communication and the complexities of conversation that cannot be categorised in a straightforward way. Direction is one of the contextual characteristics that, according to Kracauer (1952), resist the breakdown into easily countable components. This makes it impossible to determine the direction of communication, i.e. the extent to which a speaker is “for”, “against”, or “neutral” in regard to a given subject. Participants in this study spent more time in the discussion of certain topics. The coding scheme, however, did not allow the interpretation of why these issues were important to participants. Furthermore, it did not provide any information on whether participants actually experienced any improvement in these domains as a result of the groups. A possible solution to this problem would have been to attempt a quantification of positive and negative comments. However, such a procedure would result in a very big number of highly refined categories, making it difficult or impossible to obtain an accurate estimate of their occurrence.

### Alternative methodologies

A possible way to deal with some of the limitations of this study could be to use a complementary method of data collection such as video recording. Despite the criticisms it has received, there are certain benefits from its use. One of them is that it results in a permanent record that allows repeated viewing of observations as many times as necessary and by more than one observer (Benzten, 2000). Furthermore, sampling strategies as well as content analysis can be applied on the continuous record obtained by video recording (Bowling, 2002; Cozby, 2009). This would allow a second observer to review the tape and record the observations using the same time sampling strategy that was used by the first observer. In this way the reliability of observations could have been



assessed and observer bias minimised. Video recording also offers access to rich contextual information (Beins, 2009). Using an event sampling procedure, researchers would be able to focus on behaviours of interest or provide information on groups' dynamics, filling in the gaps of time sampling. The observation of the same type of behaviour or discussion topic in different situations would also be made possible. In this way researchers could assess whether the behaviour in question changes as a function of the context (Smith & Davis, 2007). Furthermore, researchers would be able to concentrate on each group member and gain in this way more insight on the individual experience of each participant. In this study video material was not used partly because of potential reactive effects and partly on ethical grounds. It has also been argued that video recording may cause considerably more disruptions than a single researcher and even potentially inhibit the group (Croll, 1986).

Using a quantitative coding scheme in this study might have led to an oversimplification of the more intricate characteristics of communication. Moreover, the numerical count of content categories has not provided a true sense of the relative importance of single, potentially significant, categories. Consequently, it may have permitted only a simplistic picture of the work that was done in the groups and of the complexity of memory rehabilitation. Although it did provide a systematic description of the prevalent discussion topics it may not have captured the subjective impact of rehabilitation on each of the participants. To achieve this, additional data collection needs to focus on participants' perspective and understanding of memory rehabilitation and directly explore its effects on their lives. It was considered that the use of interviews would strengthen the validity of the current findings and provide a different perspective of the effects of memory rehabilitation. Although the findings of this study could not be generalised to all memory rehabilitation programmes they could be used in clinical practice to inform the design and implementation of holistic neuropsychological rehabilitation groups. Establishing a causal relationship between treatment process and outcome in rehabilitation is an ambitious undertaking. Time sampling was found to be a useful tool for recording the content of verbal interactions. Future research could focus on specific components of the rehabilitation process and examine which of these factors correlates with the perceived or actual effectiveness of group rehabilitation programmes.

## **5: Qualitative exploration of participants' experience in a memory rehabilitation programme**

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### **5.1. Introduction to qualitative interviews**

Semi-structured interviews are widely used in flexible qualitative designs particularly in studies that examine the meaning of particular phenomena to the participants and where qualitative data are required to clarify the meaning of quantitative findings (King, 1994). They are also used in preliminary research in order to yield items that will later be used in more structured instruments (Waltz, 1991). Similar to structured interviews, the semi-structured interview requires that all of the predetermined topics of questions have been covered somehow with each interviewee (Waltz, 1991). This is in contrast to the unstructured approach where the complete lack of a schedule might result to the interviewer missing valuable information. Using an interview schedule helps the researcher to remain focused on the agreed topic under study without being distracted by irrelevant information. According to Waltz, (1991) covering all the topics in the schedule makes it safer to assume that each interviewee was exposed to the same set of stimuli. However, in a semi-structured interview the order of the questions should not be predetermined for all the respondents but instead it should be adapted to the respondents' willingness and readiness to discuss a topic (Denzin, 1978).

In this study, the semi-structured interview approach was considered to be the most appropriate method for the specific research purposes for several reasons. Firstly, the semi-structured approach retains the advantage of the unstructured form by allowing a natural conversational flow, and the freedom to move from one topic area to another. This element facilitates the expression of individuals' attitudes, opinions and feelings and allows the topics to be pursued with considerable depth and detail (Waltz, 1991). In this way, a deeper understanding of participants' experiences in the memory rehabilitation programme could be obtained than the one provided by the structured interviews described in Chapter 3. Moreover, the interviewer is in a position to follow up interesting points that arise from the responses and explore unexpected themes that emerge during the interview. As Smith & Eatough (2006) noted, any novel topics that arise are often the most valuable findings because they have come unprompted from the respondent and therefore may be particularly important for him or her. According to Waltz, (1991),

allowing the respondent to provide answers that may not have been anticipated by the interviewer enhances the validity of the study. The use of predetermined or closed questions does not offer that flexibility and potentially important themes might be missed.

Another advantage of qualitative interviewing is that ambiguity and misunderstanding on the part of both the interviewer and the interviewee can be minimised (Shaughnessy & Zechmeister, 1997). The interviewer has the opportunity to follow up ambiguous answers and ask the respondents to further explain and clarify their thoughts. In this way, they allow for contradictions and complexities in respondents' views to be reflected in their narratives and be taken into account during the analysis. The respondent can also ask for feedback and explanations from the interviewer if he does not fully understand a question or simply refuse to respond to a question he/she finds upsetting. Moreover, the face to face interaction offers the possibility to the interviewer to take into account the non-verbal behaviour. This might be helpful in observing the effect of a question on the interviewee and notice possible confusion or reluctance to respond. Robson (2002) observed that non-verbal cues might change or even reverse the meaning of the answer.

Qualitative interviews are particularly useful for gathering information from respondents with memory difficulties (Waltz, 1991). Memory lapses may lead to errors when completing questionnaires or answering closed questions. The flexibility of the semi-structured interview process provides a context within which recall may be facilitated. The interviewer uses probes, e.g. phrases words or questions added to the original questions in order to encourage more complete responses, which may consequently trigger respondents' memory. As the interview schedule is not fixed, the interviewer can move on to a different topic before revisiting the one that caused the confusion, offering the respondent another opportunity to recall the information. Darby (2006) stressed the importance of the interviewer being a good listener and not rushing to fill silences as the participant may be trying to recall an event or a particular word. Because of the more relaxed conversational style of semi-structured interviews, participants have the opportunity to think of their responses without the stress of giving the "right" answer.

Mild cognitive problems, other than memory loss, are frequent complaints in people with neurological disorders. Although participants in this study did not suffer from dementia, during the initial neuropsychological assessment they reported problems with attention and concentration as well as mild language difficulties. In addition to the cognitive difficulties, visual and mobility impairments, particularly common in people with MS, may affect their ability to read or write. Morse (2002) identified a number of issues

that should be taken into account when interviewing people with illnesses. Participants may experience discomfort or pain and their thinking may be slowed by brain damage or drugs. Consequently, they may have difficulty understanding complex ideas and expressing their thoughts and feelings. Semi structured interviews provide a framework within which respondents can express their ideas on their own words and at their own pace. The interviewer can reflect the content by paraphrasing or simply repeating respondents' statements in order to check that has correctly understood the meaning of what was said and sort out any confusion. The interviewer is also free to adapt the question wordings to the levels of understanding of the respondent or omit particular questions that seem inappropriate with a particular interviewee. As Denzin (1978) pointed out, standardisation of meaning is not achieved with identical wording of the questions but occurs when the questions are modified to fit respondents' comprehension and language.

### **Aim**

The aim of the current study was to explore participants' experience in a memory rehabilitation programme. This information would be used to inform the development of a questionnaire sensitive to the effects of memory rehabilitation.

### **5.2. Method**

#### **5.2.1. Design**

Similar to the observation study described in Chapter 4, this interview study was conducted in the context of the main phase of a randomised controlled trial (“ReMind”) evaluating the effectiveness memory rehabilitation for people with acquired brain injury. The study was qualitative in design and used thematic analysis to interpret the results of semi-structured interviews.

#### **5.2.2. Ethical considerations**

The study was approved by the Nottingham and Derbyshire Research Ethics Committees. Informed consent was sought and all participants agreed to have an audio-taped interview. All data were anonymised and stored in accordance with the Data Protection Act (1998).

#### **5.2.3. Participants**

Participants allocated to the memory groups which ran between May 2007 and July 2008 and were included in the observational study were contacted for an interview seven months after randomisation.

#### **5.2.4. Procedure**

Interviews were carried out at the Institution of Work, Health and Organisations, University of Nottingham, and at the Derby City General Hospital. The setting assured privacy and lack of interruptions in order to allow the unobstructed flow of information. The average duration of each interview was thirty minutes. Semi-structured format was used in order to allow respondents a high degree of control over the conversation and facilitate unprompted responses. A list of topics was developed based on the interview schedule and the themes identified in the interviews conducted during the pilot phase of the “ReMind” study (Chapter 3). At the beginning of the interview all participants were asked to indicate the most beneficial aspects of the programme. It was suggested that this generic question would help elicit unprompted answers on the positive effects of the intervention. The rest of the questions were not fixed although a list was developed to serve as a guide, helping the interviewer to remain focused and cover all the topics (see table 14 for the list of topics and examples of questions). The list included the same broad topics as the previous interview schedule, however, in this study interviewers did not have

to adhere to a strict interview structure. Instead of using closed and potentially leading questions, prompts open-ended and follow-up questions were employed in order to elicit a breadth and depth in the responses. New topics introduced by the interviewee were also discussed as they arose.

Table 14

*List of topics and examples of questions for the semi-structured interview.*

<b>Main topics and examples of questions asked in the semi-structured interviews</b>
<b>Opening questions</b> What did you think of the groups? What did you find most beneficial in the groups? Have you seen any differences in your everyday life as a result of the program?
<b>Memory knowledge</b> In the initial sessions you were given information about memory processes and theories. Did you find that useful at all? Do you still have your workbook? Are you going back to it?
<b>Memory aids</b> In your everyday life are you using any of the techniques you learned in the groups? Have you been using any strategies that you were not using before the groups? Which of the strategies you learned work better for you? Has the group made any change in the way you are using (example of MA)?
<b>Memory ability</b> At the beginning of the groups you mentioned some of the difficulties you had, like forgetting names or forgetting to take your medication. Do you still have these problems? Could you give me an example of how your ability to remember things improved?
<b>Self-awareness</b> Did you change your mind about how bad your memory problems are because of the groups?
<b>Confidence</b> Do you feel confident enough in your memory? Do you feel confident to cope with your memory problems?
<b>Dependence</b> In your everyday life do you feel that you depend on other people, your wife/husband for example, to remind you of things?
<b>Attention/Concentration</b> Have you noticed any changes in your concentration?
<b>Mood</b> Did the program have any effects on your mood? Do you feel stressed because of your memory difficulties?
<b>Personal life</b> Did you observe any changes in your professional or your social life? Has anyone from your family noticed any changes?

Are you open about disclosing your memory problems?

**Group format**

What did you think about working in a group?

Would you have preferred to have more individual sessions?

What did you think about being in the same group as people with different problems, like MS?

**Closing questions**

Do you have any suggestions on how to improve the program?

Anything else you would like to add?

A digital voice recorder was used to record the interviews. Audio recorders have the advantage of permitting the interviewers to converse naturally while allowing a quick flow of information (Coolican, 2004). According to Bowling (2009), they also cause minimal intrusion as respondents tend to forget about them over the course of the interview.

Before the start of the interviews introductory information on their purpose was given to participants. It was explained to participants that their feedback, either positive or negative could help researchers to improve the rehabilitation programme. By emphasising the fact that negative comments were equally valued by researchers it was hoped that participants would be encouraged to provide honest and full answers. The specific hypotheses of the study about the effects of each intervention were not explained to participants before the interviews so that the validity of their subsequent answers would not be compromised. Nevertheless, time for debriefing was allocated at the end of the interviews. Since interviewees would be quoted verbatim in the report, confidentiality of data could not be offered. Participants were, however, ensured that the transcripts would remain anonymous, would be stored safely and would be read only by the author and the research coordinator. It was explained to participants that they did not have to answer all the questions and they could withdraw from the interview if they wished to do so and without giving any reason. They could also ask for the recorder to be switched off at any point if they did not want the disclosed information to be transcribed and included in the analysis. Participants were also informed that the use of an audio-recorder ensured that their view was recorded correctly. At the end of each interview the interviewer thanked respondents for taking part and confirmed that they were agreeable for everything that had been recorded to be transcribed and analysed. In case they decided that they wanted some part of the interview removed, this would be excluded from the transcript and analysis. Participants were then provided with information about their treatment

allocation and they were offered the opportunity to discuss the study further and have any questions answered.

### **5.2.5. Interviewers**

Interviews were conducted by either one of two interviewers. It has been stressed that interviewing, although it focuses on individual experience, it should be seen as an interpersonal action. Therefore, the interviewer/interviewee relationship should be considered (Perry & McLaren, 2003). Failure to take this relationship into account may introduce bias and undermine the validity of the findings.

In this study one of the interviewers, the author, was also involved in participants' baseline assessments and attended the groups as an observer. Consequently, concerns were raised about the possible bias that could arise from participants' prior knowledge of the interviewer. This prior relationship could have affected the results in different ways. The development of familiarity may have helped interviewers and respondents to feel at ease with each other, facilitating disclosure and reflexive commentary. This familiarity, however, may have also resulted in participants providing responses that they thought would please the interviewer. On the other hand, participants might find it difficult to dispel the image of the interviewer being associated with evaluation. The idea that they are somehow being assessed might inhibit them from giving a sincere appraisal of the rehabilitation programme.

In order to minimise these bias, half of the interviews were conducted by a research assistant who was not involved with the assessments or intervention aspects of the trial (Miss Katherine Siu). It has, however, been suggested that the neutrality of the interviewer may not eliminate interviewer bias. As underlined by Waltz (1991), variation among interviewers can be a source of response error. This is particularly true for qualitative interviews where the quality and characteristics of interviewers' behaviour have been shown to influence the responses obtained (Waltz, 1991; Coolican, 2004). Problems might occur related to the way questions are asked, the level of the interviewer's listening and communication skills. Even elements such as gestures, facial expression and verbal intonation can affect the way the respondents perceive the interviewer and his/her attitude and interest towards their responses. In order to counterbalance the effects of the interviewers across the different three interventions, an attempt was made for each interviewer to interview the same number of participants in each intervention.



Consistency in the way the interviews were conducted also needed to be established. The research assistant was introduced to the principles of rehabilitation and definitions of memory aids and strategies. Background information on the aims and methodology of the research project was also provided. However, the findings from the previous interview study were not discussed to avoid biasing the assistant or compromising her objectivity. As she had no previous experience in interviewing, she had a training session where she received instruction and practice in basic interview techniques by role-playing with the researcher. The importance of verbal and nonverbal communication skills was also considered. After the research assistant had interviewed two participants the researcher went over the recordings in order to give her some feedback information on her performance. In addition to the training, the author developed some guidelines for both interviewers to follow in order to promote consistency in interviewing:

- Researchers had to be thoroughly familiar with the interview topics before the start.
- Some participants might have had difficulties understanding and remembering complex ideas, therefore there was a need for questions to be kept short, avoiding complex or ambiguous words and limiting each question to only one idea.
- The questions were generally arranged in a sequence that made sense to the respondent. The interview started with more general questions followed by the more specific ones. This was done in order to avoid earlier questions suggesting responses to those that followed. Unless mentioned by the respondents, topics related to mood and feelings were left for later in the session to allow the interviewee to acclimatise and relax.
- In case the interviewer failed to get the information needed, further probing could be used. The interviewers had to take care so that the probes or prompts used were non-directive and did not introduce interviewers' assumptions.
- Interviewers needed to ensure that all respondents were given an equal hearing and allow participants to respond at their own pace. They also needed to be positive and encouraging and listen to participants stories in a non-judgmental way.
- Finally, interviewers needed to pay attention to the non-verbal components of the interaction. In case the interviewee became upset as a result of a question the researcher had to ensure that this was acknowledged and offer the participants the choice not to answer the specific question.

### 5.2.6. Data transcription

Data organization began with the management of the audio recordings which were in the form of digital files. Interviews were stored in the University computers of the researcher and the research coordinator. Each file was coded with the ID each participant was given when enrolling in the RCT. All interviews were transcribed verbatim, where possible, by the researcher. However, any descriptions that did not relate to the purpose of the interview (i.e. text segments related to participants' personal or social life) were not transcribed nor included in the analysis. The transcription conventions suited to the purposes of the analysis. As noted by Braun & Clarke (2006) thematic analysis does not require the same level of detail in the transcript as other analyses (e.g. discourse analyses) and therefore paralinguistic features do not need to be included. In this study except for the verbal content some paralinguistic features were recorded (i.e. pauses, hesitations and laughter) as they could help the reader acquire a better overview of the conversation. The basic transcription conventions employed for this study were the following:

*-Natural pauses in speech represented as an ellipsis (...).*

*-Longer pauses, such as a pause of four seconds represented as follows [4].*

*-Emotions represented using square brackets e.g. [laughs].*

### 5.2.7. Data analyses

#### Thematic analysis

All interviews were analysed by the author. The thematic analysis process described in Chapter 3 was followed. Based on who the interviewer was, the dataset was organised into two groups of interviews. The author assessed whether there were any striking differences between the two datasets in: a) the questions that were asked, b) the identified themes.

Answers to the standardised opening question, asking participants to indicate the most beneficial aspects of the programme, were analysed and presented separately. It was considered important to have a clear picture of the benefits that respondents reported spontaneously and completely unprompted.

Concerns were raised about the fact that the author had also analysed the feedback interviews of the pilot phase of the RCT. The researcher could have developed preconceptions or expectations about the findings, potentially biasing the analysis.

In order to minimise this bias it was decided to involve an independent researcher in the coding process. This is considered to be the qualitative equivalent of "inter-coder reliability" (Barbour, 2001). However, in contrast to quantitative research, what is important is not the degree of agreement between the coders but the opportunity for discussion that may reveal alternative interpretations of the data and potentially lead to the refinement of the coding scheme (Ibid.). An independent researcher (Mr Tom Jeffcoate), who had not been involved in any other aspects of this study, was employed to evaluate how well the thematic network, developed by the author, described each narrative and confirm that no data had been systematically excluded. On the grounds of economy in both cost and effort it has been suggested that the cross-checking of entire datasets should be avoided (Barbour, 2010.) Therefore, a random sample of 50% of the interviews was chosen to be reviewed by the independent researcher. The researcher had no previous experience in conducting thematic analysis. Therefore, instead of proceeding inductively to identify his own thematic network, the researcher was asked to apply the already developed themes to each interview. This deductive approach has been recommended to researchers with little or no experience in identifying themes (Boyatzis, 1998). After being given some information on thematic analysis and the constructs that each theme represented, the independent researcher was instructed to:

- read through the transcripts a few times in order to become familiar with the data,
- for each interview, highlight text segments that conveyed information relevant to the research question (i.e. effects of the memory rehabilitation programme),
- examine whether these pieces of text could be coded into one of the suggested subthemes or themes,
- assess whether the thematic network covered the whole dataset and that important information was not missed due to lack of appropriate themes,
- in case a piece of text that conveyed important information could not be coded into an existing theme, develop new themes that would capture that information,
- spot repetitive and overlapping themes,
- discard themes that were not supported by the data/distorted participants views.
- make a list of the themes identified in each interview,

For each interview, an informal comparison was made between the themes identified by the researcher and the ones identified by the author. Differences were discussed between

the two researchers to assess whether the suggested thematic network needed to be revisited.

### Statistical Analyses

The demographic characteristics of the sample were evaluated using the SPSS statistical package version 16.0.

### 5.3. Results

#### 5.3.1. Participants

Interviews were conducted with 20 participants of the 24 who were allocated to the two compensation, two restitution and two self-help groups. One participant who had fully attended the compensation programme could not continue participation due to poor health (MS relapse). One participant who had dropped off the restitution programme due to health problems agreed to be interviewed. The demographic characteristics of the sample are presented in table 15. Information on the neuropsychological characteristics of participants at recruitment was presented in Chapter 4 (p.138).

Table 15  
*Demographic characteristics of participants*

Demographic characteristics			Group		
			Compensation (n= 7)	Restitution (n=6)	Self-help (n=7)
Gender	Female	n	4	3	2
		%	57.1	50.0	28.6
	Male	n	3	3	5
		%	42.9	50.0	71.4
Diagnosis	TBI	n	4	0	1
		%	57.1	0	14.3
	MS	n	3	5	2
		%	42.9	83.3	28.6
	Stroke	n	0	1	4
		%	0	16.7	57.1
Age	Median	43.0	52.0	58.0	
	IQR*	35.0-55.0	37.0-54.3	41.0-65.0	

\*IQR (Interquartile range) = Q25-Q75

#### 5.3.2. Identified themes

Reviewing the two sets of interviews indicated that both interviewers explored most of the topics specified in the interview schedule and adopted a non-directive and flexible interviewing approach. It was confirmed that the identified thematic network was valid across the entire dataset. It was also found that the themes that the second coder identified in each interview matched those identified by the author. The second coder

confirmed that the thematic network described accurately participants' narratives without excluding important information. There were no suggestions for addition of new themes or exclusion of existing ones. Therefore, no further changes were made to the thematic network.

The analysis of participants' responses to the opening question on the most beneficial components of the intervention identified 11 themes (presented in table 16).

Table 16  
*Most beneficial aspects of the memory rehabilitation programme*

Themes	Compensation (n=7)		Restitution (n=6)		Self-help (n=7)		Total (N=20)	
	n	%	n	%	n	%	n	%
-benefits of the group setting	6	85.7	4	66.7	6	85.7	16	80.0
-using memory strategies effectively	5	71.4	3	50.0	0	0	8	40.0
-learning new memory strategies	3	42.8	4	66.7	0	0	7	35.0
-memory knowledge	3	42.8	3	50.0	0	0	6	30.0
-confidence in ability to cope with memory difficulties (MD)	3	42.8	2	33.3	0	0	5	25.0
-organisational/planning skills	0	0	1	16.7	4	57.1	5	25.0
-insight into severity of MD	2	28.6	2	33.3	0	0	4	20.0
-managing stress	0	0	0	0	4	57.1	4	20.0
-regaining sense of independence	1	14.3	1	16.7	1	14.3	3	15.0
-attention (reducing distractions)	0	0	1	16.7	0	0	1	5.0
-stress related to MD	0	0	1	16.7	0	0	1	5.0

The same main themes were identified in the rest of the dataset (seen in table 17). For the following themes, frequency counts represented the number of different respondents who articulated each theme across the entire dataset: “How much information is enough”, “External feedback”, “Individual or group sessions”, “Benefits of the group setting”, “Optimal group composition”, “Difficulties in evaluating outcome”. The complexity and diversity of opinions that participants expressed in relation to these themes did not allow splitting them into clear-cut positive/negative categories. For the rest of the themes frequency counts represented the number of participants who reported benefits in relation to the area defined by each theme (similarly to the interview study described in Chapter 2). Participants who are not represented by these numbers were people who: a) reported that they did not experience any relevant benefits (although not included in the frequency table these cases were presented and discussed in the relevant theme or subtheme sections); b) did not think the question was relevant/applicable to them; c) they were never actually asked that question (i.e. interviewer’s omission).

Table 17  
Summary of identified themes and subthemes

Themes	Compensation (n=7)		Restitution (n=6)		Self-help (n=7)		Total (N=20)	
	n	%	n	%	n	%	n	%
<b>Memory knowledge</b>	<b>7</b>	<b>100</b>	<b>5</b>	<b>83.3</b>	<b>1</b>	<b>14.3</b>	<b>13</b>	<b>65.0</b>
-groups filling a gap	3	42.8	1	16.7	1	14.3	5	25.0
-understand how memory works	5	71.4	5	83.3	1	14.3	11	55.0
-modify representations	3	42.8	2	33.3	0	0	5	25.0
-how much information is enough?*	3	42.8	3	50.0	1	14.3	7	35.0
<b>Cognitive skills affecting memory</b>	<b>3</b>	<b>42.8</b>	<b>4</b>	<b>66.7</b>	<b>1</b>	<b>14.3</b>	<b>8</b>	<b>40.0</b>
-attention	3	42.8	4	66.7	0	0	7	35.0
-organisational skills	2	28.6	1	16.7	1	14.3	4	20.0
<b>Self-awareness</b>	<b>5</b>	<b>71.4</b>	<b>4</b>	<b>66.7</b>	<b>0</b>	<b>0</b>	<b>9</b>	<b>45.0</b>
-severity of memory problems (MP)	5	71.4	4	66.7			5	25.0
-strengths and weaknesses	3	42.8	3	50.0			6	30.0
-anticipatory awareness	4	57.1	2	33.3			6	30.0
<b>Memory self-efficacy</b>	<b>6</b>	<b>85.7</b>	<b>4</b>	<b>66.7</b>	<b>0</b>	<b>0</b>	<b>10</b>	<b>50.0</b>
-coping with MP	6	85.7	4	66.7			10	50.0
-specific memory skills	4	57.1	2	33.3			6	30.0
<b>Memory aids</b>	<b>6</b>	<b>85.7</b>	<b>5</b>	<b>83.3</b>	<b>0</b>	<b>0</b>	<b>11</b>	<b>55.0</b>
-learning new strategies	4	57.1	4	66.7			8	40.0
-use strategies effectively	6	85.7	5	83.3			11	55.0
<b>Feeling in control-"reclaiming independence"</b>	<b>5</b>	<b>71.4</b>	<b>3</b>	<b>50.0</b>	<b>2</b>	<b>28.6</b>	<b>10</b>	<b>55.0</b>
<b>Active coping</b>	<b>5</b>	<b>71.4</b>	<b>4</b>	<b>66.7</b>	<b>3</b>	<b>42.8</b>	<b>12</b>	<b>60.0</b>
-proactive towards MP	4	57.1	3	50.0	0	0	7	35.0
-proactive towards other problems	2	28.6	1	16.7	3	42.8	6	30.0
<b>Mood</b>	<b>4</b>	<b>57.1</b>	<b>3</b>	<b>50.0</b>	<b>6</b>	<b>85.7</b>	<b>13</b>	<b>65.0</b>
-stress related to MP	4	57.1	3	50.0	2	28.6	9	45.0
-general mood status	1	14.3	1	16.7	6	85.7	8	40.0
<b>Interpersonal relationships</b>	<b>4</b>	<b>57.1</b>	<b>3</b>	<b>50.0</b>	<b>3</b>	<b>42.8</b>	<b>10</b>	<b>50.0</b>
-disclosure	3	42.8	2	33.3	2	28.6	7	35.0
-external feedback*	4	57.1	3	50.0	1	14.3	8	40.0
<b>Group format</b>	<b>7</b>	<b>100</b>	<b>6</b>	<b>100</b>	<b>6</b>	<b>85.7</b>	<b>19</b>	<b>95.0</b>
-individual or group sessions?*	6	85.7	5	83.3	4	57.1	15	75.0
-benefits of the group setting	6	85.7	5	83.3	4	57.1	15	75.0
-optimal group composition*	5	71.4	5	83.3	4	57.1	14	70.0
<b>Difficulties in evaluating outcome*</b>	<b>3</b>	<b>42.8</b>	<b>1</b>	<b>16.7</b>	<b>1</b>	<b>14.3</b>	<b>5</b>	<b>2.0</b>

### 5.3.3. Generic memory knowledge

#### Understanding how memory works

The majority of participants in all the three programmes appeared to particularly value the information that was provided about the neurological mechanisms underlying their memory impairment. Obtaining a greater understanding of the ways their conditions can affect their memory was described as one of the most beneficial aspects of the course by six participants.

*ID 55: It helped me to rationalize some of the things I've been going through (...) understand what had been happening to me. (line 32, self-help)*

*ID 62: That was probably the most important thing that I did on that course. Actually being told how memory works. (line 98, restitution)*

Five participants (4 MS and 1 TBI patient), expressed their disappointment that health professionals had provided them with little or no information regarding the cognitive consequences of brain injury. They reported that, by meeting these information needs, the groups filled a gap in conventional neurological care. One lady with multiple sclerosis commented that health professionals had described the memory problems she experienced as "psychological problems" and "mental health difficulties".

*ID 79: "It is difficult and painful to hear myself described in these terms by those who assess me or are paid to support me" (line 103, compensation)*

Three participants in the intervention groups associated the acquisition of information with a change in the ways they perceived their memory problems. The idea that memory difficulties were an expected and normal consequence of their conditions helped to allay worries and fears and modify distressing and self-undermining interpretations:

*ID 66: I used to think I am stupid! (line, 37, restitution)*

Three participants in the intervention groups mentioned that they had already done some personal research on theoretical aspects of brain damage and memory. However, 10 interviewees reported that they had not been given any relevant information by health professionals.



*ID 49: It was the first time I got scientific explanations of what I'm going through so I thought it was quite fascinating actually. (line 125, compensation)*

*ID 66: I've been studying but never so much in depth, and it helped (...) you say "oh that's because of that!" (...). But before I had nothing. (line 56, restitution)*

### How much information is enough?

Although there was a general consensus among participants on the benefits of theoretical information, different views were expressed on the amount of information that should, ideally, be provided in the rehabilitation programme. Not all participants wanted detailed information about the neuropsychological consequences of their conditions. One participant with traumatic brain injury described how she was reminded of her physical and cognitive losses at a time that she wanted to move on in her life:

*ID 54: I didn't keep reading the information (...). I think in a way I put the accident behind me so I don't want to keep thinking. (line 93, compensation)*

That view was shared by another participant who commented that:

*ID 71: "Knowing how memory works is interesting and I think it's good to know but we spent quite a long time on memory processes and how it all works". (line 223, restitution)*

He added that he would have instead preferred to receive information and reassurance on the progress of his disorder something that was, however, out of the scope of programme:

*"I'd like to know if that will carry on going" (line, 162)*

On the contrary, three other participants reported that increasing their understanding of memory deficits was an important step towards more successful coping and, therefore, they would have liked going into more detail:

*ID 48: other members of the group might have needed not quite the detail of that while myself, I wanted a bit more information. (line 39, compensation)*

### 5.3.4. Self-awareness

#### Understanding the severity of memory difficulties

This theme was identified in the interviews of nine participants from the two intervention groups. It refers to responses in which interviewees indicated the contribution of the programme to a more realistic appraisal of their memory problems. Respondents identified different factors that helped them realize the true extent of their difficulties. These were the feedback provided by group leaders following the initial neuropsychological assessment, participants' performance in group memory exercises as well as self-reflection and self-observation triggered by comparing themselves with other group members. Although respondents already knew that their memory was impaired, they used to either underestimate or overestimate that impairment.

*ID 48: Well coming to the groups made me more aware of the level of my memory whereas I used to think I have a good memory. (line 48, compensation)*

*ID 66 I used to think they are quite bad (...) you know, cause I don't talk to anyone but now I don't feel I'm that bad as I thought I was. (line 38, restitution)*

*ID 79: It made me to take a step back and look at myself objectively. Since doing the course it's easy to be objective about myself, which I think it's been really useful. (line 88, compensation)*

One participant reported that understanding the severity of his difficulties was a distressing process in which he was reluctant to engage. He was worried that what he could discover about the level of his cognitive abilities would cause him even more anxiety about his future.

*ID 51: See I do worry where my memory is going to end up [...] these aging diseases like dementia Alzheimer they do worry me (...) while I am well I am holding on to not knowing (...) the day I know I get worried (...) I don't want to realize that. (line 72, restitution)*

#### Understanding strengths and limitations

The information on memory functioning introduced participants to the idea that memory is not a unitary function but involves different processes and memory systems. Participants reported realizing for the first time that memory impairment is not necessarily generalized but can be limited to specific components. Six participants in the two

intervention programmes talked about how they managed to identify their difficulties and become more conscious of their strengths.

*ID 62: Before that, I thought that memory was in one place (...). But as we got explained early on in the course it is not necessarily in one place (...) therefore I learned early on in the course that what I have to do is put the memory on another part of the memory process (line 66, restitution)*

*ID79: You know attention, encoding, storage (...) it hadn't really occurred me that, like you said, you could have been doing three really well but if one brakes down you lost the whole (...) I found that very useful because it makes you look at each other and assess which one you were doing better than other and which one you were doing badly and you need to try improve on [...] and so one of the things for me was that I wasn't making that effort to concentrate. So I thought that was very useful (compensation, 131-139)*

### Anticipatory awareness

Six participants from the intervention groups talked about how they learned to recognize in advance when and in what circumstances their memory failures were likely to occur. Participants had the opportunity to discuss different situations that placed great demands on their memory capacity and explore whether memory failures could be anticipated and prevented. Acknowledging the mismatch between the skills they possessed and the environmental demands, helped participants develop more realistic expectations about their memory performance. The following comments were indicative of that process:

*ID 48: It did make me aware that if I was told something by someone in the morning I would more likely have forgotten that by the afternoon whereas now if I'm told something important I will make a note of it and keep it with me in case I need it (...) and so by doing that it has made me aware that there are certain situations where I will be told information and if I don't somehow make a note of it to help me remember I'm going to forget it. (line 50, compensation)*

*ID 79: It was very useful identifying the bits I've struggled with because then it made me more aware if I'm catching that type of scenario in real life then I needed to make more effort because I wouldn't function properly (...) I think it was my verbal memory that was peculiar so when it comes to remembering somebody's name I have to make much more effort and repeat the name a number of times or try to do something with it whereas before I wouldn't have. (line 146, compensation)*

It is interesting to note that the participant who had previously expressed his unwillingness to explore the extent of his difficulties, claimed that anticipatory awareness is not really feasible.

*ID 51: It was all about programming your memory. You don't know what you are not gone know. (line 5, restitution)*

### **5.3.5. Memory aids**

#### Learning new memory aids

Being introduced to memory aids was one of the most salient themes in the responses of intervention groups' participants. It was particularly valued by the restitution groups' participants as, for four of them, learning new strategies was one of the most beneficial aspects of the groups.

*ID 71: It has been quite interesting (...) Like I said it has given me some tools that I didn't have because I used my Filofax, that's it (...) you know I thought there isn't anything else, but there are so it's quite good to know. The story telling has been really really good! I've never thought of doing that way before and I find that I do that one quite a lot now (...) cause shopping is so boring and it makes it fun! (line 276, compensation)*

*ID 48: I use the diary and the post it to make notes (...) I started using during the group and I'm still using them. (line 65, compensation)*

Five participants focused on the opportunity that the groups offered for exploration and practice of a range of different memory aids. Participants tried new strategies or reevaluated the ones they were already using and considered other alternatives that were more suitable for them. Being given different options allowed them to choose the strategies that were more appropriate in response to their abilities or environmental demands.

*ID 48: It was a general overview so I was able to pick up the bits and pieces that were more beneficial to myself. (line 24, compensation)*

*ID 71: It made me realize that in different situations there are other things I can do, because sometimes your Filofax isn't suitable for everything. (line 167, compensation)*

For two of them it was a relief to realize that not all the strategies work for everyone and having difficulties with some of them was normal.

*ID 66: Some of the techniques helped some didn't, and it was nice to know that the ones that didn't work for me didn't necessarily work for any of us either. (line 7, restitution)*

### Using strategies effectively

For the majority of the restitution group members, the use of internal memory aids was unknown before the rehabilitation programme. In contrast, five members of the compensation groups reported that they were already familiar with many of the external memory aids taught in the groups. What was highlighted however by the respondents was an improvement in the way these strategies were used. Participants appeared to feel more conscious and systematic in their efforts to compensate. The following excerpts illustrate well the content of this theme:

*ID 49: I probably used these techniques before the course, so it enhanced what I already did actually (...) I'm more aware now of what to use. (line 41, compensation)*

*ID 66: I've always used my diary and calendar but I used to forget to put things in them and I used to think I had nothing to do. Now I remember because of the stories (...). If I got the diary with me then I do use it but if I don't, I'd make up a little story and as soon as I get back I'd remember to put it in (...). So I remember! (line 83, restitution)*

*ID 71: It has given me tools to use which I haven't thought of or if I have been doing I hadn't really realized I was doing it until I actually focused on what I'm doing (...) like chunking. Because I'm more conscious that I can do it, I actually use that a lot more now than I did before (...). So I used to do a little bit about it but now I've developed it and use it a lot more now as well. (compensation,164)*

### **5.3.6. Memory self-efficacy**

#### Confidence in memory ability

Only two respondents claimed that their actual ability to recall information improved following the rehabilitation programme. Interestingly, their confidence was grounded on the systematic use of internal memory aids to organize the information they needed to memorise. After the end of the programme they continued practicing the strategies in their everyday life until their application became a routine. As they became more skillful in

the strategies they also felt increasingly confident in their own memory capacity. One participant said he was so confident in his memory that he felt he did not need to use his Dictaphone anymore. His tactic was to use the strong aspects of his memory and relocate information to different memory systems:

*ID 62: I used to carry a little Dictaphone, a little tape recorder and I used to use it quite a lot...I use it less and less these days.*

*IR: How come?*

*ID 62: If I have to remember something then I commit it to memory which before I couldn't. So I had observed, before I came here, that if I spoke something into the Dictaphone I would probably remember ...And I didn't know it was because I relocated my memory...I was speaking it out loud [...]. So now instead of using the Dictaphone I would just say it out loud...and I would remember. (lines 112-121. restitution)*

The participant added that despite being more confident in his memory he did not hold unrealistic expectations about his memory performance:

*ID 62: It either was my wife or one of my daughters that mentioned the other day that my memory is improving, but she then added "it's still not perfect". I said "no, I wouldn't expect it to be perfect". (lines 36-42, restitution)*

The other participant, a lady with traumatic brain injury, based her confidence not only on the use of internal memory aids but also on the natural recovery that she had noticed after her accident.

*ID 79: I think it probably is because I am getting better...but may also be doing the other things that we've done. I'm using my brain better, which is making, you know, stimulating pathways. (line 59, compensation)*

### Confidence in ability to cope with memory problems

Ten respondents out of the thirteen participating in the two intervention groups indicated that the programme helped them to develop a sense of confidence in their capability to deal with memory difficulties. Participants differentiated the actual memory ability, where no improvements were observed, from the belief that there were ways to prevent forgetting using the strategies they were taught.

*ID 75: I would think my memory itself hasn't improved (...). My memory itself is still the same, but I think my ability to cope with it has improved (...) my mother is always a good judge and she noticed a vast difference (line 20, compensation)*

*ID 66: I'm no different, I remember things better because I do the exercises and I check things and I make sure I take a note of this and I got an idea what to do to help myself (restitution, 40)*

*ID 76: I feel more confident that I will manage, cause if I've got a problem I know I've got ways I can look back at what we did in the group sessions "let me try this as a memory aid, or let me try that as a memory aid" (compensation, 107)*

That sense of confidence and self-efficacy observed in the narratives of the intervention groups' participants was not shared by the members of the self-help groups. One participant expressed his feelings of powerlessness towards his cognitive problems with the following comment:

*ID 68: I just rely on the chemicals of my body. (line 35, self-help)*

### Confidence in performing specific memory tasks

Participants were also asked whether they had noticed any changes in performing specific memory tasks as a result of the groups. If needed, participants were reminded of the specific memory failures they reported during the initial assessment as documented in the examiner's notes, when available. Five participants from the intervention groups reported improvements in relation to prospective memory tasks:

*IR: In terms of the specific memory problems you experienced, like remembering to take your medication or doing household activities, have you noticed any changes?*

*ID 48: They have improved! By using the alarm and the diary etc. (line 84, compensation)*

*ID 71: Usually my worse thing was (...) I've got to go into town to do things and then I'm getting to town I go "hm, what was it I'm doing?" and that would happen a lot! I would go and I'd forget to do something (...) like shopping. That doesn't happen so much now, I think because I'm more conscious about it and I take the time to come up with the story or do something (...) you know, so that doesn't happen very often now. (line 42, compensation)*

*ID 75: Appointments have improved because I use the alarm on my phone, and I try and write more things in my diary than I ever did before. (line 79, compensation)*

An improvement was also reported in remembering where things were placed in the house:

*ID 49: I had a lot of problems losing my keys, my wallet, my inhaler pretty much on a daily basis and we had some conversation in the group and came up with ideas (...) so when coming to the house just keep a checklist like keys, wallet, inhaler (...) and I did that and I put on the alarm so that when I set the alarm off when I come into the house to be reminded to put the keys and inhaler away (...) and I didn't lose them again! (lines 151-161, compensation)*

*ID 75: I still forget where I put everything, I still lose things at home but I am not forgetting that much. (line 98, compensation)*

On the contrary another common complaint, remembering names, was still an issue for four participants.

*ID 48: Things like names, no! That has definitely not improved. (line 87, compensation)*

*ID 79: I'm still not brilliant with names which I should practice, but I was never good with names before, unless I made a real effort to remember people's names I wasn't going to. (line 57, compensation)*

### **5.3.7. Feeling in control –“reclaiming independence”**

For some participants the ability to cope with their memory problems appeared to have contributed to them regaining a sense of control in their lives. Eight participants in the intervention groups mentioned that rehabilitation helped them to overcome helplessness and assume responsibility in remembering to do things.

*ID 66: I feel more in control again! Whereas before didn't feel 100% in control of what I was doing. Now I feel a lot more in control of what I'm doing so I don't need to depend on anyone. It's just nice! (line 106, compensation)*

One participant described rehabilitation as an “empowering” experience that helped her stand on her own feet and reported that the gains generalized to other aspects of her everyday life:

*ID 75: I think I've taken over quite a lot of control that I didn't have. I think specifically it has to do with memory giving me greater confidence. I've been able to reclaim my independence. And I honestly believe that it is because of the confidence the memory*



*groups have helped me to achieve I've been able to reclaim my life. Take charge of myself. (line 126, compensation)*

As it can be seen in these statements obtaining control was associated with developing self-reliance and achieving independence. Instead of expecting other people to remind them participants became more proactive and attempted to deal with their difficulties themselves before asking for help. The following statement is telling:

*ID54: I think I try and do it myself rather than straight away shout to my husband to look (...). Yes I think I'm trying to do things myself rather than keep asking. If my husband is driving I used to just totally rely on him, where he parked and just follow him. But now I just make a point of knowing where the car is parked (...) I feel being more independent than relying on him. (line 55, compensation)*

*ID 48: I've found that I'm more independent. My wife used to help me quite a lot in the memory without me actually realizing she was being used as much as she was (...) but now it's less work for her! (line 79, compensation)*

Some participants reported that they felt so confident in their own ability to manage with memory tasks that they had taken over the role of the "reminder" in the family:

*ID 71: Sometimes when you depend on people (...) I mean my family never let me down but sometimes they do and then I end up blaming them and you think there isn't their fault because it's up to me to remember really (...) but now it doesn't happen. I'm actually reminding them to do sth! (line 106, compensation)*

### **5.3.8. Interpersonal relationships**

#### External feedback

Participants in all the three programmes referred to the varying degrees of support and encouragement they received from their family and social environment. Some respondents expressed their disappointment about the lack of empathy they experienced in their social, professional and family lives. Receiving reassurance from family members and friends was particularly valued by three participants. Their positive feedback appeared to validate and reinforce participants' self-efficacy beliefs concerning the rehabilitation outcome.

*ID 75: My mother is always a good judge, we talk everyday on the telephone and she would sometimes say little things to jog my memory and I would remember them [...] and she noticed a vast difference. (lines 13-17, compensation)*

*ID 66: My family noticed a difference cause I remember things (...) Before I used to ring my dad a lot, or my husband at work. And now I amazed them because my dad rang and I said "no, I've got it" and he was surprised! (line 99, restitution)*

Two participants also shared with the interviewer their frustration and distress in response to negative remarks by other people.

*ID 66: People laugh when you don't remember things...they are not nasty but...when I made them a cup of tea and two minutes later I made them another one because I forgot they laughed...and it's quite upsetting you know. (line 15, restitution)*

*ID 51: People can be quite cruel! (line 241, restitution)*

Conversely, the improvement in participants' ability to cope with their memory problems had a positive effect on their social and family life. Changes were reported in four interviews.

*ID 62: The most of the trouble would have been at home and as I've already mentioned I'm not getting in trouble as often as I used to! (line 200, restitution)*

*ID 75: I was with a couple of good friends and they wanted me to pass a message (...).The strategies I've got from the group have helped me to do it. So socially I'm not so much of an oddity as I used to be. (line 119, compensation)*

One participant described how passing on to her family the information that she got in the groups made them more understanding towards what she was going through.

*ID 58: I got sound information from you (...). My daughter used to ask me about it and that was good for me. I think she's a bit more tolerant (...) because I have explained to her the difficulties that I was having. (line 20, restitution)*

### **5.3.9. Disclosure**

A strong theme, appearing in seven interviews, focused on changes in participants' attitude towards disclosing their memory problems. These respondents described becoming more comfortable with sharing their difficulties as a result of rehabilitation. The main element of the interventions that participants identified as facilitating this change

was the process of becoming aware and consequently accepting their problems. Participants said that they felt less embarrassed by memory failures and found it easier to admit the problem and ask for help if needed.

*ID 58: I think rehabilitation has given me an ability to feel that I can explain to people my difficulties and ask for information to be highlighted for me. (line 45, restitution)*

*ID 79: But I don't worry about asking people now, whereas before I would have been embarrassed by the fact that I've forgotten. It's just I am what I am. (line 77, compensation)*

*ID75: I' m less embarrassed by it. If I forget somebody's name I don't have to feel embarrassed, I just say "I'm sorry, I've got MS, that's how it is". I try not to use MS as an excuse, I try not to apologize for it, but that's how it is. I' m not gone be mastermind (line 95, compensation)*

Participants seemed to realize that it would be less likely for other people to show understanding and acceptance towards issues that participants themselves hadn't come to terms with.

*ID 87: People can be sympathetic when they know what your problem is. (line 156, self-help)*

One lady described how being too strict on herself made her insecure over others' reactions worrying that they were constantly "picking on her" (*ID 52, restitution*). On the other hand two participants expressed their reluctance to disclose their problems:

*ID51 :Because I don't want to be ill I don't want to admit I've got problems with my memory (...). I can have this conversation with you because it's quite open there's no pressure but in front of other people I don't want to be so open (...) I don't really tell people. (line 111, restitution)*

*ID 80: I got sick of people telling me "I'm so sorry"! (line 87, self-help)*

### **5.3.10. Active coping**

Seven participants in the intervention groups reported that rehabilitation prompted them to take a more proactive stance in dealing with their memory problems. For them the process of learning did not stop at the end of the groups. They went on to perform their personal research on memory issues, experiment with different memory aids and develop their own strategies.

*ID 54: I thought of my own sorts of strategies to try to remember things (...) and I think they work pretty well. (line 76, compensation)*

This positive attitude was not restricted to memory but applied to other cognitive functions:

*ID 62: I found something else to improve my concentration, I am identifying Galaxies for a bunch of people called "Galaxy zoo", Galaxies' identifiers! (line 75, restitution)*

The ideas of neuroplasticity and mental exercise were particularly valued by participants. They tried to apply them in their everyday life by consciously engaging in cognitively challenging situations.

*ID 51: I'm aware now that exercising the brain is good (...) I just look for challenging situations. (line 207, restitution)*

*ID 79: I started doing one of these brain training games (...). I got a memory one, and I got a vocabulary one...and I think I am improving with practice. (line 198, compensation)*

*ID 76: I particularly enjoyed the brain stimulation. It's something different, you need stimulating your brain cause sometimes you don't do anything or you are doing the same job day in and day out, it gets boring so you get your brain dead! (line 61, compensation)*

### **5.3.11. Cognitive skills affecting memory performance**

As participants acquired a deeper understanding of how memory works, they appreciated the contribution of other skills in memory performance. Three participants talked about how the groups helped them recognize the importance of planning and organizing their everyday life in order to reduce memory load and facilitate recall. Seven participants reported that the group sessions helped them make the connection between attention and memory functions. As a result, they intensified their efforts to actively pay attention to the information they wanted to remember.

*ID 67: I found out that you actually have to pay attention to something if you don't pay attention there is no way it's going to the long memory so I actually start the process and get the information in. (line 54, restitution)*

*ID 79: I used to think that memory is just remembering something; it's not actually. I found that one of the problems for me was that I wasn't making that effort to concentrate (...).*

*It's not that I couldn't concentrate before but I didn't, whereas now I sort of make more effort to concentrate. So I thought that was very useful. (line 136, compensation)*

*ID 80: I think it is because I wasn't really conscious, I wasn't paying attention that I was losing things around the house. (line 37, self-help)*

Two participants also reported improvements in finding their way around or remembering where they parked their car which they attributed to paying more attention to the surroundings.

*ID 49: I make much more notice as where I've parked whereas before I parked the car, made shopping came out and sometimes I wouldn't find the car. (line 9, compensation)*

*ID 54: Oh, it's a big car boot and there are dozens of cars and I thought "Oh my God, how am I going to remember this?" and I thought : "I've been on the course"(...) so I got out of the car, stood, look around, placed a tree, so I'm down this road! (line 42, compensation)*

### **5.3.12. Mood**

For six participants, rehabilitation seemed to have contributed in controlling stress caused by memory difficulties. Respondents talked about how forgetting used to be a source of great stress and frustration before the group sessions. Members of the intervention groups attributed the improvement to their ability to cope effectively with their difficulties. Self-help groups' participants, on the other hand, associated the reduction in stress levels with the use of a number of relaxation techniques. Another helpful element was the recognition of the reciprocal relationship between memory function and anxiety. As a result, participants reported making a conscious effort to avoid putting too much pressure on them when trying to recall information and take an opportunity to relax.

*ID 75: If I forget I just take my time and eventually it comes back to me (...) so I stop panicking I know it still lets me down but I'm now more able to accept that if I stop panicking words will come back to me, names will come back to me, events will come back to me. (line 91, compensation)*

*ID 80: I used to lose things constantly and panic. Now I take a deep breath and just start thinking instead of going around the room like a headless chicken! (line 63, self-help)*

*ID 66: Before, I used to have panic attacks (...) "I can't do this" and I'd end up not doing anything. But I don't know. (line 64, restitution)*

For the members of the self-help groups relaxation techniques found application in many different stressful situations in their everyday life. Learning and practicing these strategies was identified as one of the main benefits of the self-help programme.

*ID 53: I was losing my temper, particularly on the road (...) and that was resolved to a great extent (...). It doesn't always work but it usually does. (line 14, self-help)*

*ID 55: Some of the relaxation techniques were quite good. I just wish I could get myself organized and carry on with them because I feel they are beneficial. (line 7, self-help)*

Interestingly, most participants focused on the effects of the groups on their anxiety levels whereas only four participants talked about feelings of depression. Three participants reported feeling more positive following rehabilitation. The interaction with other people in the group was identified as a contributing factor to that improvement. The change was also related to the sense of self-efficacy and control over their lives that rehabilitation helped them to develop.

*ID66: I don't get so down anymore (...). I used to get really depressed," I can't do this". I mean I still get a bit down but everyone does don't they? But I can do things better now and I'm more daring! (line 62, restitution)*

*ID 75: I no longer feel depressed. I have some good friends now (...) I don't feel controlled anymore (...). And you can say that it's through that group, not just through memory but through mixing with other people as well that helped to just get on with my life. (line 144, compensation)*

Three participants reported that when they enrolled in the programme mood disturbances were not an issue for them. Having adopted a stoical stance about life, or having already received support in the form of psychotherapy or pharmacotherapy were some of the issues discussed by participants.

*ID 48: I suppose it did help slightly on that but I wouldn't say I was in any way depressed because of that and I slap myself every time I forget something! [laughs]. But I suppose it helped in some ways but I wouldn't say it made a vast difference. (line 139, compensation)*

*ID 71: I was never that frustrated on a long term thing, it was more an initial (...). I try not to dwell, you know I've got this disease for a long time I can't dwell. Life is too short. You know, because I have that kind of attitude that has been pretty helpful anyway. (line 160, compensation)*

Their efforts to control stress levels was also supported by the improvements in planning and goal setting. For three respondents, learning to set small and achievable goals was a big step towards successful stress management. Attaining a balance between their abilities and environmental demands was recognised as an important element of change leading participants to negotiate and set limits to other peoples' expectations on them.

*ID 51: I always used to say yes to things and since coming to the sessions it has made me look at things slightly differently (...) the sessions did actually teach me to say stop, step back a little bit and not putting too much expectation on myself, little steps, little bits at a time. (line 203, restitution)*

### **5.3.13. Group setting**

Three subthemes were identified, which centred around narratives on the influences of the group setting, its benefits and downsides.

#### Individual or group sessions?

The majority of participants across the three programmes reported that they enjoyed the groups meetings and they preferred them over individual sessions (all participants had an individual introductory session and were also offered individual sessions in case they missed a group meeting; see Chapter 3 p.70). The following excerpt is illustrative:

*ID 66. I've actually found that being in the group was more relaxing than being on my own because there was input from everyone (...). And sometimes in the groups when you've forgotten something then someone says something that triggers it off and say "oh I wanted to say that" or "oh God, I do that too!". (line 133, compensation)*

A few downsides of the group were also identified. The unpredictability of attendance was highlighted by two respondents as a potential problem. A lady with traumatic brain injury commented on some other limitations of the group setting:

*ID 71: Sometimes especially when you are in a group, you are quite loud to get involved (...) or something that might be an issue that you don't want to talk about or you haven't quite got your head around it or you forget. (line 265, compensation)*

Four participants commented that they valued the inclusion of individual sessions but they would rather have them later in the programme, to allow some familiarity to develop between them and the group leader.

*ID 71: Having the group is good as well because sometimes when you are on your own you feel under the spotlight (...) so I think once you've found your fit in the group then have the one to ones (...) rather than having one to one right at the beginning, it's quite intimidating and quite daunting. Because you don't know exactly what's going on (...) cause we are all nervous at the beginning. (line 269, compensation)*

### Benefits of the group setting

The advantages of the group setting were mentioned as one of the most beneficial aspects of the programme by the majority of respondents from all the three programmes. Some participants talked about the loneliness that they experienced prior to the groups thinking that no one else can really understand how they feel. They, therefore, expressed their relief at discovering that they were not alone and that other people face broadly similar difficulties.

*ID 52: I think group sessions make you more awake towards what's happening to other people, it's not just you. It was very interesting to realize that other people have the same problems that I've got. (line 41, restitution)*

*ID 49: For me it was quite nice to meet people with similar disabilities as yourself cause before I thought I was on my own (...). I had memory issues, I thought it was just me. So being in sessions with other people having some similar issues was quite good. (line 39, compensation)*

Furthermore, the groups allowed participants to learn new strategies and get ideas from watching each other tackling memory difficulties. Although their discussions did not focus on memory issues, four participants in the self-help groups reported exchanging information on other health issues. This information was about what group members had learned through their own experiences or through contact with professionals or specialists in a relevant area.



*ID 58: I've always been writing things down but the problem was I couldn't read my writing. And then somebody (in the group) said "I find that if you write messages imprinted it's easier to read" and I said "oh, that's a really good idea!!" (...) so that's what I do now, it's good! (line 41, restitution)*

*ID60. I discovered that I had missed out a lot about how I was treated or not treated after my stroke compared to other participants. People that I met within the group they said "oh, something went wrong", I should have seen this person or that person and I suddenly discovered that I never had that bit of treatment or rehabilitation and then someone picked it up on me. (line 25, self-help)*

The similarity of experiences facilitated the bonding between the group members. The majority of participants viewed the group as a supportive environment where they could share their distresses and fears. The company of other people made rehabilitation an enjoyable experience and afforded members the opportunity for social interaction. In some cases friendships were developed which participants expressed the desire to maintain outside the group meetings.

*D 58: The group was good (...) I liked the craick! That's my Irish thing! Good craick is when you have good conversation! (line 53, restitution)*

*ID 80: Talking, offloading helped me with stress. (line 61, self-help)*

The group developed to a social microcosm where participants could perceive themselves functioning in relation to other group members. Three participants mentioned that the group interaction helped them realise that despite their cognitive problems they could still fulfil their social roles, have interesting conversations, be liked and accepted by other people. Through this process they consequently became more accepting towards themselves and their losses.

*ID 71: I found it very frustrating that I can't remember and then being with other people who also can't remember you think "Oh, you know, in the grand scheme of thing, I can still function as a person without some of my memories". So it made me less, not so hard on myself, cause it's very hard to let something go. (line 122, compensation)*

### The optimal group composition- diversity Vs. homogeneity

This theme included responses in which participants expressed their opinions on the synthesis of the group they belonged. Being in a group of a mixture of people with different conditions was commented positively in the narratives of seven participants. One

of the advantages identified by five participants was the opportunity to look at the same problem from different perspectives as shown in the following abstract:

*ID 48: The group itself was a good mix of people (...) it was good to have people that didn't have MS but had other problems so that you could see both sides. If people had the same condition we would all be working along the same path (...) but different conditions use different situation solutions. (line 7, compensation)*

Three participants commented that the heterogeneity of impairments shifted the centre of participants' attention from the cause of the problem to the process of coping with the problem.

*ID 71: Having people with different reasons as to why they have that, made you realize that you know (...) cause I blame the MS a lot and I've focused on that a lot. I used to get quite frustrated about my memory loss "Why did my MS have to do this to me?" But now when I see other people who have similar problems I just think "Oh you know, your brain is a big thing and anything could affect it" so just find ways to deal with it rather than focusing on what I've lost. (line 142, compensation)*

For four participants gaining insight into other peoples' problems put an end to a vicious circle of self-absorption and rumination over personal losses.

*ID 75: I think being in the group has enabled me to have greater respect for other peoples' needs not just my own (...). Because they had different needs, I was able to respect their needs rather than just see my own (...). It enabled me to experience firsthand that people with brain injury have as many problems as I do. (line 80, compensation)*

However, participants differentiated between including people with "different problems" and individuals with "different abilities" in the same group. When discussing heterogeneity in terms of the severity of peoples' impairments or memory difficulties, opinions were split. Two participants identified the presence of people with worse memory problems as a factor potentially inhibiting the flow of the sessions.

*ID71: I think it was helpful that we were all at a similar stage because we didn't have to go through the stuff that we were already doing and slow down for the one person. Although we all had different problems, one wasn't so much worse than somebody else (...).The fact that we all had different problems was really really interesting, it really helped me, but I think if I had been with somebody that was quite severe , I think I would have found that quite irritating after a while. (line 250, compensation)*

Drawing comparisons between own and other members' abilities is usually unavoidable when being in a group. Although it can lead to valuable insights into ones' problems it can also be particularly distressing for some individuals. The perspectives presented in the interviews varied depending on the severity of own problems compared to the rest of the group members. A lady in her fifties identified the fact that she was placed in a group of people much younger and with better memory function as the only drawback of the programme.

*ID 58: I did feel a bit like the old lady of the group (...) they all seemed much younger than me and did so much better at the memory tests. I was like 20 years older than them! They were in their 30s (...) but it wasn't a huge thing I' m the kind of person that laughs at these things! (line 58, restitution)*

Another participant said that before joining the programme she was discouraged by the prospect of meeting people in a more advanced stage of multiple sclerosis. Meeting these people would force her to face her worries and fears about the future and the course of her condition.

*ID 80: I was a bit reluctant to meet other multiple sclerosis patients because I would see how I' m gone be in the future. (line 148, self-help)*

On the other hand a few participants reported benefiting from this comparison. A participant with traumatic brain injury and only mild cognitive impairment expressed her relief:

*ID 79: I felt quite fortunate cause I felt I was probably better of most of them (...) that was nice for me in the sense that (...) you know (...) I suppose it puts your own situation into context if you find that people are struggling more than you are and I felt quite sorry for some of them. (line 3, compensation)*

### **5.3.14. Difficulties in assessing outcome**

Three participants with traumatic brain injury reported difficulties in assessing the extent of rehabilitation's contribution in their life. All of them were within the two year post-injury time frame and therefore experiencing many changes in different aspects of their lives.

*ID 49: I can't be definite because there have been a lot of factors in my life the last six months things that have helped, things may not have helped. During these 6 months I have*

*progressed somewhat but then head injury tends to improve for a sort of 2 years so whether my improvement was due because of rehabilitation or external factors I am not sure (...).I don't know the proportion of these factors. (line 136, compensation)*

Participants who were in a very early phase of their recovery and hadn't yet been back to their old routines had probably less chances to deal with challenging memory situations. One participant felt that it is only when he returned to work that he would be able to apply the memory strategies he learned in the groups and evaluate their effectiveness.

*ID 76: I still haven't tried a lot of these strategies (...) and I haven't been in situations where (...) cause when you are at home on your own and you just do what you normally do at home (...) I' won't get to use a lot of these until I'm back at work, because then I'll be out on my own, a lot of decisions I'll have to make on my own, my own judgments and staff like that, so probably a lot of things will come into play then. (line 47, compensation)*

A degree of uncertainty about appraising the outcome of the rehabilitation programme was also evident in the interviews of two participants with multiple sclerosis. For them, this hesitancy was related to the progressive nature of their condition and the on-going need for readjustment.

*ID80: It's difficult to tell (...) since I started the groups I've been having another relapse (...) so the improvement is sort of masked. (line35, self-help)*

Despite the difficulty in isolating the effect of the groups all participants felt that they had benefited from the group sessions.

*ID 79: I' m very glad I came cause I feel I've benefited a lot from it. I might have got better having not come but I think there is a lot of things I learned that helped me a lot anyway (...) I'm using my brain better, which is making, you know, stimulating pathways. (line 234, compensation)*

### 5.4. Discussion

#### 5.4.1. Identified themes

The majority of respondents spoke very positively of their experience in the rehabilitation programme and commented on a number of perceived benefits. The themes that were identified were consistent with those that emerged in the first interview study. Although the core topics were the same in both studies the use of semi-structured interviews in the present study elicited unambiguous answers and richer descriptions that produced explicitly delineated and well founded themes.

#### Memory knowledge/Self-awareness

Similar to the first study, being informed about memory processes, learning and practicing memory aids as well as meeting people with similar problems were considered to be some of the most beneficial aspects of rehabilitation. Participants also reported overcoming the passive attitude and the feelings of discouragement related to their memory capacity and becoming more determined for action. Obtaining insight into the nature and severity of their memory problems formed one of the most prevalent themes. In this study, the positive effects of rehabilitation on anticipatory awareness emerged as a separate subtheme further stressing its importance for participants.

Contrary to other members of the group he belonged to, one participant argued that it is impossible to recognise in advance the situations where the problems are likely to occur. The same participant also appeared reluctant to receive more information on cognitive impairment and expressed his doubts on the value of compensatory strategies. Two other respondents commented that they consciously avoided learning more about brain injury and found it difficult to come to terms with their memory problems. Interestingly, one of these participants dropped the groups after a few sessions whereas the other one attended only sporadically. They both suffered from multiple sclerosis and severe memory problems. Any attempts to trace a link between participants' baseline characteristics and their levels of self-awareness would be out of the scope of this study. However, these observations stress the importance of taking into consideration individual characteristics, such as cognitive and emotional status, when addressing awareness deficits in rehabilitation. Limited self-awareness may have an organic basis but it may also serve a psychological function by reducing anxiety about impairment (Ownsworth & Clare, 2006). As a defence mechanism, denial protects the patient's fragile self-esteem and minimises

overwhelming feelings of helplessness (Martelli et al., 2000). In that case, information and feedback might be counterproductive and even increase denial and emotional distress (Langer & Padrone, 1992; Fleming, 2005). According to Martelli et al., (2000) factors such as participants' self-esteem, abstract or higher level reasoning and general coping style should be assessed before attempting to increase their awareness. Taking into account this evidence in the implementation of rehabilitation programmes might enhance participants' adherence. Stainsby (2006) suggested that every patient should be asked individually about the level and quantity of information they want at each stage.

### Control beliefs

In line with the findings of the first interview study, perceptions of self-efficacy and control in relation to memory problems were found to be salient themes. In this study, interviews also provided some information on the components of the rehabilitation programme that, according to participants, contributed to the development or enhancement of these control beliefs. Learning and becoming increasingly skilful in memory strategies as well as setting and achieving realistic goals in line with their abilities were two factors identified by participants as important in boosting their confidence. As stressed by West et al., (2003), knowledge of strategies to improve performance is a prerequisite without which motivation and confidence would not make any difference on performance. They suggested that successful performance, as long as it is attributed to internal factors (e.g. personal effort) and not external variables (e.g. luck) will further reinforce control beliefs which in turn will affect performance through a number of mechanisms (described in Chapter 3). Rebok & Balcerak (1989) on the other hand, found that improving memory performance through the use of strategies was not sufficient to raise memory self-efficacy in a group of older adults.

Another factor that may have positively affected self-efficacy beliefs was the reassurance and feedback that participants, reportedly, received from other group members. Previous studies have recognised the role of feedback in improving motivation and self-efficacy (e.g. West et al, 2003). Tam & Man (2004) compared four different forms of computer assisted memory retraining programmes. The researchers observed that only the feedback group (which, according to the authors, provided immediate feedback on performance in a clear, consistent and non-judgmental way) showed significant improvements in perceived self-efficacy. According to Berry & West (1989), social observation and persuasion may also influence self-efficacy. However, the perceived

improvements in memory self-efficacy could not have solely resulted from the dynamics of the group setting as participants in the self-help group did not report relevant changes.

### Role of significant others

In their narratives participants often commented on the attitudes that family, friends or colleagues had towards their health problems and memory. It was suggested that friends, colleagues and family might influence rehabilitation outcomes by either reinforcing or impeding participants' efforts to cope with memory impairment. Respondents expressed their need for some form of external reassurance that would validate their efforts and help them recognize their own improvement. Family members, in particular, were presented as an important source of encouragement by offering patients emotional and practical support when encountering difficulties and enhancing their motivation. This is in line with the findings of a qualitative study by Dixon et al., (2007) where neurologically disabled people talked about how support from their family environment affected their self-efficacy beliefs and their ability to actively engage in rehabilitation. The contribution of the family and close environment to the memory rehabilitation process was also found to be a prevalent topic of discussion in the observational study (Chapter 4). Although the study did not directly involve participants' families in the rehabilitation plan, these findings suggest that it could have actually been a useful addition. In line with holistic rehabilitation practice, it has been recommended that the impact of the family network and close environment needs to be considered by rehabilitation professionals even if they do not have a direct relationship with family members (Evans et al., 1992; Livingston et al., 1985). Involving the family in rehabilitation is not always easy or feasible. However, providing the family with information on memory problems and agreeing on some mutually acceptable therapeutic goals could be realistic aims for rehabilitation programmes (Sherer et al., 2003).

### Difficulties in evaluating outcomes

For three participants with traumatic brain injury evaluating the extent to which the group affected their life was not an easy task. This was partly attributed to the difficulty of differentiating the effects of the program itself from the improvements related to spontaneous recovery. Participants' concerns were justified by the fact that only a short time had elapsed since their injury (less than 2 years). Although being at a relatively early stage post-injury can be advantageous for the application of restorative strategies, the

development of compensatory strategies may be problematic (Wilson, 2000). Wilson (1991) observed that people put memory aids into practice only after they left the protective environment of the rehabilitation centre and were confronted by problems of daily living. According to Backman and Dixon (1992) compensatory behaviour occurs when the patient has to respond to environmental demands disproportional to his abilities. Consequently if these demands of everyday activities are low, patients may have sufficient abilities to respond satisfactorily without the need of compensatory aids. This was the case for some of the respondents who had not yet returned to their former lifestyles or full employment and therefore they did not have the opportunity to observe changes in their everyday activities.

In addition to participants with traumatic brain injury, two multiple sclerosis patients also found it difficult to evaluate rehabilitation outcome. The progressive nature of their disease presented new challenges and difficulties for them to overcome or adapt to. The on-going change in their skills, mood or lifestyle could mask the benefits of rehabilitation and necessitate the readjustment of the coping strategies they were taught in the groups. According to De Ridder (1997) coping is regarded as “a dynamic process which changes over time in response to objective demands and subjective appraisals of the situation” (p.418). This evidence supports the notion that it is inappropriate to treat cognitive rehabilitation like any other form of therapeutic intervention (e.g. pharmacotherapy). Unlike other interventions, it may not be possible to assess outcome within a specific, predefined time frame. Rather than following a linear course towards goal attainment cognitive rehabilitation should rather be perceived as a dynamic process with many ups and downs. From this point of view, following-up assessments in different time points seem necessary in order to monitor the outcome of this process. Regarding the current study, it might have been useful to repeat the interviews after these participants returned to their normal routines and rehabilitation input phased out.

### Group setting/composition

The benefits of the group setting were reported as one of the most positive aspects of the study by the majority of participants across the three programmes. The majority of participants agreed that they preferred group over individual sessions indicating that the presence of other people with similar problems was highly valued. Taken together, findings from both interview studies highlighted the benefits of a group approach in memory rehabilitation. The groups provided a supportive environment, where participants



exchanged information and experiences, witnessed their own behavior and developed self-awareness, shared their emotions and distresses. These findings appear to concur with evidence from studies on neurological rehabilitation. Gauthier et al., (1987) observed that a group approach in the rehabilitation of people with Parkinson's disease resulted in more behavioural changes than a more dependent one to one relationship. It was concluded that the opportunities for socialization and emotional sharing that the group setting offers make it useful for people with chronic degenerative diseases who are vulnerable to mood disorders and social isolation. Ada et al., (1999) also stressed the advantages of group sessions for people with stroke. They recommended that rehabilitation professionals should take advantage of the therapeutic opportunities associated with group dynamics such as the use of cooperation as well as competition to increase patients' motivation. Following a review of the literature on memory rehabilitation for elderly people, Verhaeghen et al., (1992), recommended that the gain of an intervention is maximal when participants can benefit from the comforting and motivating effect of sharing their concerns about memory with others. Future research needs to address this issue as, at the moment, there seems to be a lack of controlled studies directly comparing the effects of group over individual cognitive rehabilitation.

Except for the format of the sessions participants were asked to comment on the group composition. Studies on brain injured people of mixed aetiology have provided inconclusive evidence on whether diagnosis affects the outcome of memory rehabilitation (Wilson et al, 2001; Evans et al, 2003; Fish et al, 2008). Although the current study did not tackle that issue, it provided information on participants' experience of being in a mixed aetiology group. For seven participants interviewed, interacting with people with a similar problem constellation but different backgrounds and diagnoses, was a perceived benefit. Five respondents saw the advantages of taking different perspectives in dealing with memory difficulties. For four others, it was an experience that freed them from self-absorption and introspection and allowed them to be more understanding and empathetic towards others. Observing other group members leading "normal" lives, helped them realize that their diagnosis is a label that does not necessarily define who they are and how other people perceive them. Three respondents with MS reported that instead of being consumed in "blaming MS for everything", they decided to focus their efforts on dealing with the problem.

Although the interviewees appreciated heterogeneity in the aetiology of memory problems this was not the case for perceived differences in the severity of memory

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problems. Two respondents who experienced severe memory problems commented that comparing themselves with other group members was a source of frustration and disappointment. The same was true when people with early stage multiple sclerosis faced the possibility of interacting with individuals in an advanced stage of the disease. It seemed important for respondents to be in a group of people with similar levels of abilities. Homogeneity in cognitive status might be beneficial in allowing group members to work at a pace that is suitable for everyone and draw constructive comparisons from their peers.

### Healthcare

Five participants took the opportunity to express their disappointment that healthcare professionals paid little attention to the cognitive difficulties they were experiencing. For these respondents, the groups had been an important source of information on the cognitive effects of brain injury, filling a niche in the existing health care services. Previous studies on neurological populations have also highlighted patients' request for more effective information provision. A study conducted for the MS Society demonstrated low levels of satisfaction with the health care system associated, among other reasons, with insufficient provision of information (MS Society, 2003). In a study by Forbes et al (2007), information was identified as the strongest need for MS patients who were not experiencing severe physical and psychological consequences. It has been argued that MS services in the UK place a disproportionate emphasis on disease modifying therapies, overlooking other areas of importance for patients such as cognitive impairments (Forbes et al, 2003). This evidence points to the need for an integrated health care model that considers both the physical and cognitive effects of brain injury and provides sufficient information to patients and their families.

#### **5.4.2. Implications of qualitative findings**

Similar to the interview study described in Chapter 3, the positive picture that was conveyed by participants in their interviews was not reflected in the quantitative outcome measures. It is reminded that statistical analyses were performed on the combined data from both the pilot and main phases of the trial (Nair & Lincoln, 2012). Both restitution and compensation programmes appeared to lead to an increased use of internal memory aids as compared to the self-help programmes at both five ( $p=0.006$ ) and seven month ( $p=0.049$ ) follow-ups. However, comparisons between programmes and assessment points on measures of perceived and actual memory ability, mood, mental adjustment and

activities of daily living showed little evidence of significant differences of a size that would be of practical or clinical interest. As discussed in Chapter 3, this apparent discrepancy may be largely due to the outcome measures in the RCT not matching the outcomes emerging from the qualitative part of the study. It is suggested that the agreement in the findings of the two interview studies further strengthens the validity of the identified themes and highlights the need to develop an outcome measure tapping the reported areas of improvement.

What needs to be emphasised is that the quantitative and qualitative studies asked different but related questions and both were based on fundamentally different theoretical paradigms (Moffat et al, 2006). Qualitative designs do not permit controlling for confounders and identifying causal relations between the variables. Consequently, the interview studies do not provide strong evidence to support or refute the efficacy or cost-effectiveness of memory rehabilitation. The qualitative methodology, however, allowed to: a) explore reasons for the findings of the trial and gain an understanding of participants' subjective experience of the intervention, c) provide insights that could be used to guide the selection of appropriate outcome measures in future quantitative studies, d) generate research questions for examination by quantitative studies (e.g. evaluating the effect of group over individual cognitive rehabilitation). Most importantly, it is argued that this study fulfilled its aim to inform the development of a new quantitative outcome measure by identifying potential areas for inclusion.

Although qualitative research does not permit the statistical generalizability of the findings, it allows the transferability of these findings to similar contexts. The use of mixed aetiology groups suggests that a broad range of viewpoints may be represented in the narratives. It is argued that both interview studies highlighted issues related to the delivery and evaluation of memory rehabilitation that could inform the practice of researchers and practitioners adopting a holistic approach to cognitive rehabilitation. Qualitative findings stressed the importance of: a) exploring and agreeing with participants on the level of information they would like to receive, b) providing family and caregivers the opportunity to access relevant information and get involved with the rehabilitation process, c) considering the negative effects of variation in the severity of cognitive impairment between group members, d) incorporating strategies that target participants' self-efficacy beliefs, e) including outcome measures that assess participants' ability to cope with memory problems rather than their actual memory ability.

Whether qualitative findings can directly inform the wider policy making has been an issue of debate. Non-numerical findings often raise the suspicion of those unfamiliar with the “science” involved in qualitative research (Popay & Williams, 1998). On the other hand it is also acknowledged that quantitative designs are not appropriate for every research question and that numerical findings do not ensure the scientific rigour of a study. There is also increased recognition that randomised controlled trials alone cannot adequately assess complex interventions and their outcomes (e.g. Boon et al, 2006). This gap should be filled by qualitative research which, used alongside quantitative designs, can contribute in evaluating complex interventions and informing evidence-based practice (e.g. MRC Health Services and Public Health Research Board, 2006). Qualitative evaluations can pick up small but profoundly important changes resulting from interventions, which quantitative methods may not be sensitive to (Popay & Williams, 1998). They can also provide policy makers with an account of the perspectives and opinions of those delivering or receiving an intervention. It has been suggested that the co-production of knowledge by researchers, practitioners and service users could contribute in overcoming the barriers to the implementation of an intervention (Rowley, 2012). The MRC framework on complex interventions (2000) recognises that the qualitative approach has a role to play in bridging the gap between research and practice as it offers the possibility for more nuanced and contextual insights. At the bottom line of the debate between qualitative and quantitative research lies the need to adopt a pragmatic approach in order to conduct high quality research for patient benefit.

### **5.4.3. Methodological issues**

It is important that the findings of this study are considered in the context of the methodologies used. The value of qualitative methods in health-related research is well recognized. Using semi-structured interviews allowed respondents to accurately convey their opinions in their own terms. Interestingly, some participants commented that the interview process was an opportunity for them to reflect on issues they hadn't considered before. Despite its benefits, the flexibility of semi-structured interviews increases the likelihood of bias associated with interview methods. As a lot is left to the discretion of the interviewer, unstructured interviews are particularly affected by the skills of the researcher. By having an independent interviewer conduct half of the interviews the risk of bias in data collection was considered. A review of the transcripts showed that both

interviewers appeared to follow a non-directive style of interviewing, allowing for flexibility but at the same time covering most of the pre-specified topics. It was also found that the developed thematic network was applicable to the entire dataset. It is still not possible to eliminate the possibility of the interviewers unconsciously asking a leading question or the respondents giving the answers they felt were expected from them. No matter what their format is, interviews are a self-report method and therefore rely upon respondents' ability and willingness to give accurate and complete answers (Smith, 2006). In addition to the role play and the mutual assessment between the interviewers it could have been useful to ask for participants' feedback on the first interview conducted by each interviewer. This pilot phase would have provided the opportunity to practice in a real interview situation, elicit respondents' opinions on the interviewers' performance and assess what sorts of questions make sense to participants.

Some methodological issues arise from the use of thematic analysis. A potential pitfall in qualitative analyses of this kind is that raw data have been misinterpreted or over interpreted to produce meanings that were not originally there (Burman, 1994). In order to tackle that problem an independent researcher identified key themes in each interview and assessed how well the proposed thematic network covered the interview data. In the subsample of the interviews evaluated, the researcher confirmed that the thematic network described accurately participants' narratives without excluding important information. The appropriateness of seeking agreement among co-researchers in qualitative research has been an issue of debate (Graneheim, 2004). It is believed, though, that it can provide an indication of the credibility of the identified themes (Ibid.). As the assessor was not involved in the RCT, it was hoped that bias related to the coder's expectations and preconceptions would be reduced. An additional route for enhancing the credibility of the findings would be to cross check the research findings with respondents. The appropriateness, however, of modifying the results to fit respondents' interpretations has been questioned (e.g. Barbour, 2001).

As already seen, thematic analysis is interested in identifying meanings that are valid across the dataset in contrast to case study forms of analysis (e.g. narrative analysis) that look at patterns within an individual interview. It, therefore, makes it difficult to obtain a sense of continuity and an understanding of the interconnections between themes within one particular narrative (Joffe & Yardley, 2004). Some hypothetical relationships between the constructs represented by the themes were discussed in both interview studies (Chapter 3-Chapter 5) but none of these hypotheses were formally assessed. Future

research could employ a grounded theory approach in order to investigate and theorize possible connections between these themes. It would also be interesting to examine differences in the themes according to participants' psychometric and demographic baseline characteristics. This kind of analysis would be facilitated by the use of qualitative data analysis software such as NVivo.

An alternative approach to individual interviews would have been to conduct focus groups. Focus groups are small groups of people who interact with each other and the group leader. They are a particularly popular technique for assessing beliefs about health and disease and pretesting measurement scales (Fontana & Frey, 2000; Bowling, 2009). In this study, instead of interviewing participants separately, they could have been interviewed along with the group they were allocated. The familiarity that they had developed between them could have stimulated discussion and therefore generate more information (Steward, 2007). However, this method was not considered for this study due to a number of limitations. Although group dynamics might help focusing on the most important topics they may also lead to conflicts and power struggles that detract participants from the focus of the interview (Robson, 2002). The opinions of more powerful members might predominate, leaving little room for views of less articulate people to be heard. Because of the group dynamics that are present, considerable skills and experience are required on the part of the interviewer (Fontana & Frey, 2000). Furthermore, probing for elaboration of a statement is less possible in focus groups than in individual interviews making it might be more difficult to pursue a topic in greater depth (Fitzpatrick & Boulton, 1994).

### **5.5. Integration of findings from observations and interviews**

In summary, in their interviews participants in the two intervention groups stressed the contribution of the programme in helping them obtain a better understanding of their memory problems through both provision of factual knowledge and exploration of personal strengths and weaknesses. Not only did participants learn new memory strategies but they also became more proficient in the use of the strategies they already had in place. Feeling more “in control” and more confident in their ability to cope with their memory problems was reported by the majority of participants in the intervention groups. Many of them also talked about how they adopted a more proactive attitude towards their memory problems, they became more organised and paid more attention to the material to be remembered. Improvements were also mentioned in terms of memory related anxiety and interpersonal relationships-particularly regarding their ability to disclose their memory problems. Observations, on the other hand, indicated the following topics as the most frequently discussed in the two intervention programmes: information on theories and models of memory, with the association between memory and attention being particularly stressed, participants’ beliefs on their memory difficulties and exploration of their actual strengths and weaknesses, issues related to learning and applying memory aids as well as developing own strategies, stress and anxiety issues caused by memory problems and finally family related issues such as carers’ understanding of the memory problems participants’ experienced.

From the above, it appears that the findings from both studies are in agreement, highlighting similar issues. The use of a mixed methods design fulfilled its role as a means of balancing the weaknesses of each method and providing a more rounded picture of the memory rehabilitation programme. Observations provided a detailed account of the content of the groups, less affected by the subjectivity of participants’ and researchers’ interpretations. They also allowed the quantitative evaluation of the differences between the content of the intervention groups and the self-help group that allowed the identification of intervention specific topics. Qualitative data from the interviews strengthened and further extended the quantitative findings. They allowed the exploration of thoughts and feelings that participants may have not felt comfortable or confident enough to disclose during the group sessions. Themes that were dominant in participants’ interviews, such as their feelings of control and confidence, would not have been identified based on the observations alone. Participants also provided important feedback on the

strengths and weaknesses of the groups without worrying that they would be judged by the leader or other participants. Finally, the richness of information obtained from the interviews gave the opportunity to attempt an exploration of the relationships between different themes.

Based on the findings from both studies, a number of content areas were identified to be considered for inclusion in the new questionnaire. These areas represented topics prevalent in the discussions/narratives of participants in the two intervention programmes and relevant to the purpose of the questionnaire to examine rehabilitation specific effects. For example, although the benefits of the group setting formed a prevalent topic in both observations and interviews it was not considered for inclusion as it would not be applicable to patients receiving individual sessions. Similarly, improvements in the performance of specific memory tasks, particularly those related to prospective memory ability, were seen in both observation and interview data. As many relevant questionnaires are already available, it was decided not to include any questions assessing perceived frequency or severity of memory failures.

The following table shows how the content areas that were identified in the previous studies correspond to those that the new questionnaire needs to address.

Table 18  
*Areas considered for inclusion in the new questionnaire*

<b>Observations</b>	<b>Questionnaire</b>	<b>Interviews</b>
Information on memory	Memory knowledge	Memory knowledge
Attention	Attention	Attention
Self-awareness	Self-awareness	Self-awareness
Use of memory aids	Use of memory aids	Use of memory aids
Personal life	Significant others	Interpersonal relations
Memory related stress	Memory related stress	Memory relates stress
-	Active coping	Active coping
-	Control beliefs	Memory self-efficacy Feeling in control

Following the identification of the content of the questionnaire, the items comprising the scale needed to be developed and the psychometric properties of the scale evaluated. This process is described in the next chapter.



## Part C.

### **Chapter 6: Evaluating the psychometric properties of the Adaptation to Memory Difficulties Outcome questionnaire**

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This chapter describes the item development and psychometric evaluation of the Adaptation to Memory Difficulties Outcome questionnaire (AMEDO) in a group of people with neurological disabilities. As seen in previous chapters, participants in a memory rehabilitation programme (ReMind) reported improvements in domains that are not covered by existing questionnaires assessing the outcome of memory rehabilitation in neurological populations. AMEDO is intended for use with neurological patients to evaluate improvements in the way they manage their memory difficulties following memory rehabilitation interventions.

Consequently the new questionnaire should have the following properties:

- instructions and questions should be phrased using a concise, clear and unambiguous language to facilitate people with impaired cognitive abilities,
- questions should capture the content areas identified in the previous studies as important for inclusion,
- questionnaire should be responsive to improvements following memory rehabilitation interventions. Consequently it is important to demonstrate that: a) items do not suffer from ceiling effects at baseline; b) any observed variation over time is associated with the effects of the intervention and not to other variables (e.g. random error). If re-administered after an interval short enough (i.e. two weeks) to assume that no changes in the assessed characteristics could have taken place, the questionnaire should exhibit acceptable test retest stability,
- questions should be relevant to a wider neurological population (i.e. results are not significantly affected by diagnosis or age).

### 6.1. Plan of procedures

The development and evaluation of the Adaptation to Memory Difficulties Outcome questionnaire (AMEDO) was conducted in three phases, as outlined in Figure 8.

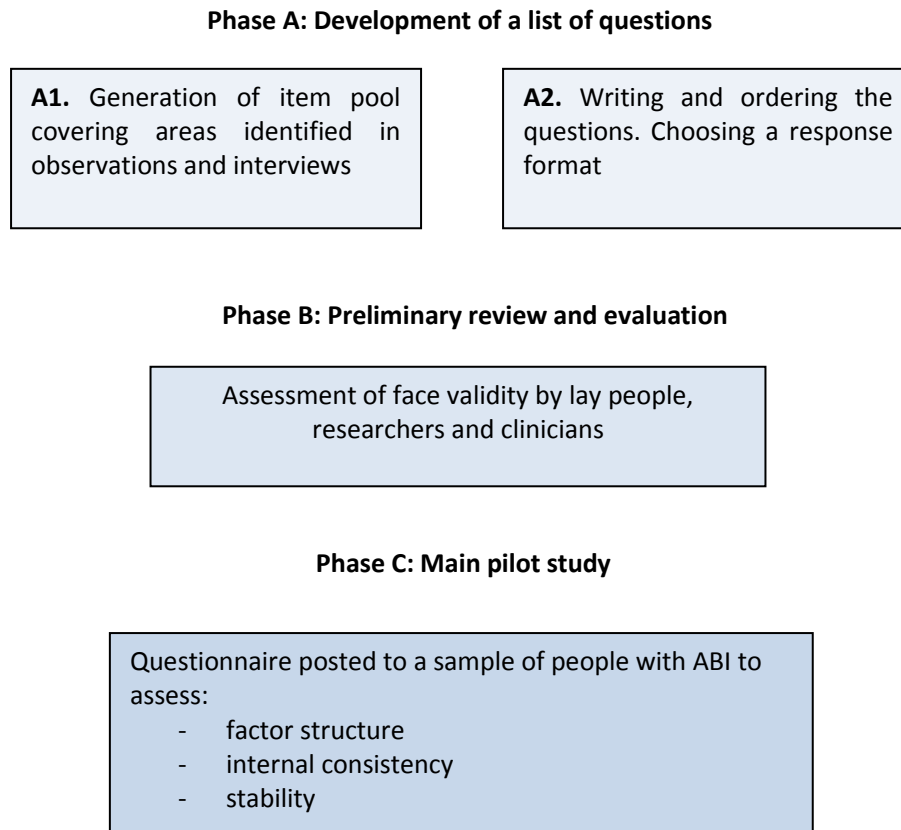


Figure 8. Phases of development and evaluation of AMEDO questionnaire.

### **6.2. Phase A: Development of initial list of questions**

An initial pool of items was developed to cover the predominant content areas identified from interviews and observations: “memory knowledge”, “awareness”, “emotional adjustment”, “active coping”, “control beliefs” (i.e. locus of control and self-efficacy beliefs), “attention”, “significant others” and “use of memory aids”. Most of the items were directly based on statements made by participants in the previous studies and were rephrased when necessary to make them appropriate for questionnaire format. The rest of the items were either generated by the investigator or adapted from previously developed scales that appeared to tap one of the dimensions (i.e., Metamemory in Adulthood Questionnaire, Dixon et al., 1988; Mental Adjustment to Cancer, Watson et al., 1988).

At this stage of the questionnaire development an attempt was made to produce a questionnaire as inclusive as possible, covering all the areas of interest. However, the characteristics of the population it was intended for had to be taken into account when deciding on the number of items. According to Waltz (1991), a major source of response bias is due to fatigue and lack of motivation. This was a concern for the study as potential respondents could have been dealing with issues of fatigue or short attention span. It was therefore attempted to keep the questionnaire manageable in terms of length. In the pilot phase the questionnaire was posted to participants and that had also implications for the questionnaire length and format, as it is suggested that postal questionnaires should be shorter and generally easier to complete than the ones administered by a researcher (McColl et al., 2001).

In developing the items, the cognitive capacity of potential participants to comprehend and answer the questions was taken into consideration. Great care was taken to avoid technical terms, complex syntax and ambiguous statements. Having to keep a large number of words in mind might impose a high load on memory, therefore sentences were kept as short as possible (Streiner & Norman, 2008). McColl et al. (2001) suggested that questions should contain a maximum of 20 words. The fact that the questionnaire was self-administered and researchers would not have the opportunity to clarify misinterpretations, further highlighted the need for the questions to be clear and concise (Waltz, 1991). Another potential problem that was taken into account was the acquiescence/affirmation bias, or the tendency of questionnaire respondents to agree with items regardless of their content (Priest et al., 1995). In order to address this bias, it has

been recommended that questionnaires include both positively and negatively worded items placed in a random sequence (Coolican, 2002; Waltz, 1991). It is thought that this strategy urges respondents to think about each item before replying. Research, however, has shown that this may not be particularly beneficial. Summarizing the findings of relevant studies, McColl (2001) noted that the inclusion of negatively worded items may result in the reduction of response validity. It has also been shown that questionnaires that include both negatively and positively worded items demonstrate lower reliability than those which are worded in the same direction (Streiner & Norman, 2008). Furthermore, having to disagree with an item in order to express a positive response is a process that people with cognitive difficulties might find confusing (ibid.). As an alternative approach, it has been proposed that items be balanced with respect to the direction of question wording (Bowling, 2010; Streiner & Norman, 2008). Following this suggestion, in this questionnaire although all items were positively worded, some of them were tapping one direction and some others the opposite direction of it. For example, agreeing with item 4 "*I understand how memory works*" signifies a positive response whereas agreement with item 5 "*I find it difficult to come to terms with my memory problems*" implies a negative response.

Another way of avoiding stereotyped responses is to reverse the direction of the response categories (Streiner & Norman, 2008). This strategy was adopted in the first version of the questionnaire where responses going from "strongly agree" to "strongly disagree" were alternated by responses in the reverse order. Once again the aim was to encourage people to think of the questions rather than habitually ticking the same response for all the questions. The sequence of the questions may also be a source of bias associated with context effects (McColl, 2001). Respondents' understanding of an item might be affected by the meaning of previous questions. It has also been suggested that respondents might attempt to appear consistent by answering questions in line with their responses to earlier questions (Streiner & Norman, 2008). Question order effects might be reduced in postal surveys as respondents have the opportunity to read all questions before responding without the time constraints and the pressure of an interview survey (ibid.). However, in the first version of the questionnaire, an attempt was made to control for context effects by placing the questions in a random order instead of grouping them by topic.

A Likert type response scale was chosen. This is an ordinal scale composed of items with hierarchical response levels, often from "strongly agree" to "strongly disagree", from which

respondents choose one option that best aligns with their view (e.g. Coolican, 2004). An example of Likert type question/response format from the AMEDO questionnaire is the following:

Question 2: *"I have had enough information on why I have memory problems"*

Response options: *"Agree", "Slightly Agree", "Slightly Disagree", "Disagree"*

Likert is one of the most popular response systems employed by attitude scales and they are considered to be easy to construct, administer and score. According to Likert (1931) the scale can yield good reliability with a small number of items because of the range of answers permitted to respondents. Furthermore, it permits the inclusion of items whose manifest content does not relate obviously to the construct in question (Oppenheim, 2001). Consequently, the exploration of different components of the construct is facilitated, each component contributing a small part in the overall measure (ibid.). Six response categories were used in the first version "strongly agree", "disagree", "slightly disagree", "slightly agree", "agree", "strongly agree". It has been suggested that the ideal number of response categories should be in the region of five to seven (Foddy, 1995; Streiner & Norman, 2008). As noted by Streiner & Norman (2008) reliability tends to drop with fewer than five categories whereas people have difficulty discriminating beyond seven alternatives. The inclusion of two extra categories than the ones required has been suggested as way to control for the "central tendency bias". This refers to respondents' difficulty in making absolute judgements which in turn may lead to avoiding the two extreme categories (Streiner & Norman, 2008). According to Streiner & Norman (2008) an even number of categories forces the respondents to commit themselves to one direction.

Whether or not a rating scale should have middle point has been a source of debate in the literature. Despite the controversy, authors tend to agree that there are different reasons for which respondents might chose the "neutral option", making interpretation difficult (Coolican, 2002; Foddy, 1995; Oppenheim, 2001; Streiner & Norman, 2008). In addition to a really neutral position in the midpoint between the two directions, the middle option could also imply the lack of knowledge or opinion, that the item does not apply, or simply that the respondent, unable to decide, resorts to the "safe" middle response. Following a review of the relevant experimental research Converse & Presser (1986), observed that about 10% to 20% of respondents that endorsed the middle position would not have voluntarily considered it as an option if it had not been explicitly offered to them. The authors concluded that providing the middle option may lead to a loss of important information about the direction in which people lean. The tendency of

respondents to avoid endorsing a definite response was one of the reasons for which a middle or “neutral opinion” position was not included in the response categories of the current questionnaire.

### **6.3. Phase B: Preliminary review and evaluation**

After a preliminary draft of the questionnaire was prepared it was submitted for review by two groups of people. The first group consisted of 10 native English speakers who did not have any previous knowledge of health related research. The purpose was to examine whether people that did not have specialist knowledge and language would understand and interpret the questions as intended. Participants were asked to think aloud, while trying to answer each question, and describe in their own words what they thought was the meaning of the items. They were also invited to comment on the general layout and appearance of the questionnaire. The second group of people that evaluated the questionnaire were three research psychologists and four researchers experienced in the area of neurological disabilities and rehabilitation. In addition to commenting on the clarity and accuracy of the wording they also provided feedback on the content and relevance of the questions.

The questionnaire was revised and a number of changes were made on the basis of the input received. Many of the items were rephrased in order to improve grammatical accuracy and reduce ambiguity. The instructions to participants were also rephrased to become more concise and easier to understand. It was also suggested that social desirability bias could be reduced by making it clear in the instructions that there are no right or wrong answers. Two more items were added, questions 1 and 12 in the final version, which served as screening questions to confirm that respondents had read the instructions carefully and they did feel they had memory problems. Question 12 was adapted from the Metamemory in Adulthood Questionnaire (MIA) (Dixon et al., 1989; described in Chapter2, p.106), questionnaire, where it tapped perceived change in memory ability (Dixon et al., 1989). Based on their experience working with people with neurological disabilities the researchers agreed that some patients may find it difficult to discriminate between six different response categories and therefore the categories were reduced to four. Some space for open comments was also added to allow respondents to expand upon answers. This was in line with the suggestions of McColl et al. (2001) who noted that the inclusion of space for free comments might increase response rates. It is

## Chapter 6

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also thought that participants' feedback can inform questionnaire development by bringing to researchers' attention problems related to specific items or issues missed by the questionnaire (Rattray & Jones, 2007).

At the end of this preliminary review the questionnaire comprised the questions that were retained in the final version which was assessed in the main pilot study (see Tables 19 and 20 for Part A and Part B items respectively). The following tables provide information on the source of each item and the content area it was developed to capture.

Table 19 .

*Part A questionnaire items*

<b>Part A Content areas</b>	<b>Item No.</b>	<b>Items</b>	<b>Source</b>
<b>Screening questions</b>	<b>1</b>	<i>I do not remember things as well as I used to</i>	Developed by researcher
	<b>12</b>	<i>I am as good at remembering as I ever was</i>	MIA± Questionnaire
<b>Memory knowledge/ awareness</b>	<b>2</b>	<i>I have had enough information on why I have memory problems</i>	Researcher
	<b>3</b>	<i>I am aware of the strengths and weaknesses of my memory</i>	Participants' statement
	<b>4</b>	<i>I understand how memory works</i>	Participants
	<b>6</b>	<i>I know how to use the strong aspects of my memory to compensate for the weaker aspects</i>	Participants
	<b>7</b>	<i>I do things that are too hard for my memory</i>	Researcher
	<b>8</b>	<i>I understand why I remember some things more easily than others</i>	Participants
<b>Active coping</b>	<b>14</b>	<i>I am well organised in how I cope with my memory problems</i>	Participants
	<b>16</b>	<i>I have been doing things that I believe will improve my memory</i>	MAC ± questionnaire
<b>Control beliefs</b>	<b>17</b>	<i>I have little control over my memory ability</i>	MIA
	<b>18</b>	<i>There are ways to cope with my memory difficulties</i>	Participants
	<b>19</b>	<i>I rely on other people to remind me of what I have to do</i>	Participants
	<b>23</b>	<i>I am confident that I can cope with my memory difficulties</i>	Participants
<b>Emotional adjustment</b>	<b>5</b>	<i>I find it difficult to come to terms with my memory problems</i>	Researcher
	<b>10</b>	<i>I avoid finding out more about my memory problems</i>	MAC

	<b>20</b>	<i>It is harder to remember things when I am upset</i>	MIA
	<b>21</b>	<i>I talk to other people openly about my memory problems</i>	Participants
	<b>22</b>	<i>I worry that I am going to forget something important</i>	Participants
	<b>24</b>	<i>It upsets me when others notice my memory problems</i>	MIA
	<b>25</b>	<i>I am anxious about my memory problems</i>	Participants
	<b>26</b>	<i>My memory problems make me feel embarrassed</i>	Participants
	<b>27</b>	<i>I panic when I forget something important</i>	Participants
<b>Attention</b>	<b>13</b>	<i>I try to concentrate hard on things I want to remember</i>	MIA
	<b>15</b>	<i>I find myself daydreaming when I am supposed to be focusing on a task</i>	CFQ± Questionnaire
<b>Significant others</b>	<b>9</b>	<i>Other people have noticed an improvement in my memory ability</i>	Participants
	<b>11</b>	<i>I think that people close to me understand how bad my memory is</i>	Participants

\*Response options: "agree", "slightly agree", "slightly disagree", "disagree"

±MIA: Metamemory in Adulthood Questionnaire (Dixon et al., 1989; see p.106); MAC: Mental Adjustment to Cancer scale (Watson, 1988); CFQ: Cognitive Failures Questionnaire (Broadbent et al., 1982)



Table 20

*Part B questionnaire items*

<b>Part B1 Content areas</b>	<b>Item No.</b>	<b>Items</b>	<b>Source</b>
<b>Importance of MA for respondents</b>	<b>29</b>	<i>Using external MA is part of my everyday life</i>	Researcher
<b>Change in the use of MA</b>	<b>30</b>	<i>I am using the same external MA I have always used</i>	Researcher
<b>Beliefs on effectiveness of MA</b>	<b>31</b>	<i>I believe that I make the most of the external MA I am using</i>	Participants
	<b>32</b>	<i>I know which external MA work best for me</i>	Participants
	<b>33</b>	<i>The external MA I am using are effective</i>	Researcher
	<b>34</b>	<i>I think the external MA I am using could be improved</i>	Researcher
	<b>35</b>	<i>I have a range of external MA that I can use for different tasks</i>	Participants
<b>Part B2</b>			
<b>Importance of MA for respondents</b>	<b>38</b>	<i>Using internal MA is part of my everyday life</i>	Researcher
<b>Change in the use of MA</b>	<b>39</b>	<i>I am using the same internal MA I have always used</i>	Researcher
<b>Beliefs on effectiveness of MA</b>	<b>40</b>	<i>I believe that I make the most of the internal MA I am using</i>	Participants
	<b>41</b>	<i>I know which internal MA work best for me</i>	Participants
	<b>42</b>	<i>The internal MA I am using are effective</i>	Researcher
	<b>43</b>	<i>I think the internal MA I am using could be improved</i>	Researcher
	<b>44</b>	<i>I have a range of internal MA that I can use for different tasks</i>	Participants

\*Response options: "agree", "slightly agree", "slightly disagree", "disagree"

It is recommended that before posting it to the main sample, a questionnaire should be administered in person to a smaller sample of intended respondents (Rattray & Jones, 2007; Waltz, 1991). This approach allows researchers to gain an understanding of how members of a specific population interpret and answer the questions (Ibid.). This is particularly important when potential respondents experience cognitive difficulties that may affect the way they respond to the questionnaire. Due to the time constraints of this thesis and the need for ethical approval, conducting a pre-test on a clinical population was

not feasible. Therefore the revised draft of the questionnaire was evaluated by 21 clinical psychologists experienced in working with people with neurological disabilities. The clinicians attended a presentation which introduced them briefly to the background and aims of the study. At the end of the presentation they were given the questionnaire and they were instructed to complete it in the way they believed one of their patients would do. They were invited to identify any parts of the questionnaire they thought their patients would have difficulty understanding and suggest improvements. Their opinions on the content, layout and clinical usefulness of the questionnaire were also sought. The procedure also allowed to obtain a rough estimate of the time needed to complete the questionnaire which was found to be about 15 minutes.

On the basis of respondents' comments some redundant words were deleted in questions in order to simplify the wording. Many clinicians thought that changing the direction of response categories might be confusing and place an additional cognitive demand on respondents. Carelessness or distraction might result in respondents failing to notice the changes and give responses difficult to interpret (Streiner & Norman, 2008). The questionnaire was therefore revised to keep the direction of the response categories constant through the questions. It was also suggested that questions should not skip between topics as that could be quite confusing and tiring for respondents. In the revised version of the questionnaire an attempt was made to keep a balance between changing the order of the topics to reduce context effects and preserving coherence and continuity. Following the suggestions of Aldridge & Levine (2001), more subtle questions related to mood were placed towards the end of the 1<sup>st</sup> part of the questionnaire. In line with clinicians' feedback, the format of Parts B1 and B2 was modified to become clearer and easier for respondents. Instead of inviting participants to report the memory aids that they were using, checklists of memory aids were added to clarify what memory aids are and trigger respondents' memory. Respondents who had not been using any memory aids were required to skip to checklists outlining possible problems related to memory aid use. Following the suggestions of Aldridge & Levine (2001), these checklists were placed at the end of sections B1 and B2 in order to minimise confusion related to the question skip (see Appendix 2 p.337).

### **6.4. Phase C: Main pilot study**

The aim of this study was to evaluate the psychometric properties of AMEDO questionnaire (see Appendix 2 p.335) on a sample of participants with acquired brain injury due to multiple sclerosis and traumatic brain injury.

### **6.5. Method**

#### **6.5.1. Sample size estimate**

Three factors were taken into account when estimating the number of questionnaires to be sent: 1) number of responses required for factor analysis, 2) prevalence of memory problems on the specific populations, 3) response rates of postal questionnaires.

1. In order to allow exploratory factor analytic techniques to be performed, the ratio of participants per variables (questionnaire items) was considered. Each of the three parts of the questionnaire would be analysed separately. For Part A, the longest part of the questionnaire, the factor structure of 25 questionnaire items needed to be examined. Five respondents per item (Bryman & Cramer, 2009; Pallant, 2005) and a minimum total of 100 respondents (Ferguson & Cox, 1993) have been recommended in order to obtain meaningful results from factor analysis. Therefore, a total of 125 (5x25) respondents would be required.

2. The questionnaire was addressed to participants who experienced memory problems. However, the proportion of the sample who had memory problems was not known (this information was not provided by referrers). Therefore, the prevalence of memory problems in multiple sclerosis and traumatic brain injury populations needed to be considered. It has been estimated that about 40 to 60% of people with MS and about 60% of people with TBI experience some degree of memory impairment (McKinley, 1999; Rao et al., 1993). Based on that, a rough estimate of about 50% of those who would be contacted would experience memory difficulties. In order to obtain 125 completed questionnaires the questionnaire should be sent to at least 250 patients (2x125).

3. It has been suggested that mail questionnaires do not usually obtain return rates greater than 50% (e.g. Jackson & Furnham, 2000). Consequently an initial sample of about 500 (2x 250) patients was needed.

### **6.5.2. Recruitment**

Potential participants were identified from patient databases in hospitals and rehabilitation centres within the NUH Trust. The identification of participants who fitted the criteria was done by members of the clinical teams who had access to the registers as part of their normal duties. People with traumatic brain injury were recruited from the patient register of the Mobility Centre at Nottingham City Hospital. This unit provides outpatient rehabilitation to people with impaired mobility. A letter was sent to all eligible patients admitted to the centre from January 2005 to February 2010. People with multiple sclerosis were recruited from the database of the MS Service based at Queens Medical Centre (QMC). A random sample of 400 patients was selected from the 1135 patients that were registered. A random number generator within the Excel computer programme was used to generate the sample.

### **6.5.3. Inclusion criteria**

Patients who met the following criteria were eligible for recruitment into the study:

- having sustained brain damage due to TBI or MS based on the information of the database
- being over 18 years of age

### **6.5.4. Procedure**

The initial contact with potential participants was made by a member of the clinical team of the hospital services/rehabilitation centres. They were sent the questionnaire, with a covering letter from the clinical team, a participant information sheet from the researcher and a pre-paid return envelope. A second letter with a replacement questionnaire was sent to all sample members three weeks after the first letter, thanking those who had replied and reminding those that had not to do so (copies of the covering letters and the information sheet can be found in Appendices 3, 4, and 5 respectively, pp. 349-351). It was hoped that sending the second letter to the whole sample would reduce the burden placed on the members of the clinical teams who would, otherwise, have to go through the databases and exclude those participants who had already responded.

Participants who reported memory problems were asked to complete and return the questionnaire. If they were not experiencing memory problems they were asked to return

the questionnaire without completing it. Participants willing to be sent another questionnaire were asked to supply their name and address. An identical copy of the questionnaire was sent to those participants two weeks after their response in order to assess the repeatability of the questionnaire.

### **6.5.5. Ethical considerations**

The purpose and procedures of the research were explained to prospective participants in the information sheet. It was made clear that participation was entirely voluntary. Participants were explained that returning the questionnaire implied their consent to participate in the study. They were also informed that by providing their name and address they agreed to be sent a second questionnaire. It was explained that if, after giving their name and address, they wished to withdraw from the study their names and contact details would be erased and they would not be sent a second questionnaire. Participants were also provided with the contact details of the researchers in case any questions arose. Questionnaires were anonymised and numbered and kept in a locker in the Institute of Work Health and Organisations, University of Nottingham.

The study received approval from the Derbyshire Research Ethics Committee (REC), and the Research & Development (R&D) department of Nottingham University Hospitals Trust (see Appendix 6 for a copy of the letter of approval, p.354).

### 6.5.6. Plan of analyses

#### Data entry

The Statistical Package for Social Sciences (SPSS, version 16.0) was employed for data analysis. Each item was scored on a 4-point scale 1-4. Items were reversed so that a higher score would signify better adaptation. Each of the three parts of the questionnaire were analysed separately.

As part of an initial screening process, data were examined for out of range cases. The percentage of missing values was also assessed. Missing scale scores and item non-response provide an indication of the quality of the data and the extent to which the questionnaire can be used successfully in a clinical setting (Hobart et al., 2004). SPSS missing value analysis procedure was employed to test whether data were missing in a random pattern.

#### Distribution of responses

The performance of a scale is defined by the characteristics of individual items (Ferketich, 1991). Therefore, the initial phase of the analysis focused on the evaluation of individual items in order to decide which items would be retained and which would be deleted. Descriptive statistics were employed to examine the distribution of item responses. Items were also dichotomised into agree/slightly agree and slightly disagree/disagree and the percentage of participants responding in each direction was assessed. This was done in order to identify and remove items with poor discriminatory power, displaying ceiling or floor effects. An item was considered for removal if more than 80% or less than 20% of respondents endorsed one of the two directions (Priest et al., 1995). It is also recommended that skewness statistics should lie within the -1 to +1 range (Holmes et al., 1996 as cited in Hobart et al., 2004) although it has also been argued that skew and kurtosis values within the -2 to +2 range are acceptable (Muthen & Kaplan, 1985).

#### Exploratory factor analysis

Exploratory factor analysis (EFA) was performed to assess the structure of the questionnaire. Separate EFAs were conducted for each of the three parts of the questionnaire (Part A, B1, B2). Exploratory factor analysis was chosen over confirmatory FA which is usually used in later stages of research to confirm specific hypotheses or theories (Field, 2005). Principal components analysis (PCA) was preferred to other factor extraction techniques because it is a psychometrically sound procedure, less complex than factor

analysis and more commonly used by researchers interested in scale development and evaluation (Pallant, 2005). Ideally, exploratory factor analysis should be applied on interval level data. In clinical practice and psychological research, however, Likert type scales are most typically used and the use of EFA with such data is considered acceptable subject to pre-analysis checks that the dataset meets certain assumptions (Ferguson & Cox, 1993). These checks related to sampling requirements, normality of item distribution and factorability of the data (KMO and Bartlett tests). In order to decide on the number of factors to extract, three heuristics were considered:

a) A first criterion for the number of factors to extract was the Kaiser 1 rule. This method recommends that all factors with eigenvalues greater than 1 should be retained (Field, 2005). Caution is needed, however, when applying this heuristic. It has been suggested that the number of components with eigenvalues greater than 1 is usually somewhere between the number of variables divided by 3 and the number of variables divided by 5 (Tabachnick & Fidell, 2007). As long as the number of items is less than 40, the sample size is large (>250), and the factor solution is meaningful, the K1 criterion is probably valid. Otherwise, it is possible that the number of factors is actually overestimated (Ibid).

b) A second estimate of the number of factors was obtained by plotting the eigenvalues for each factor against the factor number (Scree test). The plot was examined in order to identify the point at which the curve “breaks” and becomes horizontal. It is suggested that the number of factors above that break should be retained. The application of this criterion is not without problems. Identifying the break is not always easy as the break may not be obvious or there may be more than one break. Consequently, personal judgment by the researcher is often required (Tabachnick & Fidell, 2007).

c) Parallel analysis was also used to further inform the decision on the number of factors to extract. A random set of eigenvalues was produced based on the size of the sample and the number of variables. These random values were compared with those obtained from the factor analysis. Only those values that exceeded the eigenvalues from the random data set were retained. This approach has been shown to be more accurate than both K1 and Scree test which tend to overestimate the number of components (Ferguson & Cox, 1993). Ferguson & Cox (1991) recommended parallel analysis as the best option when deciding on the optimum number of factors to extract.

### Reliability

#### *Internal consistency*

For each of the subscales that were formed after factor extraction, internal consistency was tested in the following ways:

a) Corrected item – total correlations were computed by correlating each individual item with the subscale total after omitting that item. It is suggested that if the scale is homogeneous, each item should correlate with the total score of the questionnaire. An item-total correlation cut-off of  $< .30$  was applied (Ferketich, 1991). Any item showing lower item-total correlation was dropped from further analyses on the assumption that it measured something different to the scale as a whole (Ibid.). It has to be noted here, that internal consistency is not independent to the distribution of responses. For example an item showing a large number of responses to one of two directions is also likely to have low item total correlation.

b) Cronbach's alpha coefficient was calculated in order to assess how well items related to each other and to the total. A value of  $.70$  or above is usually recommended, with values higher than  $.90$  indicating item redundancy (Bowling, 2009). Individual items were considered for removal based on their effect on total alpha coefficient. Alpha is affected by the length of the scale, increasing along with the number of items. It is, therefore, recommended that with short scales (e.g. less than 10 items) homogeneity coefficients should also reported as indices of internal consistency (Ferketich, 1991, Hobart et al, 2004). Homogeneity coefficients are the average inter-item correlations and it is suggested that they are higher than  $.30$  (Hobart et al, 2004).

It has to be noted here that internal consistency is not synonymous to homogeneity. Although internal consistency is prerequisite to a homogenous (or unidimensional) scale it is not a sufficient condition. Alpha increases as a function of item inter-correlations and decreases as a function of multidimensionality (Cortina, 1993). It can still, however, be within acceptable levels despite low average inter-correlations and multidimensionality provided that there are sufficient numbers of items (Ibid.). Cortina (1993) showed that if a scale has more than 14 items then it will have an alpha of  $.70$  or higher even if it consists of different dimensions. The author suggested that alpha is particularly useful in confirming the unidimensionality or the strength of a dimension once factor analytic techniques are applied.



Item convergent and item discriminant validity were also evaluated by comparing the correlations of each item with its own scale and the correlations of each item with the other subscales (Ibid.). If the items were correctly grouped into subscales item-own scale correlations were expected to exceed item-other scale correlations by at least two standard errors ( $SE$  of a correlation coefficient =  $1/\sqrt{N}$ ). According to Hobart et al. (2004) correlations less than  $2SE$  of the corresponding convergent correlations signify limited item discrimination.

### Stability

Test-retest reliability was assessed following item reduction. The remaining items were summed and tests were performed using the total score of the revised subscales. Data were treated as interval level and preliminary analyses were performed to assess the assumptions of normality, linearity and equal variances. The normality of the distribution was evaluated by calculating Fisher's skewness coefficient which is the value of skewness/standard error of skewness. Histograms were also plotted and the shape of the distribution was inspected. One-way analyses of variance with Levene's test were performed to confirm the assumption of equal variances. Finally, plots were produced in order to evaluate the degree of linear relationship between each pair of scales. Following the preliminary checks, test-retest reliability was assessed in three ways:

a) The Pearson's product-moment correlation between the test and retest scores was computed. The Spearman correlation coefficient was used as an alternative for non-parametric data. Although there is no established cut-off score for health measures, Norman & Streiner (2008) suggested that test-retest correlations should be greater than .5.

b) Paired-samples t-test was used to assess whether there was a statistically significant difference in the mean scores for the two measures. Wilcoxon tests were employed for non-parametric data.

c) The use of correlation coefficients to assess stability has certain limitations. Correlation measures the strength of the relationship between the two measures not the agreement between them (Bland & Altman, 1986). It has been suggested that data in poor agreement can still produce high correlations (Ibid.). Furthermore, the size of correlations is affected by the range of scores in each measure with less variability leading to smaller  $r$  values (Goodwin & Leech, 2006). Measurement error is another factor affecting the size of a correlation. Measurement error may be due to intra-individual factors (e.g. fatigue,

anxiety, lack of motivation etc.), scoring errors, the ambiguity or the small number of questionnaire items, etc. As a result, the  $r$  value is reduced and the true correlation between the variables is underestimated (Ibid.). An alternative method for assessing test-retest reliability was proposed by Bland & Altman (1986). The method has certain advantages: a) it is not affected by the variability of the scores, b) it separates the random error of measurement and c) it offers a visual representation of the degree of agreement allowing the easy identification of outliers. In order to obtain the Bland & Altman plot the mean and standard deviation of the difference between each pair of subscales was calculated. The limits of agreement were defined as the mean  $\pm 2sd$ . The difference between the two measurements was then plotted against their mean. It is recommended that 95% of the data points should lie within  $\pm 2sd$  of the mean difference. The acceptable difference between the two measurements depends on the clinical context and the effect that it has on the interpretation of the scores (Rankin & Stokes, 1998). However, as a rule of thumb, the smaller the range between the two limits the better the agreement is considered to be (Ibid.).

The test-retest reliability of categorical variables (memory aids checklists) was evaluated by comparing test-retest scores using McNemar test which is recommended for dichotomous variables in related samples designs (Brace et al, 2006).

### Relationship between the revised questionnaire and demographic information

Finally, the relationship between the revised questionnaire and demographic variables- diagnosis, age and time since injury/diagnosis- was also evaluated.

### Justification for the use of parametric statistics

Issues regarding the level of measurement of Likert scale data (ordinal or internal) and, consequently, the use of parametric or non-parametric statistics have been a source of controversy in the literature. In the current study, the use of parametric or non-parametric statistics was judged upon the normality of the distribution and other assumptions of parametric data (i.e. homogeneity of variance, linearity). This is in line with recommendations that the sample size and the distribution are more important than the level of measurement in determining the appropriateness of parametric statistics (Gaito, 1980; Knopp, 1990; Munro, 2005). The major disadvantage of non-parametric statistics is that statistical power is generally lower than that of their parametric counterpart (Munro,

2005). As a result, small differences in the relationships between variables might be left undetected. Furthermore, as suggested by Zimmerman (1994), non-parametric tests are far from being immune to violations of the parametric assumptions such as that of equal variances. According to Norman (2010), parametric statistics are robust with respect to violations of assumptions such as the interval level of measurement and can be used with Likert data without concerns. On the other hand, although individual Likert items are ordinal, the sums of these items are considered to be interval level data (Carifio & Perla, 2008).

**6.6. Results**

**6.6.1. Participants**

Questionnaires were sent to 400 multiple sclerosis patients (January 2010) and to 143 TBI patients (February 2010). Responses were received between February and October 2010. Of the 543 questionnaires that were sent, 254 questionnaires were returned. About 60% of these responses were received before the reminder was sent. One hundred and ten questionnaires (43%) were returned blank by participants who did not experience memory problems. In Total, 144 participants returned the questionnaire completed. Table 21 summarises the reasons of non-response.

Table 21  
*Reasons for non-response*

	<b>Incorrect address -returned by the post-office</b>	<b>Recipient deceased -returned by relatives</b>	<b>Too ill to take part</b>	<b>No memory problems</b>	<b>Unknown</b>
<b>MS</b>	32	18	4	94	142
<b>TBI</b>	9	-	-	16	84

One hundred and ten respondents agreed to be sent a second questionnaire. Eighty seven participants returned the second questionnaire. Based on the date that participants provided on the front page of the questionnaire, 50 of them (57.5%) completed the 2<sup>nd</sup> questionnaire within one month after completing the 1<sup>st</sup> questionnaire, 31 participants (35.6%) completed the 2<sup>nd</sup> questionnaire between 1.5 and 3 months after completing the 1<sup>st</sup>, while for 6 participants (6.8%) it took 4 to 6 months to complete the 2<sup>nd</sup> questionnaire (see figure 9).

The characteristics of respondents to the 1<sup>st</sup> and the 2<sup>nd</sup> questionnaire are shown in table 22.

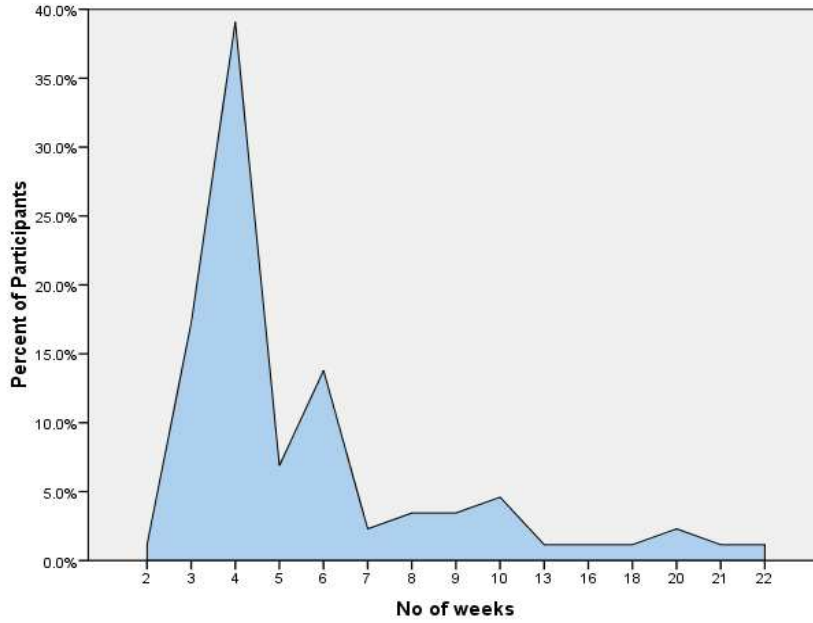


Figure 9. Percentage of participants completing the 2nd questionnaire at each week following the completion of the 1<sup>st</sup> questionnaire.

Table 22  
Demographic characteristics of respondents

		Time 1*	Time 2†
<b>Age</b>	<i>n</i>	141	87
	<i>M</i>	49.2	49.0
	<i>SD</i>	11.7	12.0
<b>Gender</b>	<b>Male</b>		
	<i>n</i>	56	39
	%	38.9	44.8
	<b>Female</b>		
	<i>n</i>	88	61.1
	%	48.0	55.2
<b>Diagnosis</b>	<b>MS</b>		
	<i>n</i>	110	61
	%	76.4	70.1
	<b>TBI</b>		
	<i>n</i>	34	26
	%	23.6	29.9
<b>Time since Onset (yrs)</b>	<i>n</i>	112	87
	<i>M</i>	12.0	9.17
	<i>SD</i>	11.53	8.82

\*Questionnaire at time 1; † Questionnaire at time 2

### 6.6.2. Data screening

Three participants were excluded from the analysis as their responses to the screening questions 1 and 12 were out of range, possibly indicating that they were not experiencing memory difficulties related to their health problems.

*Part A:* Of the remaining 141 respondents 139 completed all the items in part A of the questionnaire. As it can be seen from table 23, five missing values were found in the data set, spread across three variables. It is suggested that if each variable has 5% or less items are missing in a random pattern, then almost any procedure for handling missing data will yield similar results (Tabachnick & Fidell, 2005). The SPSS missing values analysis showed that data were missing completely at random (MCAR;  $p > .5$ ) which means that missing values are scattered randomly through a data matrix posing less serious problems (Ibid.). Missing values were pro-rated by replacing them with the average of the valid items for the case with the missing value. It was considered that omitting cases with a single item missing would unnecessarily reduce the sample size available for the evaluation of test-retest reliability.

*Part B1:* Ten respondents (7.1%) did not complete the questions related to the use of external memory aids. Eight of them reported that they had never tried using EMA. Two respondents said that they felt embarrassed to use them and/or that they had tried using them but found them ineffective (respondents could report more than one reasons).

*Part B2:* Forty two participants (30%) did not complete this part of the questionnaire. The majority of them ( $n=33$ ) reported that they had never used internal memory aids. Four participants had tried using them but found them too complicated, five participants thought they were ineffective and two were embarrassed to use them.

A problem related to the question skips in Part B was noticed in 11 questionnaires (7.8%). Despite reporting a number of memory aids and responding to the related questions, these participants also replied to questions 36 and 45, giving reasons for not using any memory aids. Six of these respondents reported that they had never used memory aids while the rest of them used the other options (embarrassed, too complicated etc.).

### 6.6.3. Distribution of responses

The results of item analysis are presented in Table 23. The distribution of responses for items 1 and 12 was assessed although the items were not included in further analysis.

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Table 23  
Response distribution and descriptive statistics (N=141)

Item No.		Response distribution (%)		Mean	Median	SD	Skew
		Strongly agree/Agree	Disagree/Strongly Disagree				
<b>Part A</b>	<i>N</i>						
<b>1*</b>	141	<b>100</b>	<b>0.0</b>	1.22	1.00	0.41	1.36
2	141	44.7	55.3	2.32	2.00	1.19	0.21
<b>3*</b>	141	<b>80.2</b>	<b>19.8</b>	3.13	3.00	0.97	-0.97
4	141	47.5	52.5	2.27	2.00	1.14	0.14
5	141	72.3	27.7	2.04	2.00	1.00	0.65
6	139	48.9	51.1	2.42	2.00	1.16	0.06
7	141	49.6	50.3	2.65	3.00	1.09	-0.05
8	141	48.9	51.1	2.40	3.00	1.14	0.01
<b>9*</b>	141	<b>14.9</b>	<b>85.1</b>	1.61	1.00	0.95	1.50
10	141	39.0	61.0	2.89	3.00	1.13	-0.44
11	141	65.2	34.7	2.89	3.00	1.10	-0.50
<b>12*</b>	141	<b>0.0</b>	<b>100</b>	1.21	1.00	0.40	1.47
<b>13*</b>	141	<b>90.1</b>	<b>9.9</b>	3.43	4.00	0.82	-1.58
14	141	40.4	59.5	2.67	3.00	1.04	-0.26
<b>15*</b>	141	<b>29.8</b>	<b>70.2</b>	2.14	2.00	1.15	0.60
16	141	54.6	45.4	2.45	3.00	1.18	-0.07
17	141	64.5	35.4	2.16	2.00	0.99	0.38
18	141	77.3	22.7	2.99	3.00	0.96	-0.79
19	141	59.6	40.4	2.40	2.00	1.13	0.24
<b>20*</b>	139	<b>76.2</b>	<b>23.8</b>	1.88	2.00	1.06	0.94
21	141	58.2	41.8	2.64	3.00	1.18	-0.23
<b>22*</b>	141	<b>78.7</b>	<b>21.3</b>	1.82	1.00	1.05	1.06
23	141	61.0	39.0	2.69	3.00	1.07	-0.28
24	140	68.6	31.4	2.16	2.00	1.17	0.56
25	141	75.2	24.8	2.10	2.00	1.07	0.74
26	141	68.0	31.9	2.22	2.00	1.16	0.51
27	141	79.8	20.2	2.09	2.00	1.12	0.68
<b>B1</b>							
<b>29*</b>	131	<b>90.1</b>	<b>9.9</b>	3.50	4.00	0.83	-1.82
30	131	71.0	29.0	2.01	2.00	1.10	0.71
31	131	82.4	17.6	3.34	4.00	0.90	-1.18
32	131	87.0	13.0	3.48	4.00	0.85	-1.64
33	131	86.3	13.7	3.35	4.00	0.75	-0.90
34	131	65.6	34.4	2.21	2.00	1.10	0.46
35	131	70.2	29.8	2.93	3.00	1.16	-0.66
<b>B2</b>							
<b>38*</b>	99	<b>79.8</b>	<b>20.2</b>	3.18	3.00	0.90	-0.89
39	99	70.7	29.3	2.01	2.00	1.01	0.64
40	99	66.7	33.3	2.88	3.00	1.00	-0.43
41	99	66.7	33.3	2.89	3.00	1.06	-0.51
42	99	74.7	25.3	2.89	3.00	0.80	-0.55
<b>43*</b>	99	<b>81.8</b>	<b>18.2</b>	1.72	1.00	0.93	1.15
44	99	55.7	44.3	2.60	3.00	1.15	-0.16

As a result of applying criteria of face validity and distribution of item responses, a total of seventeen items were removed from the questionnaire.

### 6.6.4. Rejected Items

#### Part A

*Item 3-"I am aware of the strengths and weaknesses of my memory"* : This item displayed ceiling effect with high endorsement of the favourable response categories (Strongly agree/Agree). Moreover, its face validity was questioned by reviewers during the preliminary evaluation of the questionnaire. It was suggested that the item could be considered as a double barrelled question combining two questions in one. For example, participants may feel that they are aware of their weaknesses but not of their strengths.

*Item 7-"I do things that are too hard for my memory"*: The validity of the item was doubtful due to ambiguity in the interpretation of the response. A respondent may be involved with tasks too demanding for his memory either because he overestimates his memory ability or because environmental demands oblige him to do so. It was therefore unclear whether endorsing the statement should be scored as indicative of better adjustment.

*Item 9-"Other people have noticed an improvement in my memory ability"* and *Item 11-"I think that people close to me understand how bad my memory is"*: Both items exhibited poor statistical properties. Moreover, two respondents commented on their difficulty to answer these questions as they were living on their own and did not have the opportunity to get feedback on their memory ability. These two items were not applicable to all patients and were, therefore, excluded.

*Item 13-"I try to concentrate hard on things I want to remember"* and *item 15-"I find myself daydreaming when I am supposed to be focusing on a task"*: Both items had poor response distribution indicating ceiling effect. Furthermore, during the preliminary evaluation of the questionnaire, reviewers questioned the appropriateness of including these items suggesting that people may manage to compensate for their memory difficulties despite having attention problems.



*Item 20-"It is harder to remember things when I am upset":* Apart from the poor response distribution the validity of the item was also questionable. This is because it could be interpreted as a statement assessing factual knowledge. Respondents might agree with this statement either because they are personally experiencing stress when they are trying to remember or because they are aware of the association between memory performance and stress levels.

*Item 22-"I worry that I am going to forget something important":* This item was rejected on the basis of its response distribution. There were other questions in the scale tapping similar issues that had better statistical properties.

Although items 25 (*I am anxious about my memory problems*) and 27 (*I panic when I forget something important*) displayed poor distributions it was decided to retain them in the questionnaire for the following reasons: a) they reflected an important dimension of the construct, b) floor effects would not affect the ability of the items to detect improvement, which was the purpose of this questionnaire. Furthermore, as suggested by Holmes et al. (2006; cited in Hobart et al., 2004) the skew values within the -1 to +1 range are considered acceptable.

### Part B1

*Item 29-"Using external MA is part of my everyday life":* This question attempted to address the frequency of use of EMA but it appeared to have poor response distribution with 90% of respondents endorsing the favourable response categories. This indicates ceiling effect that undermines the item's sensitivity.

*Item 30-"I am using the same external MA as I have always used":* This item was removed on the grounds of its face validity. Following memory rehabilitation participants may still be using the same memory aids as before, but in a more effective way.

*Item 34-"I think the way I use external MA could be improved":* This item was removed due to its doubtful face validity. It was suggested that it would not effectively discriminate between people who show good or poor adaptation to their memory problems. For example, people that are well adapted to their memory difficulties may feel that there is still scope for improvement in the way they use memory aids.

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Although Items 31 (*I believe that I make the most of the external MA I am using*) and 32 (*I know which external MA work best for me*) displayed poor distributions it was decided to retain them in the questionnaire as they reflected very important content areas. It has also been argued that skew and kurtosis values within the -2 to +2 range could be considered acceptable (Muthen & Kaplan, 1985).

### Part B2

*Item 38-"Using internal MA is part of my everyday life":* Similar to item 29, descriptive statistics showed that respondents did not use the full range of possible responses for this item.

*Item 39-"I am using the same internal MA as I have always used":* As item 30.

*Item 43-"I think the way I use internal MA could be improved":* As item 34.

**6.6.5. Memory aids checklists**

The frequency of use of external memory aids can be seen in table 24 and of internal memory aids in table 25. The most frequently used external memory aids were notes, diaries and calendars while the repetition, active observation and chunking (or blocking) were the most popular internal memory aids.

Table 24

*Percentage of respondents using external memory aids*

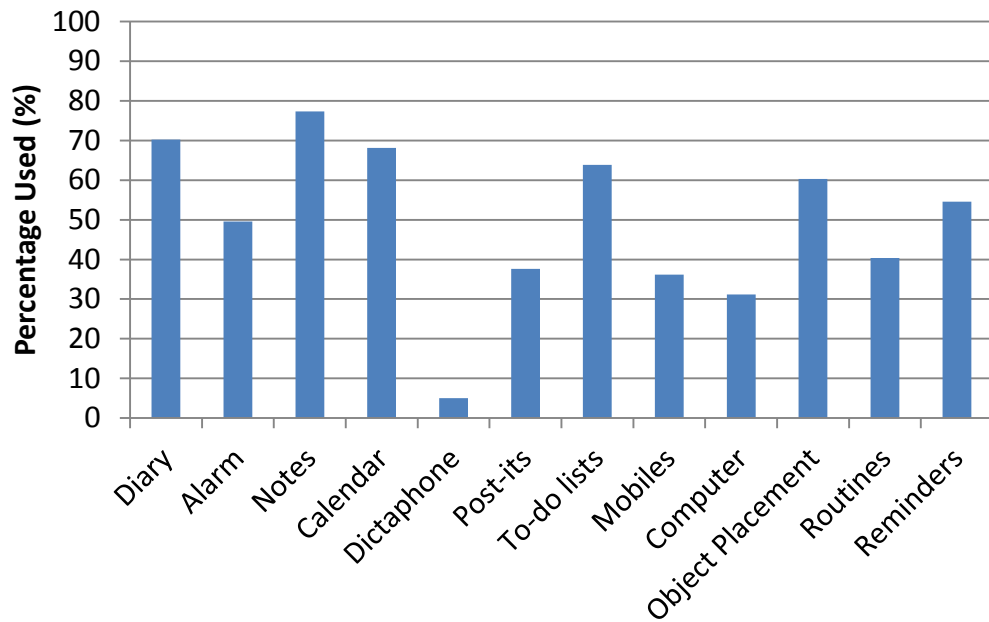
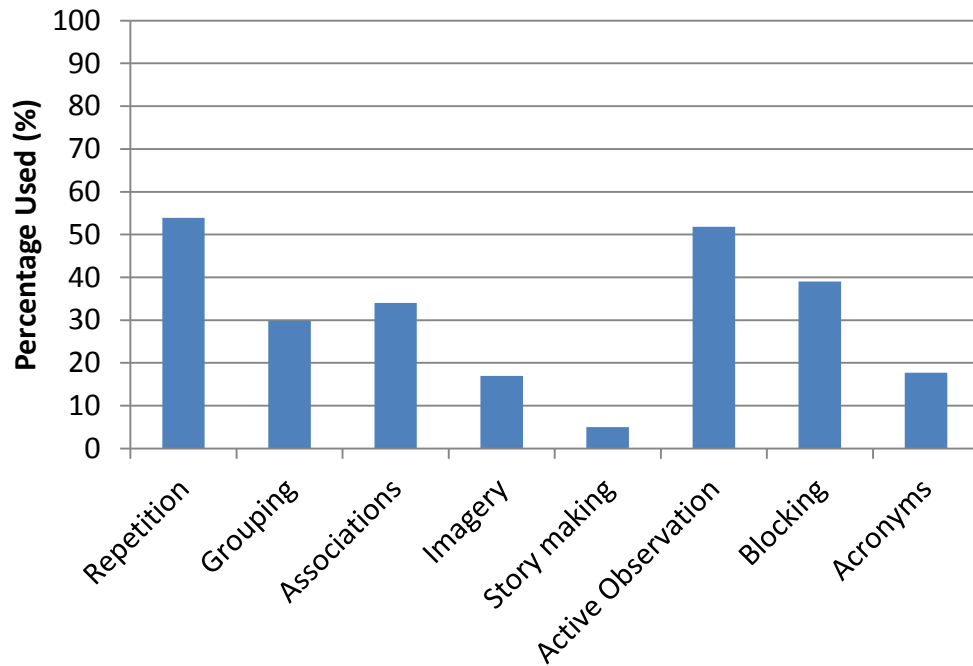


Table 25

*Percentage of respondents using internal memory aids*



#### 6.6.6. Exploratory factor analysis

The responses to the retained items were further subjected to Principal Component Analysis. Each of the three parts of the questionnaire (Part A, B1, B2) was analysed separately.

#### Preliminary assessments

##### *Part A.*

The respondents to variables ratio was 8.29:1, well above the recommended 5:1 ratio. The skew of the items ranged between -0.8 to 0.74 and kurtosis from -1.49 to -0.23. It has been suggested that as long as neither of these values is larger than +/-2.0, skew and kurtosis may not cause significant distortions in the analysis (Muthen & Kaplan, 1985).

The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was .83 which exceeds the recommended value of .6 and is interpreted as “great” (Field, 2005). It is therefore suggested that the associations between the variables can be accounted for by a smaller set of factors (Ferguson & Cox, 1993).

Bartlett's test of sphericity was significant ( $\chi^2 = 871.87, p <.001$ ) indicating that relationships exist between the variables. The anti-image correlation matrix was also inspected. The on-diagonal values, which are the KMO values for each variable, should be above .6, another requirement for good factor analysis (Tabachnick & Fidell, 2005). Except for item 10, that had a KMO value of .34, the rest of the items ranged above the recommended threshold (.72-.92). Field (2005) suggested that if any of the items is found with a value below .5 then researchers should consider either "*excluding the item from the analysis or running the analysis with and without that variable and note the difference*" (p.650). *In this study, PCA was conducted with and without item 10.*

### *Part B1.*

Sample size exceeded the suggested levels with a ratio of 26.2: 1. The skew of the items ranged between -0.16 and -0.66 and kurtosis from -0.18 to 0.10. Normality of the distribution of each item was further assessed using Fisher's skewness coefficient (skewness/standard error of skewness). This test showed that in all the items the skewness coefficient exceeded the acceptable  $\pm 1.96$  limits (ranged from -5.57 to -3.13). These results indicated that the distribution of item responses was significantly different from a normal distribution. It has been suggested that skewness might attenuate the association between the variables particularly when these variables are skewed at the opposite direction (Dunlap et al., 1995). In the last case, skewness could consequently result to questionnaire items being grouped into factors according to their difficulty –"difficult" vs. "easy" items- (Ibid.). An option that was considered was to reduce the skew by transformation. Log transformation was applied and skew was considerably reduced. Principal component analysis was conducted with and without transformation and the results were compared. PCA with and without transformation led to the same factor solution, revealing the presence of one underlying component. A major disadvantage of the method is that transformed variables are harder to interpret (Tabachnick & Fidell, 2001). Interpretation could be further hindered as the majority of items had negative skew and they, therefore, had to be reflected (reversed) before the transformation for positive skew could be applied. As the current questionnaire was intended for use in clinical practice data transformation was considered impractical.

The KMO statistic was .78, exceeding the acceptable level and Bartlett's test of sphericity reached statistical significance ( $\chi^2 = 243.36, p <.001$ ). Items on the diagonal of

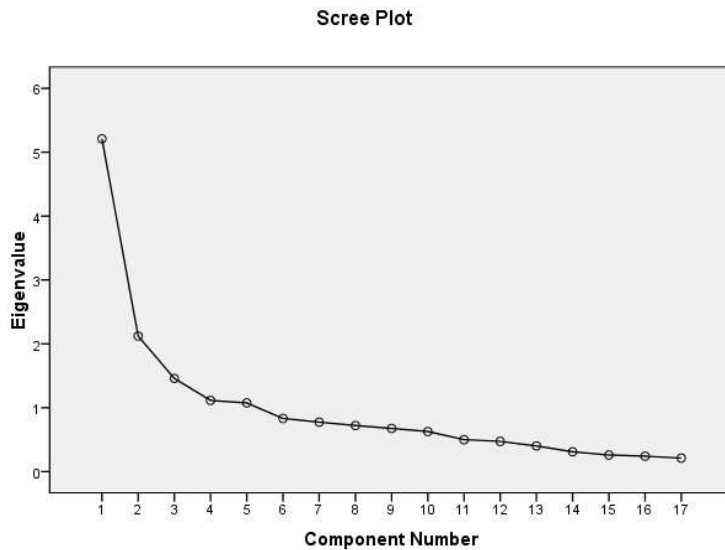
the anti-image correlation matrix ranged between .75 and .84 (>0.6), further supporting the factorability of the data.

*Part B2.*

The size of the sample size exceeded the recommended levels with a ratio of 19.8:1. Skew and kurtosis were within acceptable limits, skew ranging from -0.55 to -0.16 and kurtosis from -1.39 to 0.17. The KMO test was .78, well above the recommended value, and Bartlett's test was significant ( $\chi^2 = 167.77, p < .001$ ). Inspection of the anti-image matrix showed that all correlation coefficients were well above the acceptable level of .6, the lowest correlation being .78 and the highest .86. The appropriateness of the correlation matrix was, therefore, confirmed and PCA was performed.

### Factor extraction

*Factor analysis on 17 items of Part A.* After eliminating 10 items on the grounds of poor response distribution and face validity, PCA was initially performed on the remaining 17 items (see table 26 p.243). The unrotated principal components analysis revealed the presence of 5 components with eigenvalues exceeding 1 explaining in total 64.58% of the variance in the correlation matrix. The scree plot visually supported the five factor solution (see figure 10).



*Figure 10. Scree plot for Part A of the questionnaire (17 items).*

The rotated loading matrix was then inspected to assess the number of variables that loaded on each factor. Without changing the underlying factor solution, factor rotation results in maximizing the loading of each variable onto one factor while minimising the loadings on the remaining factors (Field, 2005). An oblique rotational technique with five factors was initially used to assess the strength of the relationship between the factors. The correlations between the factors were found to be lower than 0.32 indicating that there was no overlap in the variance among factors and therefore the application of orthogonal rotation was more appropriate. The factors were therefore rotated using an orthogonal (varimax) procedure which converged in 6 iterations.

Following rotation the acceptable magnitude of loadings was defined. Tabachnick & Fidel (2001) recommended that variables with loadings lower than .32 should not be interpreted and suggested a loading of .45 and above (indicating that a variable is a “fair”

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measure of these factors). Therefore, a minimum loading of .45 was the criterion for interpretation chosen for this study.

Table 26.

*Factor loadings and amount of variance explained by each factor for Part A(17 items)*

Part A Subscales	Component loadings				
	1 30.64% of total variance	2 12.48 % of total variance	3 8.57 % of total variance	4 6.55% of total variance	5 6.32 % of total variance
Q2.I have had enough information on why I have memory difficulties	.22	<b>.79</b>	-.13	.09	-.03
Q4. I understand how memory works	.00	<b>.78</b>	.04	-.05	.08
Q5. I find it difficult to come to terms with my memory problems	<b>.58</b>	-.04	.21	.07	.12
Q6. I know how to use the strong aspects of my memory to compensate for the weaker aspects	.09	<b>.69</b>	.39	.10	-.04
Q8. I understand why I remember some things more easily than others	.10	<b>.58</b>	.16	.02	-.46
Q10. <i>I avoid finding out more about my memory difficulties</i>	.01	-.01	.03	-.01	<b>.89</b>
Q14.I am well organised in how I cope with my memory difficulties	.22	.36	<b>.56</b>	.44	.05
Q16. I have been doing things I believe will improve my memory	-.06	.38	.60	-.22	.12
Q17. I have little control over memory ability	.30	-.05	<b>.68</b>	-.33	-.01
Q18. There are ways to cope with my memory difficulties	.22	.28	<b>.45</b>	.19	.28
Q19. Rely on other people to remind me of what I have to do	.17	-.10	<b>.67</b>	.21	-.13
Q21. <i>I talk to other people openly about my problems</i>	.16	-.01	.01	<b>.82</b>	.00
Q23. I am confident that I can cope with my memory difficulties	.52	.25	<b>.54</b>	.34	-.04
Q24. It upsets me when others notice my memory difficulties	<b>.86</b>	.06	.03	.01	.00
Q25. I am anxious about my memory difficulties	<b>.82</b>	.12	.23	.11	-.07
Q26. My memory difficulties make me feel embarrassed	<b>.83</b>	.15	.15	-.50	-.02
Q27. I panic when I forget something important	<b>.73</b>	.10	.12	.21	-.03



As it can be seen in table 26, the first three components had a number of strong loadings but the fourth and fifth factors had only one substantial loading respectively. Items 10 (*I avoid finding out more about my memory difficulties*) which defined the 4<sup>th</sup> factor and 21 (*I talk to other people openly about my memory problems*) which defined the 5<sup>th</sup> factor were developed to capture emotional adjustment (p.218) but did not load on the 1<sup>st</sup> factor as the rest of the items of this content area. The lack of other high loadings on these factors made their interpretation ambiguous. It has been suggested that if a factor has only one variable, it is poorly defined and unstable (Costello & Osborne, 2005; Tabachnick & Fidell, 2001). Concerns were raised over the appropriateness of retaining two single item subscales. The inadequacy of a single item to capture the complexity of the construct could undermine the validity of this scale (Hobart et al, 2007). Hobart et al. (2007) suggested that single item scales are scientifically weak with poor validity, reliability and responsiveness. Single items are associated with substantial random error and, therefore, adequately high levels of reproducibility are hard to achieve (Ibid).

Furthermore, as seen earlier, item 10 had a KMO value below .5, a strong indication for excluding it from factor analysis. For all the above reasons, items 10 and 21 were removed and PCA was rerun.

*Factor analysis on 15 items of Part A.* The unrotated principal components analysis revealed the presence of 3 components with eigenvalues exceeding 1 accounting for 34.27 of the variance, 14.04 and 9.38 respectively. Therefore, according, to Kaiser's criterion 3 factors should be extracted, explaining in total 57.70% of the variance in the correlation matrix. Inspection of the scree plot further supported the three-factor solution. As it can be seen in figure 11, there was a break in the curve between components 3 and 4. Parallel analysis confirmed the presence of three components with eigenvalues exceeding the corresponding criterion values for a randomly generated data matrix of the same size. As illustrated in table 27, the eigenvalue of the fourth component was below this threshold and, therefore, it could not be retained. The reproduced correlation matrix showed that there were 50 (47%) no redundant residuals greater than .5. According to Field (2005), if less than 50% of residuals are greater than .5, researchers may be more confident that the factor analysis solution gives a good explanation of the data.

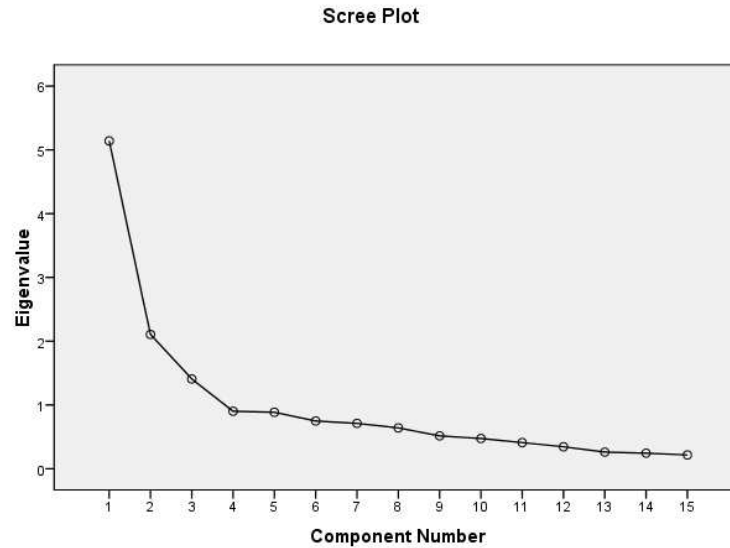


Figure 11. Scree plot for Part A of the questionnaire (15 items).

Table 27

*Comparison of the eigenvalues from PCA and the corresponding criterion values obtained from parallel analysis for Part A*

Component number	Eigenvalue from PCA	Criterion value from PA
1	5.14	1.59
2	2.11	1.45
3	1.41	1.35
4	0.90	1.26

In order to facilitate the interpretation of these factors the variables were rotated. The factors were therefore rotated using an orthogonal (varimax) procedure which converged in 5 iterations. As it can be seen in table 28, all variables had loadings of .45 and above. It was shown that the remaining 15 items loaded to the same components as before the removal of items 10 and 21. The content of variables with the highest loading on each component was assessed in order to identify the nature of the underlying component.

Table 28

*Factor loadings and amount of variance explained by each factor for part A (15 items)*

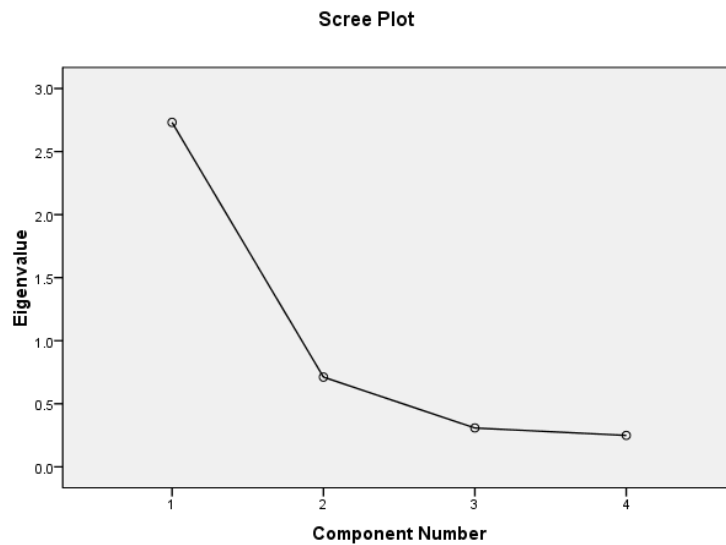
Part A Subscales Abbreviated items	Component loadings		
	1 "Emotional adjustment" (23.74% of total variance)	2 "Memory Knowledge" (17.27% of total variance)	3 "Control"  16.69% of total variance
Q2. Information on M.D. (memory difficulties)	.22	<b>.79</b>	-.10
Q4. Understand how memory works	-.03	<b>.74</b>	.08
Q5. Difficulty to come to terms with M.D.	<b>.57</b>	-.06	.25
Q6. Use strengths to cope with weaknesses	.10	<b>.71</b>	.39
Q8. Knowledge of memory strengths	.11	<b>.63</b>	.10
Q14. Organised in coping with M.D.	.28	.39	<b>.59</b>
Q16. Do things to improve memory	-.14	.35	<b>.61</b>
Q17. Have little control over memory	.21	-.09	<b>.69</b>
Q18. There are ways to cope with M.D.	.22	.26	<b>.50</b>
Q19. Rely on other people to be remind	.20	-.06	<b>.66</b>
Q23. Confident in ability to cope with M.D.	<b>.56</b>	.28	<b>.53</b>
Q24. Upset when people notice M.D.	<b>.85</b>	.06	.06
Q25. Anxious about my M.D.	<b>.83</b>	.13	.25
Q26. Embarrassed of my M.D.	<b>.80</b>	.14	.18
Q27. Panic when forgetting something important	<b>.75</b>	.13	.03

The first component comprised items related to respondents' level of emotional adjustment, the second component corresponded to the "memory knowledge" category while a combination of items from the initial "active coping" and "control beliefs" categories formed the third "control" component. The pattern matrix was reasonably simple with all but one items loading highly on only one of three factors. For item 23 the difference between loadings on two factors was less than .20. It was decided to include the item in the "Control" subscale, as it was intended to measure self-efficacy. Cross loadings may be problematic as they indicate that a variable is related to more than one factor. According to Ferguson & Cox (1993) the treatment of cross-loadings is affected by *"whether the scales are required to be psychologically pure, that is clear and distinct*

factors” (p.91). Here the cross loading may indicate a construct overlap which is meaningful considering the documented in the literature relation between self-efficacy and emotional adjustment. This overlap is, therefore, of theoretical interest itself and will be taken into account when interpreting the results. Furthermore, it was found that retaining the item in the “Control” factor enhanced the internal consistency of the subscale (results on internal reliability presented in page 251).

### *Part B1.*

As seen in page 236, three items were dropped due to poor response distribution and face validity. PCA was, therefore, performed on the remaining 4 items (Table 30, p. 248). Kaiser’s criterion indicated the extraction of one component with an eigenvalue exceeding 1, which accounted for 68.29% of the variance. Catell’s scree test (Figure 12). Parallel analysis (Table 29) further supported the presence of one underlying component. Factors loadings are shown in table 30.



*Figure 12. Scree plot for Part B1 of the questionnaire.*

Table 29

*Comparison of the eigenvalues from PCA and the corresponding criterion values obtained from parallel analysis for parts B1 and B2*

	Component number	Eigenvalue from PCA	Criterion value from PA
<b>Part B1</b>	1	2.73	1.20
	2	0.71	1.05
<b>Part B2</b>	1	2.74	1.22
	2	0.55	1.06

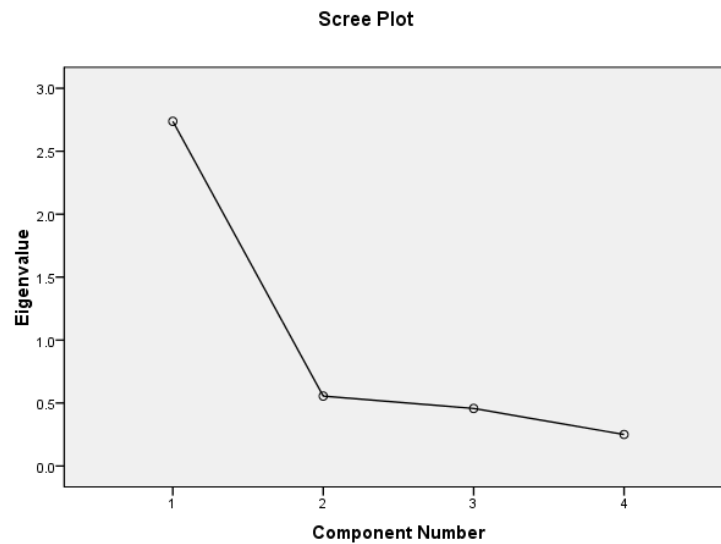
Table 30

*Factor loadings and amount of variance explained by each factor for Part B*

Part B Subscales Abbreviated items	Component loadings
<b>B1</b>	<b>External memory aids</b> (68.29 % of total variance)
Q31. I believe that I make the most of EMA I am using	.85
Q32. I know which EMA work best for me	.90
Q33. The EMA I am using are effective	.88
Q35. I have a range of EMA that I can use for different tasks	.65
<b>B2</b>	<b>Internal memory aids</b> (68.44% of total variance)
Q40. I believe that I make the most of IMA I am using	.83
Q41. I know which IMA work best for me	.90
Q42. The IMA I am using are effective	.81
Q44 I have a range of IMA that I can use for different tasks	.76

### *Part B2.*

Factor extraction was performed on four items (Table 30). PCA indicated the presence of one component with an eigenvalue exceeding 1, accounting for 68.44% of the variance. The scree plot visually suggested a break after the first component (Figure 13). These findings were further supported by Parallel Analysis (Table 29). As it can be seen in table 30, all items loaded substantially on only one component.



*Figure 13. Scree plot for Part B2 of the questionnaire.*

**Distribution of scores in the revised scales***Part A.*

The descriptive statistics for the total score and the three subscales are presented in table 31. The normality of the distribution of scores on each of the subscales was tested by inspecting the histograms and calculating Fisher's skewness coefficient. When the total score of Part A was assessed, it was found to be normally distributed ( $z = 0.06/0.20 = 0.30$ ). Similarly, the "Memory knowledge" ( $z = 0.08/0.20 = 0.37$ ) and "Control" ( $z = -0.16/0.20 = -0.80$ ) subscales were roughly normally distributed. The "Emotional adjustment scale" was positively skewed ( $z = 0.63/0.20 = 3.1$ ) as the majority of cases was clustered towards the more negative scores. Skewness, however, was still within the recommended  $-1+1$  range.

Table 31  
*Distribution of scores in the revised scale*

<b>Revised Subscale</b>	<b>N</b>	<b>Mean</b>	<b>Median</b>	<b>SD</b>	<b>Skew</b>
<b>Part A total</b>	141	2.36	2.40	0.63	0.06
<b>Emotional Adjustment</b>	141	2.12	2.00	0.88	0.63
<b>Memory knowledge</b>	141	2.35	2.25	0.86	0.08
<b>Control</b>	141	2.56	2.67	0.71	-0.16
<b>Part B1</b>	131	3.27	3.50	0.74	-1.13
<b>Part B2</b>	99	2.80	3.00	0.82	-0.38

*Part B1.*

The distribution of the total scores was negatively skewed ( $z = -1.13/0.21 = -5.7$ ) as the majority of people obtained high scores (Table 31).

*Part B2.*

Participants' scores on this scale were fairly normally distributed ( $z = -0.38/0.24 = -1.6$ ).

### 6.6.7. Reliability of revised scales

#### Internal consistency

##### *Part A.*

The results of PCA indicated that further item reduction was not needed. Therefore, the revised first part of the questionnaire consisted of 15 items. Cronbach's alpha for the total scale score was .85 and all items correlated to the total score at a level of above .30.

All the three subscales that were formed following factor analysis displayed a high level of internal consistency (Table 32). Coefficient alpha for each of the three subscales and for the composite score sum were calculated. Item 23, that loaded on two factors, was included in the "Control" subscale, resulting to an improvement of alpha coefficient for this subscale. Inter-item correlations for the "Memory knowledge" subscale ranged from .30 to .52 and the mean was 0.42. For the "Emotional adjustment" subscale inter-item correlations ranged from .32 to .70 ( $M= 0.53$ ) and for the "Control" subscale they ranged from .22 to .68 ( $M=0.34$ ). All item total correlations in the three subscales were substantial ( $>.35$ ). In the "Emotional adjustment" and "Memory knowledge" subscales item-total correlations exceeded item-other subscale correlations by at least 2 *SE* of a correlation coefficient. Item 23, as already seen, correlated slightly higher with the "Emotional adjustment" than the "Control" subscale.

Inter-correlations between the subscales were also computed (Table 33). Spearman correlation coefficient was used to assess the relationship between "Emotional adjustment" and the other two subscales. Fair correlations were observed between the "Control" and "Emotional adjustment" subscales [ $r(139) = .52, p < .001$ ] and between the "Memory knowledge" and "Control" subscales [ $r(139) = .43, p < .001$ ]. A weaker association was found between the "Emotional adjustment" and the "Memory knowledge" subscales [ $r(139) = .26, p < .001$ ].



Table 32  
*Item-scale correlations and Cronbach's  $\alpha$  for each subscale*

Part A Subscales	Correlations		
	Corrected own scale	Other scales	Difference*
Emotional Adjustment $\alpha = .82$	.46-.78	.10-.51	.27-.57
Memory knowledge $\alpha = .74$	.48-.58	.10-.27	.20-.42
Control $\alpha = .75$	.38-.62	.10-.62	-.00-.34

\*(item-own scale correlation)-(item other scale correlation)

Table 33  
*Correlations between the subscales of Part A*

	Memory knowledge	Control	External MA	Internal MA
Emotional adjustment	.26	.52	.24	.27
Memory knowledge		.43	.45	.56
Control			.47	.48

*Part B1.*

No further items were removed as a result of PCA. Cronbach's alpha was .81 and item total correlations ranged from .47 to .76. Inter-item correlations ranged from .33 to 0.73 and the mean was 0.57. The distribution of the total scores was negatively skewed ( $z = -1.13/0.21 = -5.7$ ) as the majority of people obtained high scores.

*Part B2.*

PCA did not result in further item reduction. Four items were retained in this part of the questionnaire. Cronbach's  $\alpha$  was .84 and item-total correlations ranged from .60 to .79. Inter-item correlations ranged from .46 to .72 and the mean was 0.58. Participants' scores on this scale were fairly normally distributed ( $z = -0.38/0.24 = -1.6$ ).

### Stability

Following item reduction, test-retest reliability analyses were performed on the revised versions of parts A, B1 and B2. For part A, stability was assessed for both the total score and for each of the subscales that emerged from factor analysis.

#### *Part A.*

Test-retest reliability was computed for 87 participants. Nine missing values were found in 6 questionnaires in questions 6, 9, 11, 13, 18 and 24. SPSS missing value analysis showed that omitted items were missing completely at random (MCAR) posing less serious problems ( see also p.233). Similarly to the 1<sup>st</sup> questionnaire missing values were replaced with the mean of the valid responses of each participant.

Total score: The test and retest scores were both normally distributed. The Fisher's skewness coefficient for the test scores was 0.70 and the retest scores 0.74. The value of Levene's statistic comparing test and retest scores was 1.46 ( $p=.14$ ) indicating that the variances of the two measures did not significantly differ. A visual inspection of the plot showed a linear relationship between the test and retest scores. Given the results of these analyses, parametric tests were used for assessing reliability.

"Emotional adjustment" subscale: The data met the criteria of equal variances ( $F= 1.53$ ,  $p=.12$ ) and linearity but violated the assumption of normality as scores on both occasions were positively skewed (time 1:  $z= 2.1$ ; time 2:  $z= 3.0$ )

"Memory knowledge" subscale: Data in this subscale met the assumptions of normality (time 1:  $z=-0.26$ ; time 2:  $z=-1.40$ ), linearity and equal variances ( $F=0.59$ ,  $p=.62$ ).

"Control "subscale: Parametric tests were used for the reliability analyses of this subscale as data met the criteria of normality (time 1:  $z=0.92$ , time 2:  $z=.94$ ), linearity and equal variances ( $F=0.83$ ,  $p=.62$ ).

#### *Part B1.*

Test-retest reliability was computed for 81 respondents after excluding three people who reported that they had never used external memory aids (3.4%) and, therefore, did not complete this part of the questionnaire. Another three people were excluded as they had not completed this part in the first questionnaire without providing an explanation.

The data violated the assumptions of normality and equal variances. Both test and retest scores were negatively skewed. The Fisher's skewness coefficient for the test scores was -2.6 and the retest scores -3.9. The value of Levene's statistic for the test and retest scores was 4.81 ( $p < .001$ ). A visual inspection of the plot showed a fairly linear relationship between the test and retest scores. These results indicated that non-parametric tests should be used in subsequent analyses.

### Part B2.

Reliability for this subscale was computed for 65 respondents after excluding nineteen people (22%) who did not fill in this part of the questionnaire as they were not using internal memory aids. Fourteen of them reported that they had never tried using them and five believed they were too complicated and/or ineffective. Reliability could not be assessed for three people who had not completed this part in the first questionnaire without giving any reasons. The data met the assumptions of normality, equal variances and linearity. The Fisher's skewness coefficient for the test scores was -0.8 and the retest scores -0.7. The value of Levene's statistic for the test and retest scores was 1.913 ( $p = .70$ ). Therefore, parametric statistics could be used to evaluate test-retest reliability.

Once again the problem related to question skips was encountered, although to a lesser extent. Four people (4.6%) reported using memory aids while also completing the questions 36 and 45. Half of them noted that they had never tried using memory aids and the rest endorsed the other options (embarrassed, ineffective, etc.).

As it can be seen in Table 23, Pearson's correlations showed a very strong relationship between test and retest on Part A total scores [ $r(85) = .82, p < .001$ ] and a moderately strong association between scores for Part B2 [ $r(63) = .64, p < .001$ ]. A significant correlation was also found between scores for Part B1, as indicated by the Spearman's correlation coefficient [ $r(79) = .60, p < .001$ ]. Regarding the Part A subscales, Spearman's coefficient indicated a very strong correlation between test and retest scores for the "Emotional adjustment" subscale [ $r(85) = .82, p < .001$ ] while Pearson's correlations showed moderately strong correlations for the "Memory knowledge" [ $r(85) = .66, p < .001$ ] and the "Control" subscales [ $r(85) = .79, p < .001$ ].

Paired samples t-tests were conducted to compare the test and retest scores for Parts A and B2 of the questionnaire. As shown in table 34, there was no significant difference between Part A test scores ( $M = 37.09, SD = 8.21$ ) and retest scores ( $M = 37.97, SD = 8.25$ ;

$t(85)=-1.66, p=.10$ ). Similarly, no significant difference was found between Part B2 scores for time one ( $M=11.80, SD=2.81$ ) and time two ( $M=11.74, SD=2.75; t(63)=0.36, p=.72$ ). In order to compare the mean scores for Part B1, Wilcoxon Signed Rank Test was performed and the result was converted to a z-score. It was found that test scores were significantly higher ( $Mdn=14.50$ ) than retest scores ( $Mdn=14.0; z=-1.96, p=.05$ ). The difference however, represented a small sized effect  $d=0.20$ . When the subscales of Part A were examined separately, a significant difference was observed between the “Memory knowledge” subscale for time one ( $M=2.5, SD=.84$ ) and time two [ $M=2.6, SD=0.74; t(85)=-2.12, p=.03, d=0.22$ ]. No significant difference was found for the “Control” subscale between time one ( $M=2.7, SD=.62$ ) and time two ( $M=2.7, SD=0.60; t(85)=-0.64, p=.52$ ). Similarly, Wilcoxon Test showed that scores on the “Emotional adjustment” subscale did not differ significantly between test ( $Mdn=2.0$ ) and retest ( $Mdn=1.8; z=-0.19, p=.85$ ).

Table 34  
Correlations and comparisons between test and retest scores

Scale	Time 1		Time 2		Correlations	Comparisons	
	Mean	SD	Mean	SD		Pearson Correlation	t value
<b>Part A total (N=85)</b>	2.47	0.54	2.53	0.55	.82	-1.66	.10
<b>Memory knowledge</b>	2.51	0.84	2.66	0.74	.66	-2.12	.03*
<b>Control</b>	2.71	0.62	2.73	0.60	.79	-0.64	.52
<b>Part B2 (N=63)</b>	2.95	0.71	2.91	0.70	.64	0.36	.72
Non-Parametric analyses	Median	IQR	Median	IQR	Spearman Correlation	Z score	p value
<b>Emotional adjustment</b>	2.0	1.4-2.6	1.80	1.4-2.8	.82	0.19	.85
<b>Part B1 (N=79)</b>	3.75	3.25-4.0	3.50	3.0-4.0	.60	-1.96	.05*

\*Correlations significant at  $p<.05$

Bland and Altman plots showed acceptable levels of agreement for Total A scores, "Emotional adjustment", "Control" and "Internal Memory Aids" subscales whereas the "Memory knowledge" and "External Memory Aids" subscales showed lower levels of agreement. More specifically for Part A total score, the plot indicated that on average, scores on the second questionnaire differed from the first questionnaire by 0.06 points (Figure 14). The 95% levels of agreement were +1.2 -1.12.

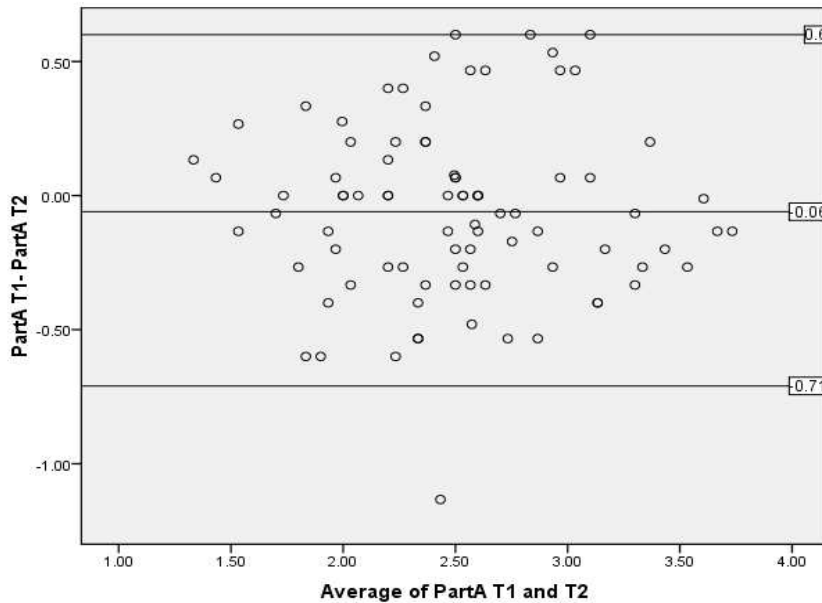


Figure 14. Bland-Altman plot for Part A total score.

## Chapter 6

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For the “Memory knowledge” subscale the degree of difference between the scores ranged from 1.17 to -1.45 points (Figure 15).

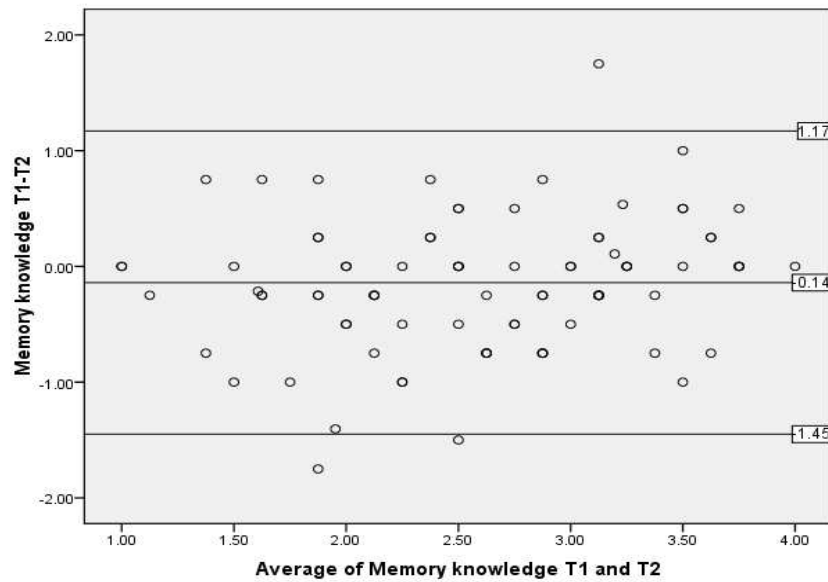


Figure 15. Bland-Altman plot for the “Memory knowledge” subscale.

Regarding the “Emotional adjustment” subscale, as it can be seen in Figure 16, it was estimated that 95% of the time, respondents’ scores at retest differed in a range of 0.96 to -1.0 from the first measurement.

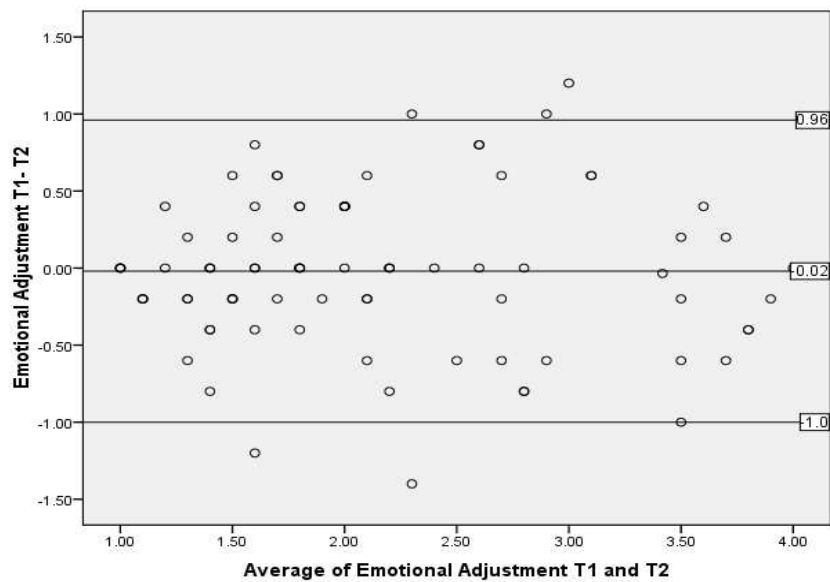


Figure 16. Bland-Altman plot for the “emotional adjustment” subscale.

In relation to the “control” subscale, plots revealed a bias of 5% to 95% limits of agreement from 0.77 to -0.83, as it can be seen in Figure 17.

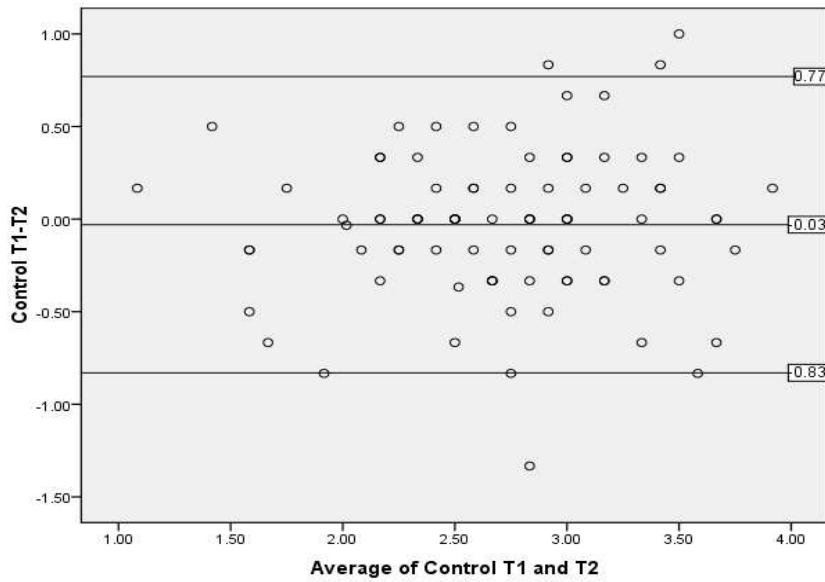


Figure 17. Bland-Altman plot for the “Control” subscale.

In Figure 18 it can be seen that, when measured at retest, respondents’ scores on B1 subscale were on average 0.12 points higher than the average of the measurements.

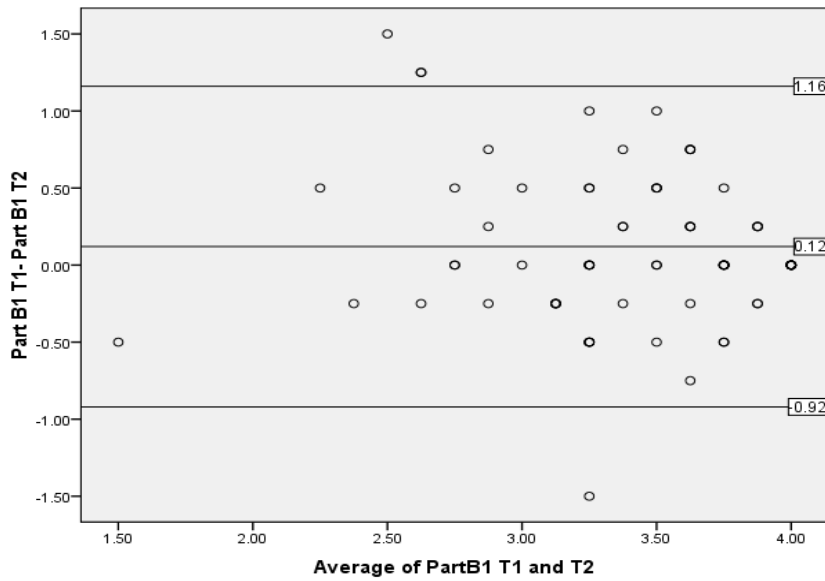


Figure 18. Bland-Altman plot for “External memory aids” subscale.

As seen in Figure 19, for Part B2 of the questionnaire the average difference between test and retest was 0.04.

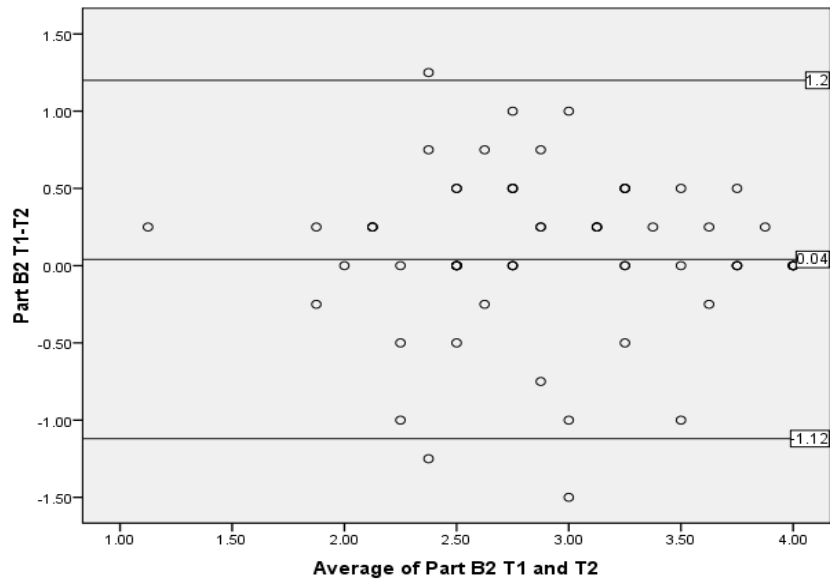


Figure 19. Bland-Altman plot for "Internal memory aids" subscale.

#### 6.6.8. Test-retest reliability of memory aids checklists

The results of test retest reliability for external and internal memory aids checklists are summarised in tables 35 and 36 respectively. Data at Time 1 and Time 2 were compared using the McNemar test . The only significant difference between the two time points was seen in the use of post-it notes which increased at Time 2 ( $N=81$ ,  $p=.04$ ).



Table 35  
 Comparisons between Time 1 and Time 2 for external memory aids checklists

External Memory Aids	Time 2	Time 1			Exact $p$
		Non-use	Use	Total	
Diary	Non-use	17	2	19	1.0
	Use	2	60	62	
	Total	19	62	81	
Alarms	Non-use	29	9	38	.80
	Use	7	36	43	
	Total	36	45	81	
Notes	Non-use	7	5	12	.73
	Use	3	66	69	
	Total	10	71	81	
Calendar	Non-use	12	8	20	.81
	Use	10	51	61	
	Total	22	59	81	
Dictaphone	Non-use	73	1	74	1.0
	Use	2	5	7	
	Total	75	6	81	
Post-it notes	Non-use	34	2	36	<b>.04*</b>
	Use	10	35	45	
	Total	44	37	81	
To-do lists	Non-use	14	9	23	.61
	Use	6	52	58	
	Total	20	61	81	
Mobiles	Non-use	35	4	39	.12
	Use	11	31	42	
	Total	46	35	81	
Computers	Non-use	41	5	46	.58
	Use	8	27	35	
	Total	49	32	81	
Object placement	Non-use	15	3	18	.23
	Use	8	55	63	
	Total	23	58	81	
Routines	Non-use	33	4	37	.75
	Use	6	38	44	
	Total	39	42	81	
Reminder	Non-use	25	10	35	1.0
	Use	10	36	46	
	Total	35	46	81	

\*correlation significant at  $p < .05$

Table 36  
 Comparisons between Time 1 and Time 2 for internal memory aids checklists

Internal Memory Aids	Time 2	Time 1			Exact $p$
		Non-use	Use	Total	
Rehearsal	Non-use	11	6	17	1.0
	Use	5	43	48	
	Total	16	49	65	
Categorisation	Non-use	26	9	35	.80
	Use	7	23	30	
	Total	33	32	65	
Association	Non-use	24	11	35	.82
	Use	9	21	30	
	Total	33	32	65	
Imagery	Non-use	38	6	44	.61
	Use	9	12	21	
	Total	47	18	65	
Story-making	Non-use	55	3	58	1.0
	Use	3	4	7	
	Total	58	7	65	
Active Observation	Non-use	3	4	7	.4
	Use	8	50	58	
	Total	11	54	65	
Chunking	Non-use	22	7	29	.55
	Use	4	32	36	
	Total	26	39	65	
Acronyms	Non-use	40	8	48	1.0
	Use	8	9	17	
	Total	48	17	65	

### 6.6.9. Exploration of factors affecting scores at Time 2

#### Ceiling effects at Time 1

A hypothesis was raised that the observed drop in the scores of parts B1 and B2 at retest could be linked to the ceiling effects in these items observed at Time 1. Changes to both directions may have occurred but due to the negative skewness of the items only deterioration could be detected. Analysis was repeated excluding participants with a total score of 16 (endorsing the most favourable response in all 4 questions). This meant the exclusion of 21 people completing Part B1 and 11 people completing part B2. Fifty eight respondents to part B1 and 52 respondents to part B2 were included in the analysis. For

part B1, the skeweness of test and retest scores (time 1=-1.02; time 2= -0.98) was lower than that of the whole sample analyses (time 1=-1.90; time 2=-1.55) and within the recommended levels (Table 37). Part B2 test and retest scores were also negatively skewed but within the recommended range (time 1=-0.45; time 2=-0.26) and in similar levels as those of previous full sample analysis (time 1= -0.31; time 2=-0.26). In agreement with the results of the full sample analyses, a drop in scores at Time 2 was observed for both B1 and B2. Wilcoxon Signed Rank test indicated that for part B1 this drop was significant ( $z=-2.03$ ,  $p=.04$ ) but the difference represented a small sized effect ( $d=0.31$ ). No significant difference was found between part B2 scores for time 1 ( $M=2.77$ ,  $SD= 0.64$ ) and time 2 ( $M=2.74$ ,  $SD=0.66$ ,  $t=0.1$ ,  $p=.92$ ), replicating previous findings.

Table 37  
*Test-retest stability in Part B after excluding patients scoring at ceiling*

Scale	Time 1		Time 2		Correlations	Comparisons	
	Median	IQR	Median	IQR	Spearman $r$	$z$ score	$p$ value
<b>B1 (EMA)</b>	3.27	3.0-3.75	3.16	2.75-3.75	.43	-2.03	.04*
	Mean	SD	Mean	SD	Pearson $r$	$t$ value	$P$ value
<b>B2 (IMA)</b>	2.77	0.64	2.74	0.66	.38	0.1	.92

\*correlations significant at  $p<.05$

#### Time between test and retest

It is suggested that the observed variability between test and retest scores could be reflective of changes that occurred in the meantime. As seen in page 229, in this study about half of the respondents reported completing the 2<sup>nd</sup> questionnaire 5 to 12 weeks after completing the first one ( $N=37$ , 43%). This interval might be sufficient for important changes to take place. In order to evaluate this hypothesis analyses were repeated including only those participants who completed the 2<sup>nd</sup> questionnaire within a month after the first one ( $N=50$ , 57%). Results indicated improved correlations between Time 1 and Time 2 for the “memory knowledge” subscale of Part A and the two memory aids subscales in Part B (see table 38). Contrary to when the whole sample was included in the

analyses, this time Wilcoxon Tests showed no significant differences between test and re-test scores for the “Memory knowledge” and the “External memory aids” subscales.

Table 38  
*Correlations and comparisons between test and retest scores (questionnaires completed within four weeks)*

Scale	Time 1		Time 2		Correlations	Comparisons	
	Median	IQR	Median	IQR		Spearman Correlations	Z value
<b>Part A total</b> (N=50)	2.53	2.3-2.9	2.6	2.23-2.96	.84	-0.96	.33
<b>Memory knowledge</b>	2.75	1.93-3.25	2.98	2.18-3.25	.67	-1.26	.21
<b>Control</b>	2.83	2.33-3.33	2.83	2.45-3.16	.76	-0.33	.74
<b>Part B2</b> (N=37)	3.00	2.5-3.75	2.75	2.5-3.75	.86	-1.93	.06
<b>Emotional adjustment</b>	2.20	1.6-2.85	2.10	1.6-2.8	.86	-0.07	.94
<b>Part B1</b> (N=47)	3.75	3.25-4.0	3.75	3.25-4.0	.85	-0.88	.38

Bland & Altman Plots

Bland & Altman Plots indicated improved levels of agreement between test and retest for all five subscales (Figures 20-24). In all the subscales, the degree of difference between scores at Time 1 and Time 2 were less or equal to one point on the four point scale. The greatest improvement was seen in subscales that had previously exhibited the biggest discrepancies between test and retest. For the memory knowledge subscale the degree of difference between scores ranged from 0.91 to -1.0 (1.17 to -1.45 when all cases were included), Part B1 0.53 to -0.43 (1.16 to -0.92, full sample) Part B2 0.86 to -0.62 (1.2 to -1.12, full sample).

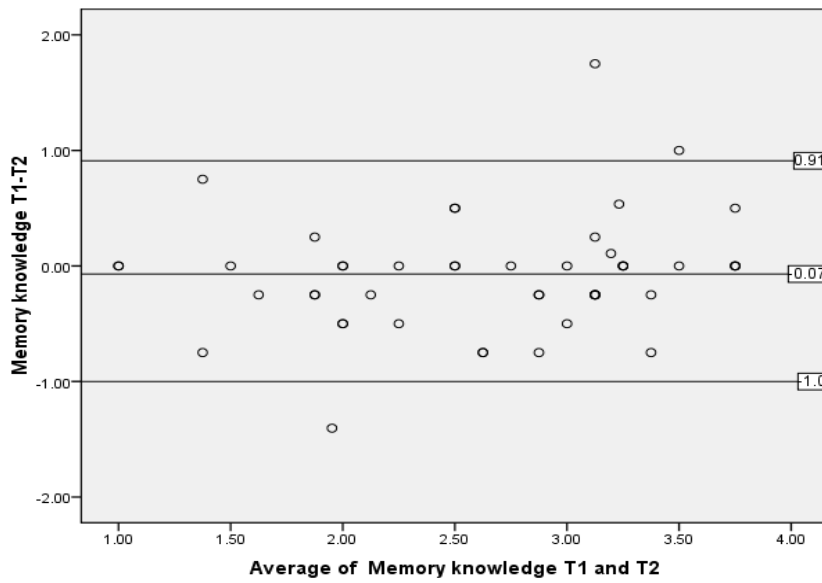


Figure 20. Bland-Altman plot for the “Memory knowledge” subscale (questionnaires completed within four weeks).

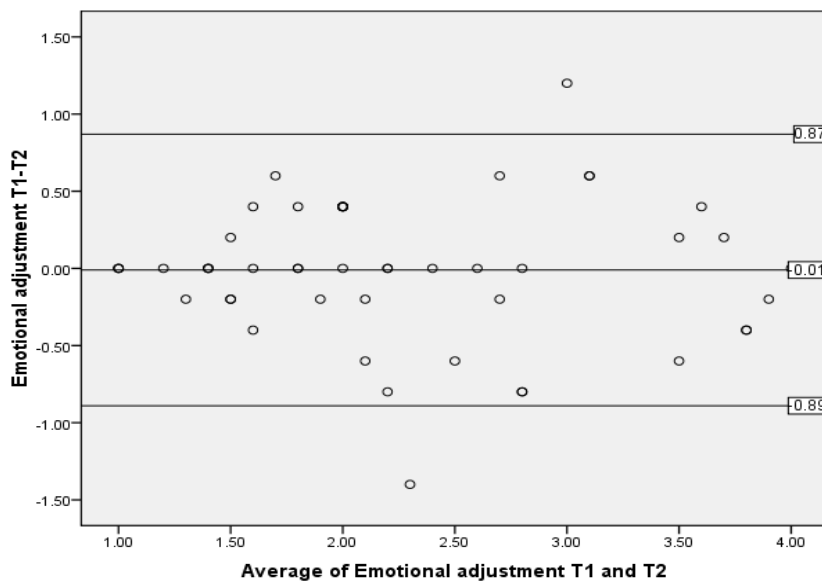


Figure 21. Bland-Altman plot for the “emotional adjustment” subscale (questionnaires completed within four weeks)

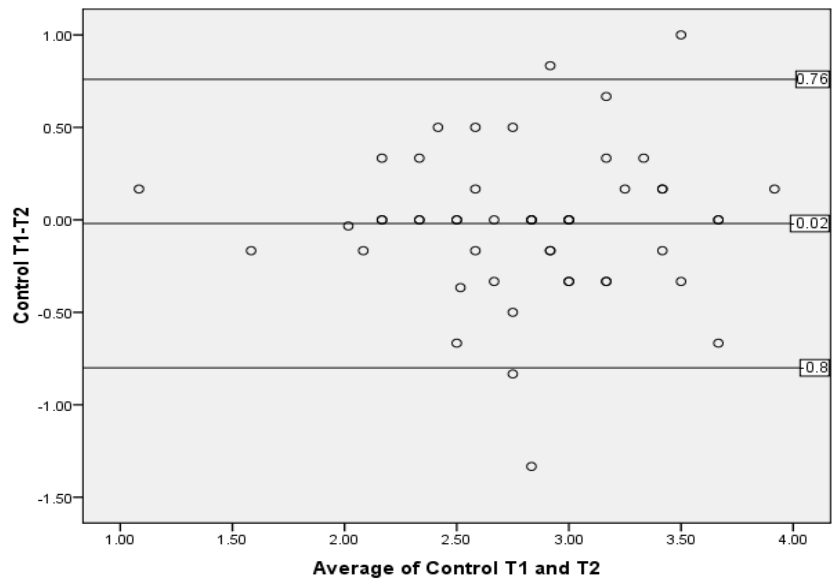


Figure 22. Bland-Altman plot for the "Control" subscale (questionnaires completed within four weeks).

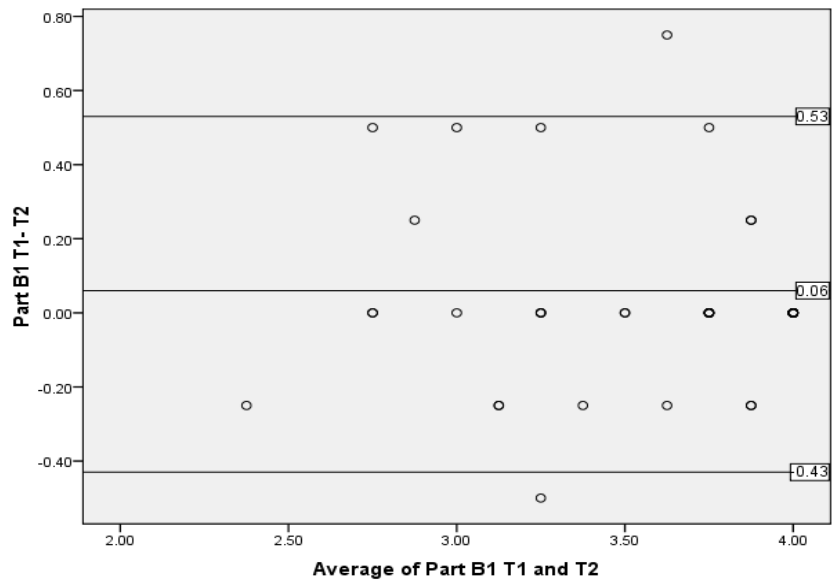


Figure 23. Bland-Altman plot for the "External memory aids" subscale (questionnaires completed within four weeks).

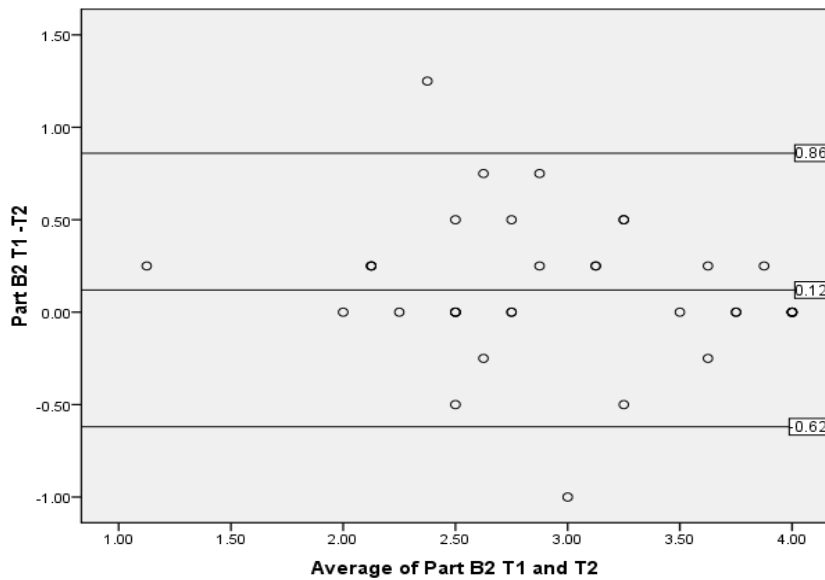


Figure 24. Bland-Altman plot for the "Internal memory aids" subscale (questionnaires completed within four weeks).

Regarding the memory aids checklists, there were no significant differences in the number of memory aids used by participants between test and retest. The increase in the use of post-it notes that was observed when the whole sample was analysed ( $p=.260$ ) was no longer significant ( $p=.06$ ).

#### 6.6.10. Demographics

Pearson's correlation coefficient was used to assess the relationship between age and total scores for Parts A and B2 of the questionnaire. No significant correlation was found between age and Part A scores ( $r=.09$ ,  $p=.29$ ) or Part B1 scores ( $r=.043$ ,  $p=.67$ ). Spearman's correlation showed that age was not related to scores for Part B1 ( $r=-.02$ ,  $p=.81$ ). Spearman's correlations were used to assess the relationship between time since injury/diagnosis and scores in the three parts of the questionnaire. No significant correlations were found between time since injury/diagnosis and Part A ( $r=-.01$ ,  $p=.92$ ), Part B1 ( $r=.05$ ,  $p=.59$ ) or Part B2 ( $r=.04$ ,  $p=.71$ ). The effect of diagnosis (TBI, MS) was also explored. Independent t-tests indicated no significant differences between the two groups of patients on the "Memory knowledge" subscale [ $t(140)=-2.92$ ;  $p=.24$ ], "Control" [ $t(140)=-1.0$ ;  $p=.25$ ] and "Internal memory aids" [ $t(99)=-1.1$ ;  $p=.73$ ] subscales. Similarly,

Mann-Whitney tests showed that diagnosis did not have an effect on the "Emotional adjustment" [ $U(140)=1733.5$ ;  $p=.74$ ] and "External memory aids" scores [ $U(131)=1493.5$  ;  $p=.68$ ].



### 6.7. Discussion

#### 6.7.1. Distribution of responses

In the revised Parts A and B2 of the questionnaire, the distributions of item response categories were satisfactory. The total scores in these two parts showed approximately normal distributions. The only exceptions were two items in the “Emotional adjustment” subscale, tapping anxiety (Q25 and Q27). These two items were positively skewed, reflecting the fact that the majority of respondents experienced anxiety related to their memory problems. Floor effects are not an uncommon finding in scales measuring health-related topics in clinical populations (Bowling, 2010). In this case it was considered that floor effects would not compromise the ability of these items to detect improvement in participants’ levels of anxiety which was the purpose of this questionnaire. Furthermore, the skeweness of these items was within an acceptable range. On the contrary, part B1 items demonstrated ceiling effects with the majority of participants endorsing the more favourable response options. After removing three items on the grounds of poor distribution and face validity, four items were retained in the scale as they were considered important for its content validity. The decision to retain these items in the “Emotional adjustment” and “External memory aids” subscales is in line with Streiner & Norman’s (2008) suggestion that items should not be dropped solely on the skewness of their distribution but the strength of the mean inter-item correlation should also be taken into account. The mean inter-item correlation for these subscales was found to be above the recommended cut-off, further supporting the inclusion of these items in the questionnaire. It is acknowledged, however, that the ceiling effects in Part B1 may compromise the responsiveness of the subscale to improvements following rehabilitation. Caution is therefore warranted by future users of the questionnaire when interpreting the results of this subscale.

It has been suggested that skewness might lead to an underestimation of correlations between the variables (Dunlap et al., 1995). As already discussed one option that was considered was to transform the variables (Tabachnick & Fidell, 2001). This solution was, however, rejected as it could compromise interpretation. Furthermore, as noted by Dunlap et al. (1995), it cannot be ensured that the relationships observed in the transformed data would be representative of the population, particularly when this population might be skewed. Even if the strength of correlations in a specific sample is increased following transformation, it cannot be assumed that correlations will be increased by that

transformation in all future samples (Ibid.). On the other hand, it has been shown that transformation of skewed item responses does not necessarily lead to improvements in Cronbach's alpha and Pearson correlation values (Norris & Aroian, 2004).

It has been suggested that floor and ceiling effects are more likely to be found on measures with a small number of response categories (Vermeersch, 2000; Bowling, 2009.) Therefore, these effects might be reduced by increasing the number of response categories from four to five, by adding a middle point, or to six. The inclusion of five to six categories is recommended in attitude scales as it is considered to allow respondents to express their views without needing to endorse the most extreme categories (Priest, 1995). This solution, however, carries certain disadvantages that have already been discussed in the previous section (p.216). For example, there is concern about the ability of people with cognitive problems to discriminate between options such as "agree", "slightly agree" and "strongly agree". On the other hand, B1 was the only part of the questionnaire demonstrating significantly skewed distribution and, therefore, revising the whole scale might be unnecessary.

The most frequently used external memory aids were notes, diaries and calendars and the least frequent mobiles, computers and Dictaphones. These findings were consistent with those of Evans et al. (2003) who observed that calendars and notebooks were the most popular EMA whereas electronic organisers were not preferred by many individuals. As expected, fewer people used internal memory aids and the main reason for that, as reported by the majority of the respondents, was that they had never been informed about these strategies. This is in line with the observation that most brain injured people will not use internal memory aids spontaneously (Wilson & Kapur, 2008). An alternative explanation could be that cognitive impairments, other than memory difficulties, may have hampered respondents' capacity to effectively use electronic or internal memory aids. However this hypothesis could not be tested in this study as there was no information on participants' nature and extent of actual cognitive impairments. The use of objective cognitive neuropsychological measures in conjunction with the self-report AMEDO questionnaire is recommended in order to answer this question.

The fact that the majority of participants reported being competent in the use of external memory aids was a quite unexpected finding. One possible explanation might be that participants actually overestimated their ability to effectively use external memory aids. This hypothesis brings up the issue of respondents' self-awareness and its effects on the validity of self-completion questionnaires. However, over/under estimation of one's

performance is not necessarily due to impaired ability for accurate self-perception. In this case, it might actually be related to a lack of knowledge and information on the subject. External memory aids are widely used by many people—having memory problems or not—and involve common everyday objects such as diaries and notebooks. They might seem quite straightforward in their use and therefore people may feel that they have already been making the most out of them. This is not the case for internal memory aids with which people are less familiar. This hypothesis may explain why the scores in the internal memory aids scale were more evenly distributed.

Self-awareness issues might also be responsible for the pattern of responses seen in some questions of Part A. Question 3 was highly skewed as most participants reported being aware of the strengths and weaknesses of their memory. At the same time, a high percentage of respondents reported finding it difficult to come to terms with their memory problems. It might be worth assessing the relationship between these variables in a future study.

### **6.7.2. Validity**

#### Face and content validity

The satisfactory response rates and the good completeness of item responses provide some evidence on the relevance and clarity of the questions and, consequently, the face validity of the questionnaire (Bowling, 2009). The methods used for the item generation and selection reinforced the content validity of the scale (Hobart et al., 2004). As noted by Haynes et al. (1995), open ended interviews with people from the targeted population increase the chance that the items are representative of the construct. Rather than being defined by researchers, the content areas covered in this questionnaire reflected the dimensions highlighted by patients themselves. The questions tapped domains of interest to participants and incorporated their perspective and, in that sense, participants were treated as the “experts” in this study. A broad spectrum of people with neurological disabilities was involved in the interview and observational studies making it less likely that important content areas be omitted. It was also ensured that all the important domains that emerged in these previous studies were represented in the items, further supporting the scale’s content validity. The only areas that the questionnaire had been designed to tap but were finally dropped from the questionnaire were “attention” and “significant

others" (Item 9: "*other people have noticed an improvement in my memory ability*"; item 11: "*I think that people close to me understand how bad my memory is*"). The psychometric properties of some of these items as well as their applicability to all the respondents, in the case of the "others" category, were questionable. These findings, however, do not negate the conceptual relevance of these areas to the questionnaire. The very small number of items representing these domains meant that there were not any alternative items that could be retained in place of those discarded. Alternative items need to be developed and tested if these content areas are to be included as distinct subscales in the questionnaire.

### Construct validity

Principal component analysis confirmed that the questionnaire covered most of the content areas it was designed to capture, providing evidence on the internal construct validity of the scale. It was shown that Part B1 and B2 formed two distinct and unidimensional scales representing external and internal memory aids respectively. Part A represented a multidimensional construct requiring three components for its adequate description. The components "Memory knowledge" and "Emotional adjustment" were fairly easy to label as they corresponded to the initial grouping of the items. The categories of "Active coping" and "Control beliefs" merged to form one factor which was labelled "Control". The association between the constructs relating to personal control over the problem (i.e. self-efficacy and locus of control) and active coping has been documented in the literature although the nature of this relationship has not been clarified. According to Bandura (1977), self-efficacy determines the initiation of coping and the stronger the self-efficacy expectations the more active the coping efforts will be. Similarly, Maibach & Murphy (1995) showed that individuals are more motivated to cope actively with their problem when they believe that their efforts will produce the desired outcomes. Active coping has also been conceptualised as a multidimensional construct with self-efficacy being an integral component (Gerin et al., 1996). Carver et al. (1987) found that variations in active coping were related to the amount of perceived controllability of the problem. For example, it was observed that active coping and planning were positively associated with an internal locus of control and "the feeling of being able to do something about the specific stressful situation". It has also been shown that an external locus of control undermines active coping and results to avoidance (Sheppard & Crocker, 2006). Folkman & Lazarus (1980) differentiated between "problem focused coping" which emphasises action (i.e taking action over the problem) and "emotion focused coping" which focuses on

cognition (i.e. cognitive reappraisal of the problem). In this study, the “control” dimension referred to both actions and cognitions that are proactive. These results are in line with the Latack’s (1986) conceptualisation of coping processes which integrates the two types of coping strategies into one dimension labelled “Control”. As suggested by Latack (1986), this coping category involves both “mentally taking control of the situation as well as generating proactive, problem focused actions” (p. 378). Latack also defined two additional coping strategies, the “Escape”, referring to avoidant behaviours and the “Symptom management strategies”. The framework proposed by Latack, has been used to develop and evaluate scales tapping work related stress.

The item convergent validity of the these subscales was corroborated by showing that items correlated more highly with the subscale they belonged to than with the other two subscales. The exception to this was item 23 which, based on both the item-discrimination criteria and PCA, could be included in either the “Emotional analysis” or the “Control” subscale. Although items that do not discriminate between the factors are usually dropped from scales, in this study it was decided to retain the item. It was included in the “control” scale as it was intended to measure memory self-efficacy and it was also shown that it enhanced the internal consistency of that subscale.

The observed overlap was not totally surprising and it was interpreted as reflective of the close association between the constructs of mood and self-efficacy. This assumption was supported by the results of the correlations between the three subscales. A strong association was noticed between the “Emotional adjustment” and the “Control” subscales even when item 23 was omitted. As already discussed in Chapter 3, previous studies have demonstrated an inverse relationship between control beliefs and levels of stress (Bandura, 1982; Felton & Revemon, 1984; Jopson & Morris, 2003). The nature of this relationship, however, has not yet been clarified in the literature. It has been argued that anxiety and avoidance might be a result of low levels of memory self-efficacy (Valentijn et al., 2006) and an external locus of control (Sheppard and Crocker, 2006). Jex et al. (2001) suggested that confident people are more likely to use effective ways of coping with stressors or use coping methods that prevent stressors from occurring in the first place. Gal & Lazarus (1975) on the other hand, proposed that it is active coping which provides a sense of control over the environment and consequently affects stress levels. As seen in previous chapters, although mood problems were never directly addressed in the intervention groups, participants reported improvements in their emotional adjustment. It was proposed that these improvements could be due to participants regaining a sense of

control over the management of their memory problems. In the present study, there was a significant association between “emotional adjustment” and “control”, however, they differed in the way they related to the memory aids subscales. Memory aids subscales were found to correlate significantly with “control” subscale. This was not a surprising finding as the items comprising the MA subscales were essentially measuring participants’ perceived efficacy in relation to the use of MA. In contrast to the control subscale, emotional adjustment correlated only poorly with the use of memory aids. Based on these findings, combining anxiety and self-efficacy items in one scale, as in the case of the Metamemory in Adulthood questionnaire, is not advisable as it can mask the differential effects of these constructs on the use of memory aids.

“Control” also demonstrated a fair positive correlation with “Memory knowledge”. This is in line with the findings of Carver (1989) who showed that active coping and planning were inversely associated with denial. In contrast, “memory knowledge” correlated weakly with “Emotional adjustment”. A possible explanation for this finding could be traced in the contradictory responses of participants regarding the acquisition of knowledge and awareness. As already seen in previous chapters, memory knowledge can improve coping and consequently mood, however, it can also induce denial and increase stress levels. Regarding the use of memory aids scales, these were found to correlate significantly with the “Memory knowledge” subscale. “Memory knowledge” correlated more highly with the “Internal memory aids” subscale possibly indicating that the effective use of these strategies requires users to be more knowledgeable and well informed than the application of external memory aids. The importance of information and awareness for the effective use of coping strategies has been well established and has been discussed in previous chapters (Gass & Apple, 1997; Lundqvist et al., 2010). It is not possible, however, to draw conclusions on the exact relationship between the subscales in part A and those in Part B. Regression and mediation analyses would need to be employed in order to evaluate the direction of these associations.

Assessing the criterion validity of the questionnaire was not possible because of the absence of a criterion standard measure of adaptation to memory problems. Therefore, the construct validity of the questionnaire should be further assessed by testing hypotheses concerning the expected relationship between the questionnaire and other measures. Convergent and discriminant validity could be assessed separately for each of the subscales that compose the questionnaire. For example the “Memory anxiety” and “Locus of control” subscales of the MIA questionnaire would be expected to correlate

positively with the “Emotional adjustment” and “Control” subscales respectively. A future study should aim at obtaining information on the actual memory ability of people completing the questionnaire by administering a standardised neuropsychological battery such as the RBMT-E. The questionnaire could be then evaluated against the performance of participants on the battery. Developing hypotheses on the relationship between memory impairment and level of adaptation to memory problems may not be a straightforward process. It has been suggested that control beliefs are relatively independent of actual ability (West et al., 2003). Depending on the type of the task, memory self-efficacy may or may not be related to actual memory performance (McDougall & Kang, 2003). Moreover, as noted by Pakenham et al. (1997), there are conflicting findings in the chronic illness literature regarding the extent to which illness related variables (i.e. level of disability and functional impairment) impact on emotional adjustment and coping. Despite the controversy, a lack of significant relationship between neurological impairment and adjustment has been consistently reported in many studies (Ibid.). Studies on stroke patients showed little evidence of the neurological impairment predicting distress (Morrison & Johnston, 2000) and control beliefs (Johnston et al., 1999). Similarly, the study of Jean et al. (1999) indicated the absence of a relationship between performance on neuropsychological tests and the use of active coping strategies in MS patients. The lack of an association between impairment severity and coping behaviours was also demonstrated in a sample of people with TBI (Dawson, 2007).

Regarding memory use, Bäckman & Dixon (1992) suggested that the relationship between impairment severity and compensatory behaviour could be conceptualised as a U-shaped curve where people with very mild or very severe cognitive deficits will be less likely to compensate. Wilson & Watson (1996) on the other hand, criticised that view based on their observations that people with very severe memory impairments may also be able to compensate effectively, provided that they do not have further cognitive deficits. In the current study, no significant relationship was found between demographic factors (i.e., age, diagnosis) and scores on the questionnaire. This might indicate that the constructs represented in the questionnaire are independent of specific neurological impairment and, possibly, level of disability. On the other hand, the sample of respondents may not be fully representative of different memory ability levels. Based on the existing data it is proposed that actual memory ability will not correlate highly with scores on the questionnaire except for people with severe memory and/or other accompanying cognitive impairments. Information on the severity of memory problems would also permit

the exploration of the way self-efficacy and locus of control influence the relationship between memory ability and use of memory aids. Clarifying the nature of this relationship could inform goal setting in future rehabilitation programmes (Dawson & Winocur, 2008).

### **6.7.3. Reliability**

#### Internal consistency

Internal reliability in this early development of the questionnaire was satisfactory. Inter-item correlations in all the subscales were found to be within the acceptable range with no evidence of item-redundancy. Item-total correlations were high and Cronbach's alpha coefficients did not improve through further deletion of items. Due to the small number of items in the newly formed subscales homogeneity coefficients were also computed which further supported their good internal consistency. Although the reliability values could be increased by adding more items to each scale, considerations of economy and utility suggested otherwise. It has been suggested that scales should be no longer than is necessary to achieve the necessary reliability (Streiner & Norman, 2008).

#### Stability

Good reliability is particularly important if the scale is to be used as an outcome measure. It is essential to ensure that changes are attributable to the presence of an intervention and not a result of measurement error or non-intervention factors (e.g. mechanical responding). As noted by Streiner & Norman (2008), reliability has a direct impact on the sample size required to detect a statistically significant effect of an intervention. Unreliability inflates the variance of the scores and a big sample size would be needed to reduce the error variance in comparison to the variance related to group differences (Streiner & Norman, 2008). In this study, variability was noticed between the subscales of the questionnaire in relation to their stability over time. Regarding Part A total score, all the three test retest indexes that were used indicated acceptable levels of stability. When, however, the subscales comprising Part A were analysed separately, it was found that the "Memory knowledge" subscale exhibited the lowest consistency over time. Retest scores were higher in both the "Memory knowledge" and the "Control" subscales but only in the former case this increase was significant. The opposite pattern was



observed in the “Emotional adjustment” and the memory aids subscales where scores were found to be lower at retest. Regarding Part B, the biggest change was seen in the external memory aids subscale which showed a significant decrease over time. The Bland & Altman plots indicated that in the scales with the lowest stability, changes greater than one point, on the four point scale, would be needed to ensure that the differences were not due to random error. With regards to the memory aids checklists, the only significant difference was an increase in the use of post-it notes.

The observed variability might be related to limitations of the questionnaire. Participants may have found the wording of some questions confusing or non-relevant to them and as a result, replied to these items in an inconsistent manner (i.e. carelessly or randomly). Other factors related to the measurement process, such as low motivation or, might have also introduced response bias such as acquiescence and mechanical responding. In order to assess whether participants respond randomly, researchers often use markers such as responses to item pairs of very similar content (Crede, 2010). The consistency with which participants answer these items might be indicative of the way participants respond to the rest of the questions. In the current questionnaire, items 1 and 12 could provide some indication of the degree to which participants responded without considering the content of the items. As already seen, the vast majority of participants replied consistently to those questions. Although the possibility of response bias cannot be excluded based only on these two items, it is suggested that the incidence of random responding was low.

A hypothesis was raised that the reduction in B1 and B2 scores might be related to the ceiling effects at time 1. In order to assess this possibility, further analyses were conducted, excluding those participants who endorsed the most favourable response in all four questions. That led to the exclusion of about 30% of respondents to part B1 and about 20% of people responding to part B2 questions. Although the skewness at time 1 was reduced to acceptable levels, a drop in both B1 and B2 scores was observed at time 2. Interestingly, the difference between B1 test-retest scores was more significant ( $p=.4$ ) than the one found in full sample analysis ( $p=.5$ ). These findings defy the argument that the reduction in B1 and B2 scores could be attributed to the ceiling effects at time 1.

An alternative explanation could be that the variability of scores was a product of real change in the way participants cope with memory problems. Distinguishing between true change and unreliability of the measure is not an easy task, particularly when it comes to health-related constructs. As noted by Hempel (2005), it is common to misinterpret real

changes in health and clinical psychology measures as lack of reliability. Health measures time (e.g. mood). Neurological conditions, such as MS, are characterized by fluctuation of the nature and severity of symptoms. The degree of variation is greatly affected by the amount of time allowed between the two measures. In this study about half of the respondents reported completing the 2<sup>nd</sup> questionnaire more than a month after completing the first one. It was suggested that this interval between measurements might have allowed for important changes to take place. In order to evaluate this hypothesis, analyses were replicated including only those participants who completed the 2<sup>nd</sup> questionnaire within a month after completing the first one. Results showed that differences between test and retest scores for the “Memory knowledge” and the “External memory aids” subscales as well as the use of post-it notes were reduced to non-significant levels. Furthermore, Bland & Altman Plots indicated improved levels of agreement between test and retest for all five subscales. In all the subscales, the degree of difference between scores at Time 1 and Time 2 were less or equal to one point on the four point scale. This suggests that changes no greater than one point would be needed to indicate that the difference is not due to random error. These findings support the hypothesis that the differences between test and retest scores that were observed in previous full sample analyses may be actually reflective of real changes that occurred during that interval.

This hypothesis could better account for the pattern of changes that were noticed in the full sample analyses. The “Memory knowledge” subscale demonstrated the lowest reliability with scores at retest being significantly higher. This discrepancy could be related to changes in participants’ levels of awareness regarding their memory problems. Completing the questionnaire on the first occasion may have actually prompted participants to seek more information on memory problems and coping strategies. The questionnaire could have also encouraged participants to engage in a self-observation process and become more aware of the way they had been using memory aids. The observed decrease in the scores of the two memory aids subscales may be a result of this process. It is possible that participants re-evaluated their beliefs of how well or poorly they were using memory aids. For example some participants may have realised that they were not as competent as they initially thought in the use of memory strategies or that the aids they were using up to that point were not very effective. This phenomenon, which is called “response shift”, is commonly found in health related measures and it refers to the fluctuation of the standards against which people evaluate a specific construct over time (Streiner & Norman, 2008). An increase in the levels of self-awareness is often followed by

a decrease in mood which might explain the lower retest scores on the “Emotional adjustment” subscale.

What needs to be stressed here is that it is not possible to ensure that respondents provided accurate accounts of the dates they completed the questionnaire or that they completed the whole questionnaire at once (i.e. complete different parts at different time points). This is an important disadvantage of postal questionnaires as researchers have no control on when the questionnaire would be completed and returned. In this study, the two weeks that were allowed before sending the second questionnaire may have been an unnecessary long interval. It would have been preferable to send the second questionnaire one week after receiving the first one in order to account for possible delays related to the postal service. However, shortening the retest interval could not prevent delays in returning the 2<sup>nd</sup> questionnaire. Therefore, a letter could have been sent to people who had not replied within three weeks of sending the second questionnaire to remind them to return the questionnaire as soon as possible.

### Scoring

Likert scale is sometimes called a “summative” scale because the ratings for all the items are summed to yield a total score. The advantage of this method is that any individual item error or bias tends to be cancelled out across the items providing a more valid measure of the construct (Bowling, 2010). Summing the items of a scale, however, assumes that each item contains the same amount of information about the construct and therefore weighting of responses is not required (Hobart et al., 2004). In this study, the substantial inter-item correlations (>.30) and alpha values observed in all the subscales provided evidence in support of this assumption. According to Streiner and Norman (2008), if a scale consists of relatively homogeneous items then the effect of weighting might actually be minimal. Furthermore, following item reduction, each subscale contained items with roughly similar distribution of responses, another indication that the subscales could be used as summed rating measures (Hobart et al., 2004).

As already seen, Parts B1 and B2 were found to be internally consistent and homogeneous, suggesting that each part should be scored as a separate subscale. Regarding Part A, a decision needs to be made on whether to treat the three subscales as separate or combine them into a single score. The current study provided information on the distribution and repeatability of both total and subscale scores. An issue that has to be taken into consideration is that the contribution of each subscale to the total score is

proportional the number of items included in each subscale (Streiner & Norman, 2008). The three subscales in part A contained a roughly equal number of items so it could be assumed that had a similar contribution to the total score. That means that the sum score of the three subscales was not disproportionately influenced by one of the three content areas (Haynes et al., 1995). The main advantage of deriving a single score is that it is easier to analyse and apply (Bowling, 2009). It is, however, recommended that subscales be analysed separately, because single total scores may result in a loss of information (Ibid.). The reason is that very different combinations of responses may actually lead to the same total score. The interpretation of this score might, therefore, be problematic. This has important implications for an outcome measure as it might limit its ability to detect small changes in specific domains. On the other hand, although the estimates of overall internal consistency were high this cannot ensure that the subscales are part of the same construct (Cortina, 1993).

#### **6.7.4. Limitations and future directions**

The study design made it difficult to determine the exact response rate. Although non-response could be interpreted as refusal to participate in the study, the possibility that non-respondents simply did not experience any memory problems cannot be excluded. Bias related to non-response needs to be considered. This problem is greater in postal surveys where lower response rates are common and it is not always possible to confirm that non-respondents share the same characteristics with respondents (McColl, 2001; Bowling, 2009). As noted by McColl, (2001) postal questionnaires carry the risk that respondents will differ significantly from non-respondents. For example, it has been observed that respondents generally tend to be better educated and more literate (Ibid.). It has also been suggested that people who experience more severe cognitive or mobility problems might be less likely to respond (Aldridge & Levine 2001). This could have certain implications for the current study. Respondents may have actually been more educated and/or more motivated to learn more about their memory difficulties and consequently could have had already done their research on memory problems and strategies to improve them. On the other hand, completing and returning a questionnaire is a memory task itself. Therefore, people who experienced less severe memory problems or had found ways of effectively dealing with these problems might be actually overrepresented in the sample. This could be an alternative explanation to the ceiling effects observed in Part B1

of the questionnaire. It could be argued that people who responded to the questionnaire are not representative of the population as, for example, they might have higher educational level and cognitive abilities. In order to establish the generalisability of the findings, the questionnaire needs to be administered on a sample with known demographic (e.g. education) and neuropsychological (e.g. cognitive abilities) characteristics.

A problem that was observed in the second part of the questionnaire related to the use of question skips. Some participants who had previously reported using memory aids and answered the relevant questions went on to complete the question intended for respondents who were not using any memory aids. Although this problem was found in less than 10% of the questionnaires, it has to be taken into account in future revisions of the measure. The pattern of responses found in these questionnaires suggests two possible explanations for this mistake. About half of these respondents reported that they had never used memory aids before. It seems possible that these respondents got confused by the use of the question skip, a problem often seen in self-administered questionnaires. Another possibility is that participants did not read the instructions or that they forgot what the term “memory aids” referred to. If that was the case, these mistakes would be prevented or minimised if the questionnaire was administered by an interviewer (Aldridge & Levine, 2001). It would be useful, however, to slightly modify the format of this part of the questionnaire in order to improve its use as a self-administered measure. One way to reduce confusion could be to have respondents explicitly state whether they are using memory aids, by ticking a “yes” or “no” box. The downside of this solution is that the list of memory aids needs to precede the question in order to ensure that participants understand what is meant by the term “memory aids”. Alternatively, a brief comment or a reference to the list in the previous page could be added before questions 36 and 45 in order to remind respondents about the meaning of the term “memory aids”.

Forgetfulness and confusion may not be the only reasons for which some respondents did not follow the instructions of the question skips. It could have actually been a conscious option rather than a mistake. Participants might have ticked the alternative options (e.g. embarrassed, too complicated etc.) as an explanation for not using memory aids frequently rather than for not using them at all. This assumption could be supported by the fact that a few respondents added frequency words or made relevant comments next to the checklists (e.g. “occasionally” or “often”). These comments might reflect the need of respondents to use some sort of quantifiers in order to provide an accurate and

full picture of their use of memory aids. An attempt was made in this questionnaire to avoid the use of behavioural frequency questions in order to reduce demands on participants' memory. These findings, however, indicate that the lack of quantifiers may actually limit the validity of the questionnaire. The omission could be corrected by incorporating quantifiers in the lists of memory aids. Caution is needed, however, as the accuracy with which participants with memory problems respond to behavioural frequency questions has been an issue of concern (McColl, 2001). The existing literature is inconclusive regarding the most appropriate use of time framing and quantifiers (Ibid.). The use of response categories that refer to a specified time period (e.g. last seven days) has been recommended over the use of more vague categories such as "often", "rarely" and "sometimes" (Aldridge & Levine, 2001). It is also suggested to keep this time period as short as possible in order to minimise ambiguity and recall bias (Ibid.) Bowling (2009) noted that time periods between three and seven days are considered as the most valid and reliable frames to use. These suggestions could be taken into account in order to make relevant amendments to the second part of the questionnaire.

In the current study it was not possible to have the questionnaire reviewed by people with memory difficulties before posting it. The application of cognitive testing techniques during future administrations of the questionnaire would provide direct feedback on the questionnaire from respondents themselves. The "double interview" technique would be particularly useful in confirming that the questions are not misinterpreted by participants. Following the completion of the questionnaire participants could be asked to provide feedback on selected items and explain how they came up with their answers. As with all self-report measures, poor memory and limited self-awareness could have undermined the accuracy of the responses. One way to tackle this problem could be to involve proxy respondents (i.e. family members or health care providers) and use their reports as a point of reference. A rating by the patients' spouse or partner could provide some further evidence on the validity of the scale. For this reason, a questionnaire version for proxy respondents could be a useful addition. It would still, however, not be possible to ensure the objectivity and accuracy of the evaluations as carers and relatives may also hold an unrealistic appreciation of patients' abilities. A further complication is that proxy respondents may not be able to make judgments on behaviours which are not directly observable, as, for example, internal emotional states or cognitions (Streiner & Norman, 2008). Finally, as commented by a few respondents in this study, it may not always be possible to find people who know participants well enough to answer these questions.

A very useful addition to the questionnaire would be a subscale addressing specific memory failures. Items in this scale would tap areas of memory functioning where participants in the “ReMind” study noticed some degree of improvement following rehabilitation. These improvements were mentioned by participants themselves in their interviews raising the possibility that they represent areas that can actually be tackled by memory rehabilitation. The questions could be assessing the frequency of memory failures or, preferably, self-efficacy judgments regarding the ability to cope with these memory failures. For example participants could be asked to rate how confident they feel about successfully dealing with a specific memory problem (e.g. “how confident are you that you can cope with your difficulty to remember names?”). Despite its perceived importance, the construct of self-efficacy is probably underrepresented in the current questionnaire as there is only one question directly addressing perceived self-efficacy. Furthermore, the questionnaire does not differentiate between the constructs of self-efficacy and locus of control. Although the constructs bear some degree of conceptual overlap, as stressed by Dawson & Winocur (2008), literature has not yet clarified whether they represent separate or the same underlying construct. Some authors suggest that a distinction should be drawn between these constructs. According to Gerin et al (1996), a person may perceive that there is something to be done to influence performance but have little confidence in their ability to do what is needed in order to affect the outcome. Incorporating a separate self-efficacy subscale could help address these issues and provide additional evidence on the construct validity of the other subscales.

Reliability and validity are not stable properties of a questionnaire but they vary depending on the population they are assessed on and the inferences that are to be drawn from the data (Streiner and Norman, 2008). Similarly, a different factor structure could emerge if principal component analysis was conducted on a different population (Field, 2005). Therefore, in order to corroborate the findings of this study the psychometric properties of the questionnaire need to be evaluated on other neurological populations (e.g. stroke, epilepsy etc.). Furthermore, confirmatory factor analysis could be used to test the factor solution obtained in this study. The questionnaire was designed to be used as an outcome measure and it is, therefore, essential that its ability to measure meaningful and clinically important change is investigated by a future study. Responsiveness to change needs to be addressed by evaluating within subject changes on the scale following memory rehabilitation. Any differences observed could be reported as an effect size, a standardised change score. Ideally, the results of the intervention group will be compared with a control

group in order to ensure that changes are not a due to unreliability of the questionnaire. Evidence on the effectiveness of the intervention could be obtained by interviewing the participants as well as people who could provide more objective reports on their progress such as clinicians and relatives. As it was shown earlier, the subscales of the questionnaire demonstrated variability over time which might be indicative of the content areas they were representing. For example, the “information” subscale includes items that are more susceptible to change than the “active coping” subscale with taps into constructs that are more resistant to change (e.g. self-efficacy). This possibility needs to be further assessed in a future study by examining changes in each subscale over the course of the rehabilitation programme. Repeated assessments would allow testing hypotheses on the expected progress of participants at different stages of rehabilitation.

The development of this questionnaire was grounded on a pragmatic perspective that aimed to address both patients’ needs and the priorities/reality of clinical practice. The selection of items was mainly empirically driven although theoretical issues related to the included constructs were also considered. What needs to be taken into account is that patients’ views and experiences that informed this outcome measure were derived and interpreted within the context of a specific memory rehabilitation programme. Therefore, the degree to which this outcome measure would be sensitive to the effects of other memory rehabilitation interventions depends on the interventions’ specific aims and goals of these programmes. It is argued that the programme described in this thesis can be considered representative of cognitive rehabilitation interventions that adopt a “holistic” approach, targeting not only cognitive difficulties per se, but also their effects on patients’ awareness, mood and coping style. The observational study offers a reference point for future users of the questionnaire interested in obtaining a more detailed appreciation of the running and content of the rehabilitation programme.

As already discussed, the data were treated as interval level in order to perform the analyses. Concern is raised, however, as the analysis of reliability, validity and responsiveness might be compromised by that assumption. Likert scales provide ordinal level data and they can, therefore, offer information on the ordering of respondents’ attitudes but not on how far apart or close these attitudes are (Bowling, 2009). It would, therefore, be wrong to assume that the true distance between the response categories is the same. For example, the difference between agree and strongly agree may actually be greater than between agree and disagree. This problem makes it difficult to decide on whether a 3 point improvement on a Likert scale is a clinically meaningful change.



Consequently, the computation and interpretation of change scores based on ordinal variables might lead to spurious conclusions (Stucki et al., 1996). An alternative technique that could be used to evaluate the questionnaire is Rasch analysis. Rasch analysis is a probability model that converts the ordinal scores obtained by summing item scores into linear interval scale measures (Duncan et al., 2003). The advantages of this model are recognised and it has been increasingly applied to rehabilitation research in order to develop and validate health status outcome measures (Tesio, 2003). A future study should evaluate the psychometric characteristics of the questionnaire using a Rasch analysis computer programme (e.g. RUMM- Sheridan et al., 1996). Provided that the items fit the Rasch model, they would be transformed from ordinal scores into interval level measurement. Estimates of the items' difficulty would be obtained, producing a hierarchy of items from the easier to the more difficult to perform. These estimates are independent from the particular sample of respondents, facilitating between groups comparisons (Stucki et al., 1996). The model could then be used to evaluate the results of the current study. As seen earlier, the methods of item reduction used in this study resulted in the deletion of highly skewed items. However, as Tennant et al. (2004) explained, these items might actually be very important in the scale by covering the extremes of the construct range. Rasch analysis would allow assessing whether the retained items represent all the levels of difficulty. The model could, therefore, lead to the addition of new items that fill in the gaps or to the deletion of any redundant items that represent the same level of difficulty (Stucki et al., 1996). Rasch model could also be used to assess the extent to which items measure a single construct and to obtain a better understanding of the magnitude of change in patients' scores over time (Duncan et al., 2003).

Many patients used the open space provided in the questionnaire to give feedback on the way they dealt with their memory difficulties/ health issues and make other general comments. Systematic analysis of this qualitative feedback was out of the scope of the current study. However, it is interesting to note that the lack of professional input and information regarding cognitive impairment was an issue addressed by many respondents, mainly people with MS. Some of them commented that before receiving the questionnaire they were unaware of the link between multiple sclerosis and memory difficulties. The fact that the same issue was discussed by participants in the "ReMind" study highlighted the importance of this feedback. These findings seem to point to the need for studies that will directly assess the amount and quality of information that neurological patients receive on

the cognitive consequences of their conditions. The ways neurological patients cope with cognitive difficulties would also worth further investigation.

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## Summary and conclusions

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*Chapter 1* introduced theoretical concepts describing memory function and provided a brief account of how memory is affected by acquired brain injury related to stroke, multiple sclerosis and traumatic brain injury. Using the WHO classification system of disease as a framework, the principles and aims of different approaches to memory rehabilitation were presented and discussed.

*Chapter 2* provided an overview of the measures that the author identified as most commonly used to assess outcome in memory rehabilitation (MR). Both neuropsychological and self-report measures were reviewed to identify strengths and weaknesses in relation to their use as outcome measures in memory rehabilitation. The review led to the following observations:

- The majority of studies relied on the use of laboratory measures in order to evaluate the effectiveness of MR despite the fact that these tests were developed to measure impairment and their ability to detect meaningful functional gains has been widely questioned.
- A number of self-report memory questionnaires have been used to complement standardised batteries, offering valuable information for rehabilitation professionals. However, their ability to tap changes following MR for neurologically impaired individuals may be undermined due to certain limitations. The majority of these questionnaires have been developed on normal populations failing to consider the characteristics and needs of neurological patients. Their length, wording and response format may place heavy demands on patients' cognitive abilities. Regarding the content, the included items often reflect issues not addressed by MR.

The main research aim of Chapters 4 and 5 was to identify the content areas of the questionnaire based on participants' input in a memory rehabilitation programme (main phase of "ReMind" study). A mixed methods design was followed and information was drawn from: a) real time observations of the running of the memory rehabilitation programme (Chapter 4) and b) participants' post-intervention interviews (Chapter 5).

*Chapter 4* described the use of a time sampling method to record the activity and the content of group discussions. Following a content analysis procedure, observations were grouped into categories representing major patterns that occurred repeatedly in the text. Categories were then assigned a numerical code and their frequency was calculated. It was found that the two intervention groups spent significantly more time than the self-help groups in discussion of topics related to: theories and models of memory- particularly the importance of attention in memory performance-, participants' beliefs about their memory difficulties and exploration of their actual strengths and weaknesses, issues related to learning and applying memory aids as well as developing own strategies, and finally stress and anxiety issues caused by memory problems. Activity observations provided some evidence on the balance of talking and listening in the interaction between the group members and the leader in each programme and across the three programmes. The study introduced a novel method of collecting observations by employing a time sampling schedule, traditionally used to collect quantitative information, in order to qualitatively record the content of speech. This method allowed the collection of a large sample of observations, the systematic description and the quantitative comparison of the content of the groups without placing heavy demands on the observer. It is also suggested that it helped to minimise bias introduced during the analysis, such subjectivity in selecting the units of analysis, and therefore, contributed in achieving high inter-coder reliability. Moreover, it allowed benefiting from the advantages of observational methodology over methods of retrospective data collection such as interviews and self-report measures. The downside of this method, however, is that it may have led to an underestimation of infrequent but potentially important issues introduced by participants.

In *Chapter 5*, semi-structured interviews were used to explore participants' experience in the memory rehabilitation programme. The vast majority of participants in the intervention groups (83.3- 100%) reported that the programme responded to their needs for information on brain damage and memory function while only 14% in the self-help groups described similar benefits. About two thirds of interviewees (67-86%) talked about how the intervention groups helped them explore the nature and extent of their memory problems, enhanced their sense of confidence and control over the management of memory difficulties and introduced them to memory aids and ways of using strategies more effectively. No self-help group members reported improvements in these domains.

More than half of the respondents from the intervention groups (50-57%) said that the programme contributed to them adopting a more proactive attitude towards their memory problems (no such improvement was discussed by self-help group participants). Similarly, more than 50% of intervention group interviewees perceived improvements in their ability to control anxiety and stress related to memory difficulties as opposed to less than 30% of self-help group respondents. Finally, between 33% and 67% of participants in compensation and restitution groups said that the intervention helped them appreciate the importance of paying attention to the information to be recalled (0% in the self-help groups). These findings were in line with the core themes identified in the structured interviews presented in Chapter 3. The use of semi-structured interviews in Chapter 5, however, allowed obtaining richer descriptions and less ambiguous responses and consequently led to the development of more clear-cut themes. Participants' input highlighted a number of issues which may have implications for future research and implementation of memory rehabilitation interventions.

- Based on their reports, not all participants were ready to receive information and explore the nature and extent of their memory difficulties. In these cases denial may function as protective mechanism reducing anxiety and frustration about impairment. It is recommended that rehabilitation professionals explore and agree with participants on the level of information they would like to receive at each stage of rehabilitation. It may also be useful to assess the coping mechanisms participants have in place before attempting to tackle awareness issues. Future studies could assess the contribution of these strategies in promoting active participation in rehabilitation and in reducing drop outs.
- The contribution of family and carers in the rehabilitation outcome was stressed in the interviews. Providing the family with some basic information on memory problems and ways of coping with them could be a useful and feasible addition to cognitive rehabilitation programmes.
- Some participants with TBI reported that their difficulty in appraising the effects of the programme was related to the fact that they had not yet returned to their normal routines, the current environmental demands were low and, therefore, they were not required to use compensatory strategies. A few participants with MS discussed that it was the ongoing change in their skills, associated with the

progressive nature of the disease, that presented challenges in appreciating the contribution of the programme. These factors need to be taken into account by researchers both when deciding on the timing of follow-up assessments and when interpreting the outcomes, particularly if self-report measures and interviews are used.

- Findings from both interview studies highlighted some possible benefits of a group based approach in memory rehabilitation. The majority of participants reported that the groups provided a supportive environment and an opportunity to exchange information, socialize and witness own behavior. Most participants recognised the combination of a group based approach, along with one or two individual sessions, as their preferable format. Future research could address this issue by examining the effectiveness of group based over individually administered cognitive rehabilitation.
- Regarding the composition of the groups, most respondents perceived participation in a mixed aetiology group as a beneficial experience. Heterogeneity in relation to the severity of cognitive deficits, however, was commented as a disadvantage of the rehabilitation programme. Perceived differences in cognitive performance were a source of frustration particularly for a few people with multiple sclerosis. This issue needs be considered in future rehabilitation studies by, for example, allocating participants in groups of similar ability levels.
- Although not directly addressed by the memory rehabilitation programme, changes in participants' sense of self-efficacy and control over memory difficulties (control beliefs) were identified as a core domain of improvement in both interview studies. These findings are in line with research recognizing control beliefs as an important component of effective health interventions (e.g. Dawson & Winocur, 2008). To date, the few studies that have included control beliefs as a memory training component were conducted in samples of elderly healthy adults (e.g. McDougall & Kang, 2003). There is a need for studies which directly address control beliefs and evaluate their contribution to the effectiveness of cognitive rehabilitation interventions for people with neurological disabilities.
- In both interview studies some participants reported benefits in relation to prospective memory tasks. Currently, the assessment of rehabilitation

effectiveness is mainly based on retrospective memory outcome measures. Participants' reports suggested that prospective memory function may improve following rehabilitation and stressed the need to incorporate relevant outcome measures in the neuropsychological assessment.

The findings from both observations and interviews were integrated in order to define the content areas included in the questionnaire. It is suggested that the use of mixed methods methodology allowed the strengths of each method to compensate for the weaknesses of the other, and provided a fuller perspective than either method alone. The directness of observations permitted the minimization of bias introduced by respondents' memory ability, levels of awareness or their wish to please the researcher, and provided information that was not affected by participants' experiences after the completion of the programme. Semi-structured interviews on the other hand gave participants the opportunity to express their views in their own words, unaffected by the presence of other group members, and facilitated an extensive exploration of their experiences in the programme.

*Chapter 6* described the generation of the item pool and the evaluation of the psychometric properties of the newly developed questionnaire on a group of people with acquired brain injury. At this phase the questionnaire included 45 items covering the following content areas: "memory knowledge", "awareness", "emotional adjustment", "active coping", "control expectancies" (i.e. locus of control and self-efficacy beliefs), "attention", "significant others" and "use of memory aids". Questionnaires were sent to 400 multiple sclerosis patients and 143 TBI patients. In total, 144 participants returned the first questionnaire completed and 87 of them returned the second questionnaire assessing stability. After applying the criteria of face validity, response distribution, and construct validity 15 items were retained in Part A of the questionnaire, and four items in Parts B1 and B2 respectively.

- In Parts A and B2 of the questionnaire, the distributions of item response categories were satisfactory. The total scores in these two parts showed approximately normal distributions. However, items in Part B1 were skewed towards the favourable response options.
- In relation to the MA checklists, it was found that the most frequently used external memory aids were notes, diaries and calendars and the least frequent

mobiles, computers and Dictaphones. Fewer people used internal memory aids and the main reason for that, as reported by the majority of the respondents, was that they had never been informed about these strategies. These results were consistent with those of previous studies (e.g. Evans et al., 2003).

#### *Reliability*

- The internal reliability of the subscales was satisfactory. Inter-item correlations in all the subscales were found to be within the acceptable range with no evidence of item-redundancy. Item-total correlations were high and Cronbach's alpha coefficients did not improve through further deletion of items.
- The levels of test-retest reliability varied between the subscales. The "Control", "Emotional adjustment" and "Internal MA" subscales displayed acceptable levels of test-retest reliability. The "Memory knowledge" and the "External MA" subscales exhibited the lowest consistency over time. When analyses were repeated only for these respondents completing the 2<sup>nd</sup> questionnaire within a month after completing the 1<sup>st</sup> one, differences between test and retest scores dropped to non-significant levels. This finding indicates that the discrepancies observed in full sample analyses may be reflective of actual changes occurring during the interval. These changes may be related to participants gaining access to memory related information, re-evaluating their beliefs and/or the actual way they manage their memory problems. Future studies need to assess the stability of the questionnaire over a shorter period, no longer than two weeks.

#### *Validity*

- The satisfactory response rates and completeness of item responses provided evidence on the face validity of the questionnaire. The methods used for the item generation and selection reinforced the content validity of the scale.
- Principal component analysis confirmed that the questionnaire covered most of the content areas it was designed to capture, providing evidence on the internal construct validity of the scale. It was shown that Part B1 and B2 formed two distinct and unidimensional scales representing external and internal memory aids respectively. Part A represented a multidimensional construct including three components: "memory knowledge" and "emotional adjustment", which corresponded to the initial grouping of the items, and "control" comprising the



“active coping” and “control beliefs” categories. The categories “attention” and “significant others” were dropped from the questionnaire due to poor psychometric properties and low relevance of the included items. In order for these areas to be included in the questionnaire, alternative items would need to be developed and tested.

- The item convergent validity of the Part A subscales was corroborated by showing that items correlated more highly with the subscale they belonged to than with the other two subscales.
- Correlations between the subscales indicated that the constructs they represented were related in ways consistent with those suggested in the literature. A strong association was noticed between the “emotional adjustment” and the “control” subscales but they differed in the way they related to the other subscales. Control demonstrated a fair positive association with the “memory knowledge” and the two memory aids subscales whereas emotional adjustment correlated only poorly with those subscales. It was suggested that control beliefs may affect emotional adjustment and be better predictors of the use of MA than mood. Regression and mediation analyses would be needed in order assess these hypotheses.

#### *Suggestions for future research*

- Increasing the number of response categories from four to five, by adding a middle point, or to six may help reduce ceiling effects and increase the questionnaire’s responsiveness to change.
- The addition of frequency indicators to the memory aids checklists might reduce confusion related to question skips and improve the accuracy of responses. Another useful addition would be a subscale assessing self-efficacy judgments regarding the ability to cope with specific memory failures. Items in this scale would tap reported areas of improvement in the memory rehabilitation programme.
- The construct validity of the questionnaire should be further assessed by testing hypotheses concerning the expected relationships between the questionnaire and other measures (e.g. MIA, MCI).

- It is recommended that the psychometric characteristics of the questionnaire be also evaluated using a Rasch analysis computer programme (e.g. RUMM) that would allow the transformation of ordinal scores into interval level measurement.
- In order to establish the generalisability of the findings, the questionnaire needs to be administered on other neurological populations (e.g. stroke) with known neuropsychological (e.g. cognitive abilities) characteristics.
- The association between actual memory ability and performance on the questionnaire needs to be evaluated. It is suggested that questionnaire scores will show a modest relationship with objective memory performance.
- Responsiveness to changes needs to be addressed by evaluating within subject changes on the scale following memory rehabilitation. Any differences observed could be reported as a standardised change score.

In conclusion, this thesis presented the development and evaluation of the first questionnaire developed to assess the effects of memory rehabilitation programmes for people with acquired brain injury. One of its advantages over other memory questionnaires is that, rather than being defined by researchers, the questions tapped domains of interest to participants and incorporated their perspective. Its brevity, layout and simplified wording facilitate its use with cognitively impaired individuals. It was found to have good internal consistency and factor analysis identified meaningful dimensions. The questionnaire is not intended for use as a single measure of outcome but should be used in combination with standardised memory batteries and established generic questionnaires. Its responsiveness to change following memory rehabilitation needs to be assessed by future studies.

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## **Appendix 1: Content Analysis Coding Scheme**

### **1) PROCEDURAL ISSUES**

Introducing oneself  
Aims/structure of the programme  
Inviting people to talk about themselves  
Group rules  
Giving a summary of the session  
Miscellaneous

### **2) THEORIES/MODELS OF MEMORY**

2) General theories/personal beliefs  
e.g. "I'd say memory is like a filing cabinet"  
Memory as a network  
e.g. "it's clever how your brain works, it's like a USB stick"  
3) Encoding  
4) Memory storage  
Working memory  
Storage /retention  
Short-term memory  
Long -term memory  
5) Memory retrieval  
Recognition/recall  
Anterograde memory  
6) Forms of memory  
Emotional memory  
Memory for music  
Verbal /visual memory  
Procedural memory  
Memory for numbers  
7) Attention distractors  
8) Ways to improve attention  
9) Divided attention/multitasking  
10) Sustained attention/concentration  
11) Association of attention with memory  
12) Stress effect on memory

### **3) SELF-APPRAISAL/INSIGHT**

13) Premorbid memory ability  
distinguishing between symptoms preceding & following disease/accident  
time memory problems were first observed  
14) Gaining insight through assessment/practice  
Assessment helped gain insight into the problems  
e.g. "now I realized what I was doing in order to remember"  
"homework helped me clarify the frequency of my memory problems"

## Appendices

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- 15) Severity of memory problems/level of ability  
e.g. "I've already found my memory is improving"  
Memory improved with MA  
Confident in ability to handle memory problems  
Memory declining  
Struggling with memory problems
- 16) Pacing oneself according to severity of problems  
e.g. "I would say go for the difficult"  
"It's important to give yourself the time to learn sth"  
"You have to pace yourself- say my memory is not very good have to find sth that's not too demanding"  
"Novels are interesting when time is not linear but it makes it too demanding for memory"  
"I'm telling my wife just give me one piece of info at the time"
- 17) Distinguishing between memory processes/ placing individual problems  
e.g. "My visual memory is better than my verbal memory"  
"I think it's a problem of consolidation"
- 18) Personal research on memory issues  
e.g. "I've read this book on memory"

### **4) OTHER COGNITIVE SKILLS**

- 19) Organisational skills/executive functions
- 20) Spatial orientation
- 21) Other cognitive skills

### **5) MEMORY AIDS**

- 22) General theories
- 23) Using the right technique depending on one's strengths/occasion
- 24) Normalisation of use of memory aids  
Problems associated with the use of MA
- 25) Forgetting to look at the diary/to do list
- 26) Forgetting what the alarm/ hints in the diary are for
- 27) Difficulty in keeping notes (mobility issues)
- 28) Ability to handle technological aids
- 29) Other e.g. forgetting the names of MA, not getting the opportunity to use a technique (e.g. limited activities)
- 30) Personal ways of remembering info/developing own techniques  
Other tips helping memory/improving MA use
- 31) Relocating info
- 32) Structuring environment/follow a routine  
Putting things in a certain place
- 33) Having someone as a reminder
- 34) Other tips, e.g. summarizing info  
Internal MA
- 35) Rehearsal, 36) visual imagery, method of loci, 37) rhymes, 38) story method, 39) PQRS, 40) errorless learning, 41) spaced retrieval 42) deep level processing, 43) cueing, 44) categorisation, 45) chunking, 46) 5Ws, 47) associations, 48) active observation

## Appendices

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### External

49) Diaries, e.g. personal organiser, diaries for medication/injections, 50) outlook/excel, 51) mobile, 52) Dictaphone, 53) timer, alarm, 54) to do lists, 55) calendar 56) post-its +notice board, 57) “writing sth down”,

### **6) MEMORY FAILURES**

#### Forgetting:

- 58) medicine dose,
- 59) to do sth was asked to,
- 60) to drink water/eat
- 61) to do sth planned to e.g. TV programmes
- 62) appointments
- 63) household activities/safety behaviours
- 64) what intended to buy in a supermarket
- 65) what was about to say, repeating oneself
- 66) word finding difficulty/ tip of the tongue phenomenon
- 67) where the car was parked
- 68) finding his way around (walking/driving)
- 69) names
- 70) faces
- 71) phone number/pins
- 72) past events/ episodic memory, learned ability (e.g., foreign language)
- 73) where one has put sth/losing things ,personal belongings
- 74) what has just read/done/said
- 75) follow the plot

### **7) PERSONAL LIFE**

#### Family life

- 76) Dependency /self-containment issues feel that puts pressure on family  
e.g. Depending on others to be reminded
  - Dependence on family for driving
  - Depending on own abilities if needed
- 77) Effect of memory problems on family life
- 78) Family’s awareness of impairment/disability
- 79) Support from family
- 80) Other info on family life

#### Professional life

- 81) Professional status (premorbid/ current)
- 82) Effect of memory problems on professional life
- 83) Effect of health problems on professional life
- 84) Support from professional environment

#### Social life

- 85) Leisure/recreational activities
- 86) Plans for initiating a new activity
- 87) Effect of health problems /memory problems on social life
- 88) Disclosure issues
- 89) Support -understanding from acquaintances/ others/ policies



## Appendices

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### **8) GENERAL HEALTH ISSUES**

- 90) General info on Illness/accident/diagnosis/health condition
- 91) Nervous system
  - Brain plasticity
  - Effect on the brain/ physiological/neurological changes
- 92) Other health problems
  - Mobility
  - Sleep disturbance
- 93) Physical Exercise
- 94) Other Interventions/therapies

### **9) GROUP SETTING**

- 95) Benefits of being with people with similar problems
  - Socialising with people with similar problems
  - e.g. "Being on the same boat"-knowing one is not on his own
    - Encouraging a fellow member
    - Comparing ability to other group members
- 96) Giving/getting suggestions from other group members

### **10) MOOD**

- 97) Stress /Somatic response to stress
    - e.g. Feeling flies in the stomach
      - Lack of sleep
  - 98) Stress related to memory problems/ get panicked when forgetting sth
  - 99) Feeling stupid /embarrassed because of memory problems
  - 100) Feeling frustrated/ worthless because of memory problems
  - Stressors
    - 101) Stress related to health problems
    - 102) Work-related stress
    - 103) Stress related to social occasions
      - e.g. being stressed of going out
        - feeling uneasy in social occasions
    - 104) being anxious in conversation
    - 105) other stressors e.g. people/family, worrying about other people, attention problems
  - Feelings
    - 106) worrying about the future, worrying about getting worse, fear, focusing on the dark side of things, feel cannot control what is happening, Frustration
    - 107) losing temper/snapping at someone, getting angry at people
    - 108) trying to keep positive, motivation to do things, trying to keep self-active/challenging oneself
  - Feelings following diagnosis
    - 109) normalisation of low mood after accident/diagnosis
    - 110) feeling shuttered following diagnosis, avoid finding out more about the problem
      - accepting the problem, thinking of other people who are worse off
  - Personality
    - 111) Personality, change, Illness as a life lesson
  - Tips to improve mood
    - 112) importance of releasing emotions/relaxing
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- 113) goal setting/ things in life that act as motivators
- 114) importance of being confident
- 115) tips to relax/improve mood

### **11) EXERCISE**

- 116) Importance of practice/stimulating brain
- 117) Describing exercise/homework
- 118) 5 Ws
- 119) PQRS
- 120) attention exercise
- 121) chunking
- 122) categorisation
- 123) active observation
- 124) mental imagery
- 125) cueing
- 126) errorless learning
- 127) 3 MA that they used the most
- 128) list of memory problems currently facing
- 129) strategies they are using to deal with MP
- 130) associations
- 131) story method
- 132) relaxation exercise
- 133) problems with relaxation exercise

### **12) MISCELLANEOUS**

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<b>Categories</b>	<b>Subcategories</b>	<b>Item codes (examples)</b>	<b>Raw data (examples)</b>
<b>Theoretical Information</b>	<i>Models of memory</i>	Encoding Memory storage Memory retrieval	<i>"I'd say memory is like a filing cabinet"</i>
	<i>Attention</i>	Attention distracters Sustained attention Ways to improve attention	<i>"If you don't pay attention you won't be able to store information"</i>
<b>Self-appraisal/insight</b>	<i>Levels of ability</i>	Gaining insight through assessment	<i>I didn't think I got a bad memory until I got tested"</i>
		Severity of problems	<i>"I've already found my memory is improving"</i>
		Pacing oneself according to difficulties	<i>"It's important to give yourself the time to learn"</i>
	<i>Nature of problems</i>	Distinguishing between memory processes	<i>"My visual memory is better than my verbal memory"</i>
<b>Cognitive skills</b>	<i>Executive functions</i>	Organisational skills	
	<i>Spatial Orientation</i>	Route finding	<i>"I've always been really bad with directions"</i>
	<i>Other cognitive skills</i>	Mathematical ability	
<b>Memory aids</b>	<i>General theories on MA</i>	Internal Vs External MA	<i>"External MA focus on adaptation"</i>
	<i>Problems associated with use of MA</i>	Forgetting to use them Difficulty in keeping notes (mobility issues) Forgetting what the alarm was for	<i>"I've got a to do list and a calendar but I forget to check them"</i>

<b>Category</b>	<b>Subcategory</b>	<b>Items Codes (examples)</b>	<b>Raw Data (examples)</b>
<b>Memory aids</b>	<i>Using the right MA</i>	Using the right MA depending on one's strengths/occasion	<i>"When you've got many reminders you have to find what suits you best"</i>
	<i>Developing personal MA</i>	Individualised techniques	<i>"I put prompts on my screensaver to remind me to do things"</i>
	<i>Other ways of helping memory</i>	Following a routine Structuring environment Having someone as a reminder	<i>"I try to put my keys at the same place"</i> <i>"I've got specific pockets for specific things"</i> <i>"My mother calls me to remind me of my appointments"</i>
	<i>External memory aids</i>	Diaries, alarms, Dictaphones etc.	<i>"If it's not in my filofax it won't be done"</i>
	<i>Internal memory aids</i>	Visual imagery, associations etc.	<i>"Categorisation makes shorter what you need to remember"</i>
<b>Memory Failures</b>	<i>Prospective memory</i>	Forgetting appointments Take medication	<i>"I usually forget to do the injections"</i> <i>"I sometimes even forget names of good friends"</i>
	<i>Verbal memory</i>	Word finding difficulty Forgetting names	
	<i>Visuospatial memory</i>	Finding way around Forget where has put sth	<i>"I kept losing my way on the road"</i> <i>"I don't have clear recollections about certain events in the past"</i>
	<i>Episodic/Semantic</i>	Past events	
<b>Personal Life</b>	<i>Family Life</i>	Dependency Issues	<i>"I get annoyed when my family is patronising me using MS as an excuse"</i>
	<i>Professional Life</i>	Professional status Effect of memory problems	<i>"My colleagues sometimes forget that I had a stroke and I am recovering"</i>
	<i>Social Life</i>	Recreational activities Disclosure issues	<i>"Other people cannot understand, I think they laugh at me, not in a bad way"</i>
<b>General health issues</b>	<i>General health</i>	General information on illness Nervous System Interventions/therapies	<i>"I suffer with MS related fatigue"</i> <i>"MS affects the myelin sheath"</i>

<b>Categories</b>	<b>Subcategories</b>	<b>Item codes (examples)</b>	<b>Raw data (examples)</b>
<b>Group setting</b>	<i>Group setting</i>	Benefits of peer support Giving/Getting suggestions	<i>"It's good to know I am not on my own"</i>
<b>Mood</b>	<i>Stress related to memory</i>	Panic when forgetting sth.	<i>"I used to run around like headless chicken when forgetting sth."</i>
	<i>Other Stressors</i>	Work related stress Stress related to social occasions	<i>"When I meet someone new it is a bit scary"</i>
	<i>Other emotions</i>	Feeling embarrassed Feeling frustrated/worthless	<i>"Cognitive problems make me feel quite an idiot"</i>
	<i>Feelings following diagnosis</i>	Feeling shuttered Accepting the problem	<i>"It is when you accept the problem that you start looking for things to help you"</i>
<b>Exercise</b>	<i>Tips to improve mood</i>	Releasing emotions/relaxing Set goals/ get motivated	<i>"Talking, offloading helps me with stress"</i>
	<i>Importance of practice</i>	Importance of stimulating the brain	
	<i>Attention exercise</i>	Letter cancellation etc.	<i>"Attention is one of the functions that can improve by practice"</i>
	<i>Memory exercise</i>	Story method, chunking etc.	
<b>Procedural issues</b>	<i>Relaxation exercise</i>	Mental imagery	
	<i>Procedural issues</i>	Aims of the programme Inviting people to talk	<i>"Session 6 introduces internal memory aids"</i> <i>"How did the week go for everybody?"</i>
<b>Miscellaneous</b>	<i>Miscellaneous</i>	Humorous remarks Statements not related to the above categories	<i>"I think it's your turn to bring the chocolates next week"</i> <i>"I found myself speeding in the ring road"</i>

## Appendix 2: AMEDO Questionnaire

### Adaptation to Memory Difficulties Outcome Questionnaire

We are interested in the ways people are coping with memory problems. If you are experiencing memory problems you are invited to complete the following questionnaire. If you are not experiencing memory problems please return the questionnaire without completing it.

*For an electronic version of the questionnaire please contact:  
lwxnc3@nottingham.ac.uk*

Please record your age, gender and diagnosis:

Age.....

Gender (F/M).....

Diagnosis (traumatic brain injury/ multiple sclerosis/ stroke).....

Time since injury/diagnosis.....

This questionnaire is anonymous. However, if you are willing for us to contact you again please complete your name and address:

Your name.....

Address.....

.....

.....

.....

Today's date.....

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This is a set of questions about how you think you cope with your memory problems. There are no right or wrong answers. Please take your time and answer all questions. Tick which answer you feel best applies to you:

### Part A.

#### 1. I do not remember things as well as I used to.

Agree       Slightly Agree       Slightly Disagree       Disagree

#### 2. I have had enough information on why I have memory problems.

Agree       Slightly Agree       Slightly Disagree       Disagree

#### 3. I am aware of the strengths and weaknesses of my memory.

Agree       Slightly Agree       Slightly Disagree       Disagree

#### 4. I understand how memory works.

Agree       Slightly Agree       Slightly Disagree       Disagree

#### 5. I find it difficult to come to terms with my memory problems.

Agree       Slightly Agree       Slightly Disagree       Disagree

#### 6. I know how to use the strong aspects of my memory to compensate for the weaker aspects.

Agree       Slightly Agree       Slightly Disagree       Disagree

**7. I do things that are too hard for my memory.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**8. I understand why I remember some things more easily than others.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**9. Other people have noticed an improvement in my memory ability.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**10. I avoid finding out more about my memory problems.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**11. I think that people close to me understand how bad my memory is.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**12. I am as good at remembering as I ever was.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**13. I try to concentrate hard on things I want to remember.**

Agree       Slightly Agree       Slightly Disagree       Disagree



**14. I am well organised in how I cope with my memory problems.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**15. I find myself daydreaming when I am supposed to be focusing on a task.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**16. I have been doing things that I believe will improve my memory.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**17. I have little control over my memory ability.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**18. There are ways to cope with my memory difficulties.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**19. I rely on other people to remind me of what I have to do.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**20. It is harder to remember things when I am upset.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**21. I talk to other people openly about my memory problems.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**22. I worry that I am going to forget something important.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**23. I am confident that I can cope with my memory difficulties.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**24. It upsets me when others notice my memory problems.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**25. I am anxious about my memory problems.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**26. My memory problems make me feel embarrassed.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**27. I panic when I forget something important.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**Part B. MEMORY AIDS**

**Memory aids are strategies we may all use to help us remember things. They can be external or internal:**

**B1. External memory aids:** can be objects or other cues in our surroundings to help us remember things without relying on our memory.

**28. The following is a list of external memory aids. Please indicate which of these you are using. If you are NOT using any external memory aids please go to question 37 on page 8.**

Tick as many as applicable:

- Diary/personal organiser**
- Alarms/timers**
- Making notes of anything you need to remember**
- Calendar/year planner**
- Dictaphone/ tape recorder**
- Post it notes**
- To do lists**
- Mobile phone**
- Computer**
- Object placement**   
e.g. putting things in an obvious place where you will notice them  
/putting things at the same place all the time
- Following a routine**   
e.g. doing specific things at specific times
- Ask someone else to remind you of things to do**   
**Any others:**

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**Please consider the external memory aids you are using and complete the following questions:**

**29. Using external memory aids is part of my everyday life.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**30. I am using the same external memory aids as I have always used.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**31. I believe that I make the most of the external memory aids I am using.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**32. I know which external memory aids work best for me.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**33. The external memory aids I am using are effective.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**34. I think the way I use external memory aids could be improved.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**35. I have a range of external memory aids that I can use for different tasks.**

Agree

*Slightly*   
*Agree*

*Slightly*   
*Disagree*

Disagree

**36. If you are NOT using external memory aids please indicate the reasons by ticking one or more of the boxes:**

-I have never tried to use them

-I feel embarrassed to use them

-I have tried but found them too complicated

-I have tried but they don't work for me

Any other reasons:

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**B2. Internal memory aids** are “tricks” to help us remember things when we only have our memory to rely on.

**37. The following is a list of internal memory aids. Please indicate which of these you are using. If you are NOT using any internal memory aids please go to question 46 on page 11.**

Tick as many as applicable:

**Repeating something you want to remember** (silently or out loud)

**Putting similar things into groups** (e.g. things you want to buy into vegetables, clothes, stationary etc.)

**Relating what you want to remember with something you already know** (e.g. a friend’s name on the 26<sup>th</sup> December as one day after Christmas)

**Making a picture in your mind of things you want to remember** (e.g. to remember the name Victoria Waters picture Queen Victoria by a waterfall)

**Making up a little story including things you want to remember**

**Paying attention to details** (e.g. when parking the car try to observe the surroundings and watch for a landmark)

**Blocking information into chunks that make sense for you** (e.g. telephone numbers: 9515698 → 95-15-698)

**Acronyms** (e.g. lists of groceries → MEMORY: milk, eggs, matches, olives, rice, yeast)

Any others:

**Please consider the internal memory aids you are using and complete the following questions:**

**38. Using internal memory aids is part of my everyday life.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**39. I am using the same internal memory aids as I have always used.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**40. I believe that I make the most of the internal memory aids I am using.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**41. I know which internal memory aids work best for me.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**42. The internal memory aids I am using are effective.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**43. I think the way I use internal memory aids could be improved.**

Agree       Slightly Agree       Slightly Disagree       Disagree

**44. I have a range of internal memory aids that I can use for different tasks.**

Agree

Slightly  
Agree

Slightly  
Disagree

Disagree

**45. If you are NOT using internal memory aids please indicate the reasons by ticking one or more of the boxes:**

- I have never tried to use them
- I feel embarrassed to use them
- I have tried but found them too complicated
- I have tried but they don't work for me

Any other reasons:



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**If you have any comments you would like to make about this questionnaire please write them on this page.**

**MANY THANKS FOR YOUR HELP**

### Appendix 3: Letter of invitation to participants



#### Adaptation to Memory Problems Outcome Questionnaire

We are contacting people with traumatic brain injury who have been seen by the Nottingham Traumatic Brain Injury Service to inform them of a research study being conducted by Miss Niki Chouliara at the University of Nottingham. You are invited to participate in a research project to develop a questionnaire of the ways people cope with memory problems.

Along with this letter you will find the Adaptation to Memory Problems Questionnaire. On the front page of the questionnaire you will be asked whether you are experiencing memory problems. If you think you have memory problems you are kindly requested to complete the questionnaire and send it back to the researchers using the pre-paid envelope. If you are not experiencing memory problems please return the questionnaire without completing it.

The questionnaire should take about 15-20 minutes to complete. By returning the questionnaire you show your agreement to participate in the study.

If you are willing for the researchers to send you another questionnaire please complete your name and address on the front page. By providing your name and address you show your agreement to be sent a second questionnaire.

Participation is voluntary. Please find enclosed a copy of the "Information for Participants" sheet and read it carefully before deciding whether to take part. If you require further information about the questionnaire or the research please contact the researchers using the contact details on the "Information for Participants" sheet.

Yours Sincerely

## Appendix 4: Letter of reminder to participants



### **Adaptation to Memory Problems Outcome Questionnaire**

About three weeks ago we sent a letter to people with multiple sclerosis who are registered on our data basis to inform them of a research study being conducted by Miss Niki Chouliara at the University of Nottingham. The aim of the study is to develop a measure of the ways people cope with memory problems. You were invited to participate in the research project by mailing the enclosed questionnaire back to the researchers.

If you have already mailed the questionnaire, thank you very much. For those that have not received the first letter please find enclosed a copy of the Adaptation to Memory Problems Outcome Questionnaire. On the front page of the questionnaire you will be asked to indicate whether or not you are experiencing memory problems. If you think you have memory problems you are kindly requested to complete the questionnaire and send it back to the researchers using the pre-paid envelope. If you are not experiencing memory problems please return the questionnaire without completing it.

The questionnaire should take about 15-20 minutes to complete. By returning the questionnaire you show your agreement to participate in the study.

If you are willing for the researchers to send you another questionnaire please complete your name and address on the front page of the questionnaire. By providing your name and address you show your agreement to be sent a second questionnaire.

Participation is voluntary. Please find enclosed a copy of the "Information for Participants" sheet and read it carefully before deciding whether to take part. If you require further information about the questionnaire or the research please contact the researchers using the contact details on the "Information for Participants" sheet.

Yours Sincerely

## Appendix 5: Participant information sheet



### Participant Information Sheet

**Title: The Adaptation to Memory Problems Outcome Questionnaire**

**Investigators: N B Lincoln, N Chouliara**

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. It is up to you to decide whether or not you wish to take part.

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

We would like to develop a measure of the ways people with acquired brain injury cope with memory problems. The aim of this study is to assess the quality of that measure; for example, how it responds to changes over time. The developed questionnaire may be eventually used to assess the usefulness of rehabilitation programmes for memory problems after brain damage.

#### **Why have I been chosen?**

The enclosed questionnaire is being sent to 500 people with brain injury, stroke or multiple sclerosis identified from patient registers in hospitals and rehabilitation centres.

#### **What do I have to do?**

If you are experiencing memory problems you are invited to complete the enclosed questionnaire and send it back to us using the pre-paid envelope. If you are not experiencing memory problems please return the questionnaire without completing it. This is necessary so that we know it has been received and has not been lost in the post. Please record your gender, age and diagnosis on the front page of the questionnaire. If you are willing for us to contact you again you should also complete your name and address. In this case we would like to send you another questionnaire after two weeks. This is necessary to analyse how the responses of the questionnaire change over time.

#### **How long will this take?**

The questionnaire should take about 15-20 minutes to complete.

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### **Do I have to participate?**

It is up to you to decide whether or not to take part. By returning the questionnaire you show your agreement to participate in the study. By giving us your name and address you show your agreement to be sent a second questionnaire.

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

If after giving us your name and address you decide that you no longer want to be involved in this study you are free to withdraw without giving a reason. Your name and contact details will be erased from our database and you won't be sent a second questionnaire.

### **What are the possible risks of taking part?**

There are minimal risks involved in this study. Some people may find a few questions upsetting. If you feel upset or concerned by any of the issues raised in this study do not hesitate to contact one of the researchers (the contact details are given below).

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

There are no direct benefits of taking part in this study. The information we get from the study may help in the development of a new measure to assess the usefulness of memory rehabilitation programmes.

### **What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (the contact details are given below). Alternately, if you have a complaint you can contact the Patient Advice and Liaison Services (PALS) (08001830204).

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

All information collected about you will be kept strictly confidential. If you wish to remain anonymous please complete and return the questionnaire. However if you are willing for us to contact you again please complete your name and address on the front page of the questionnaire. Your name and address will be removed from the questionnaire so that you cannot be identified. No-one other than the researcher and her supervisor will have access to any of the data collected.

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

The results of this study will be submitted for a PhD. Papers may be presented at scientific conferences and journals. A new outcome measure will be developed to evaluate the effects of memory rehabilitation. Individual results will not be released to any third party. If you would like to receive a copy of the published results please contact one of the researchers using the contact details given below.

### **Who is organising the research?**

The study is being conducted by a Postgraduate student in University of Nottingham as part of her PhD degree programme. The research is being sponsored by the University of Nottingham.

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### **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 and rights. This study has been reviewed and given favourable opinion by Derbyshire Research Ethics Committee.

### **Further information**

If you have any questions or concerns about the questionnaire do not hesitate to contact:

Niki Chouliara, IWHO, International House, Jubilee Campus, Wollaton Road, Nottingham, NG8 1BB

Email [lwxc3@nottingham.ac.uk](mailto:lwxc3@nottingham.ac.uk) or phone 0115 846 6929

Prof Nadina Lincoln, Room B19, IWHO, International House, Jubilee Campus, Wollaton Road, Nottingham, NG8 1BB

Email [nadina.lincoln@nottingham.ac.uk](mailto:nadina.lincoln@nottingham.ac.uk) or phone 0115 951 5315

**Thank you for taking the time to read this.**

## Appendix 6: Letter of approval by REC

Derbyshire Research Ethics Committee  
Derwent Shared Services  
3rd Floor  
Laurie House  
Colyear Street  
Derby  
DE1 1LJ

Telephone: 01332 868765  
Facsimile: 01332 868930  
25 September 2009

Professor Nadina Lincoln  
Professor of Clinical Psychology  
Institute of Work, Health and Organisation  
The University of Nottingham  
8 William Lee Buildings  
Nottingham Science and Technology Park  
University Boulevard  
Nottingham  
NG7 2RQ

Dear Professor Lincoln

**Study Title:** Evaluating the psychometric properties of Adaptation to Memory Problems Outcome Questionnaire in people with brain injury.  
**REC reference number:** 09/H0401/51  
**Protocol number:** Draft 1.1/final version 1.0

Thank you for your letter of 01 July 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

### Confirmation of ethical opinion

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

### Ethical review of research sites

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

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### Conditions of the favourable opinion

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

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

For NHS research sites only, management permission for research (“R&D approval”) should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary. Sponsors are not required to notify the Committee of approvals from host organisations. It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).*

### Approved documents

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

Document	Version	Date	
REC application	16103/42710/1/251	09 June 2009	
Investigator CV		05 June 2009	
Investigator CV	Student researcher	20 April 2009	
Letter from Sponsor		03 June 2009	
Sponsorship Agreement		03 June 2009	
Compensation Arrangements		05 August 2008	
Letter of invitation to participant	1	28 May 2009	
Letter of reminder to participant	1	28 May 2009	
Questionnaire: Adaption to Memory Problems	1	20 April 2009	
Peer Review		01 June 2009	
Protocol	Draft 1.1/final version 1.0	28 May 2009	
Participant Information Sheet	2	30 June 2009	
Response to Request for Further Information		01 July 2009	

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

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## Appendices

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Now that you have completed the application process please visit the National Research Ethics Service website > After Review

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

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

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

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

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

<b>09/H0401/51</b>
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<b>Please quote this number on all correspondence</b>
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Yours sincerely

**Mr Phil Hopkinson**  
**Chair**

Email: [jenny.hancock@derwentsharedservices.nhs.uk](mailto:jenny.hancock@derwentsharedservices.nhs.uk)

Enclosures: “After ethical review – guidance for researchers” SL-AR2

Copy to: Mr Paul Cartledge, University of Nottingham  
NUH R&D Office